

My Beautiful PDF Document

Subheading 1

Changing the narrative around screening

Joining OnFocus today is Alan Doherty, Clinical Director at the Birmingham Prostate Clinic, and recently voted one of the UK's top ten prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail. Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer, and joined the Focal Therapy Clinic last year to develop his expertise in delivering focal therapy. In addition to HIFU focal therapy, Alan has embraced IRE or NanoKnife focal treatments with great success for his patients, which has reinforced his views on early diagnosis and, in particular, prostate cancer screening. He's here today to speak with me about how advancements in and success with focal therapy change the discussion around screening. NanoKnife treatment for hard to reach prostate cancers. thefocaltherapyclinic.co.uk

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Alan Doherty, clinical Director at the Birmingham Prostate Clinic and recently voted one of the UK's top ten prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail. Alan has been an innovator advocate and dedicated practitioner of precision treatments for prostate cancer and he joined the Focal Therapy Clinic last year to develop his expertise in delivering focal therapy. In addition to HIFU focal therapy, Alan has embraced IRE or Nanoknife focal treatments with great success for his patients, which has reinforced his views on early diagnosis and in particular, prostate cancer screening. He's here today to speak with me about how advancements in and success with focal therapy change the discussion around screening. And one of the reasons I wanted to have this conversation this week is because there's been in the last few weeks a real sort of acceleration of discussion around screening. Because I guess evidence is building on both advanced diagnostics and focal treatments and the whole argument about the harm of over or under diagnosis is actually being challenged quite significantly. Alan Doherty I think screening has been controversial ever since I started in urology 30 years ago, and the population studies have been somewhat conflicting and they never really showed that the benefits were hugely better than the harms which came with the diagnostic process and the treatments. And that probably explains why there isn't a government screening programme for prostate cancer. And the use of PSA is really driven by individuals or groups of maybe charities, but not really by the NHS or by any government policy. And I think sometimes that helps to clarify the situation with prostate cancer in particular. Because when somebody doesn't have any symptoms, which is virtually by definition what screening is because what you're trying to do is to identify a problem in the future, a potential problem in the future, because it's not a problem now because you haven't got any symptoms. And the problem in the future could be ten years away, it could be 20 years away, it could be 30 years away, and the size of the problem could vary from death to just having to take a few tablets. But when we do make a diagnosis is to say, well, what is the potential problem in the future? So we look at the level of PSA, we look at the imaging, we look at the Gleason score, and increasingly, we're starting to use genetics. And so what we are trying to do is to get this looking glass into the future, to make an accurate assessment of what is coming your way. And if we think that what's coming your way is a big problem and it's not far away, then we're going to obviously want to treat that. And patients are prepared to take on some side effects if they think that the benefit is worth it. Now, the trouble with prostate cancer is that so many of these cancers, and this has been shown in a number of studies, in particular, the ProtecT study, is that the natural history of a PSA detected, organ confined prostate cancer is really good. So why would you take on a potential problem that's miles away with a treatment that gives you a problem now? I think the media have made patients hyper concerned about an early prostate cancer, and that means that they're prepared to take on treatments which give them potential life changing side effects. And they're prepared to take that because they probably wrongly think that the type of cancer that they're going to, the effects of the cancer that they've been diagnosed is going to be much worse than the side effects of

the treatment. And it struck me that when these screening studies were published, that there were still quite a few deaths from prostate cancer. And you would have thought that if you were doing a screening programme, you wouldn't have any deaths, you might get harm, you might get side effects of treatments. It struck me that the studies were badly designed because the fact that there weren't deaths at all in the prostatectomy group. So if you treat someone by removing the prostate, well, how can you die of prostate cancer? Well, the answer is either you don't do it properly or the cancer has already spread before you take it out. Because I suspect the people who are going to die of prostate cancer have quite aggressive cancers that present very early, probably before the age of 50. So screening studies that use PSA and by the way that's another important point that the screening studies so far published were using PSA only as their criteria on who they would go on to biopsy and treat. Now we're far more sophisticated because we use the MRI scan to decide who we're going to biopsy and treat. You can see that the jury is still out as to whether screening is good and I think the answers to whether it's good or not will depend on how accurate we are at diagnosing it without harm and then whether the treatments cause any harm or not. Clare Delmar So on that point, I want to pick up on something I said in introducing you earlier, which was that, you know, you've become a recent adoptee of the Nanoknife with patients, and we've spoken to some of your patients, and I've spoken to you about this, and both you and they have been extremely positive. I think the focal therapies, and of course Nanoknife is one of the focal therapies, has allowed us to offer a treatment to patients with minimal harm being done. It's not without risk and in fact, the more I've been involved in focal therapy the more I realise just how powerful these tools are. But the fact you can precisely destroy the cancer where you see it in the prostate is just such an advance and potentially for a patient that reassurance. And so it makes sense to me that if you find something that is treatable with a focal therapy why would you just leave it and monitor it? I mean there are some situations where you would say that removing the prostate or using radiation therapy is needed because of the type of cancer you've got. So I don't think focal therapy is the answer to all men with all prostate cancer but if you're going to pick up early prostate cancers that are likely not to harm you for years, then why would you just leave it if you can just treat it with minimal side effects? So I think as an alternative to doing nothing, the ProtecT study showed that even if you've got Gleason seven or eight or even worse, leaving it until it was obvious you needed another treatment sometime in the future did not compromise your survival at ten or 15 years. So I think what screening does is it picks up lots of early prostate cancers, which you don't necessarily want to go in and cause harm with prostatectomy or radiation therapy, but you can control it with a focal therapy. To be fair to surgery and radiation therapy, and we should give a balanced view, is that the techniques have improved and so the amount of harm is reducing. In the radiation field, you have things like MR linac which allows the minimisation of collateral damage from the radiation. So the trend is very much going towards minimising collateral harm and the focal therapies are right up there in delivering that. So if we're going to start adopting screening, you have to have the focal therapy weapon up your sleeve. Clare Delmar Yeah, I mean, I think one question would be do you think that just the very existence of focal and getting the message out to men that if it's caught early, it can be treated in a less harmful way that you've described, do you think that would be enough of an impetus to actually bring men forward so that they're not afraid? And maybe asking it in a different way do you think men are afraid to come forward and request a PSA test because they're simply just terrified of all the implications of much more interventionist treatment? Alan Doherty I think some are definitely terrified, but others now are terrified of dying of prostate cancer because in the news and celebrities are being highlighted as having it. Some people are over scared of prostate cancer and other people are over scared of an early diagnosis and potentially impact on particularly the erectile function. One of the things that is always going to play a part in all this is cost and focal therapies require high quality MRI scanning and they require surveillance with MRI scans after the treatment. These are cost implications which I suspect will influence any government decision on implementing a screening programme. Clare Delmar Except on the other side of that, the very existence of those MRI scans and the precision interpretation of those is that it reduces the biopsies and potentially ultimately the treatment. On that point, I wanted to ask you one of the arguments now in the last few months, few weeks even, and I know Prostate Cancer UK has shifted its view of it and they've published this on PSA screening and they specifically mentioned that they've done so in light of advancements in the MRI diagnostic pathway. So given that that's all happened, that's now accepted and granted there is way to go still. Why do you think that even in the presence, multiparametric MRI, which reduces the amount of biopsies by what, 30%, sometimes even more, why has it remained unchanged? Alan Doherty I think that now that I've left the NHS and I've sort of not doing the group think, you open your mind to other

ideas and other concepts and I think the group think is to achieve cure at all cost. Alan Doherty There isn't this concept of a trade off between perhaps a lower cure rate, but less morbidity. And this radical approach is, I think, fine for some people, and I think that's the discussion you have with people, with your patients, but it's not fine for a lot of people. And so it's not really up for the consultant to put his views, say, these are the only views that you can consider, because that's clearly not the case. There are other approaches and I think consultants need a bit of humility here to say there are other ways which you may or may not agree with, but you shouldn't exclude them at all. I think the other point on the diagnostic side is that there's still a long wait before MRI scans are done reliably enough that consultants can sort of confidently say, well, I'm not going to biopsy you because I think perhaps in the future with artificial intelligence. It's relatively new that people are using MRI scan in this diagnostic way, maybe on average three or four years or something like that. And you and I have talked in the past, I think, on another podcast about the MRI and the advancements, and we've talked about this issue of uniformity, or you would put it potentially non uniformity, and the variation of the imaging that you see. Would you say that of all the MRI scans done for prostates in this country, there's a variability of what percent? I would say as many as 50% of them are substandard, and I suppose that's not a very fair percentage in a way, because I get a very small group of people coming in for a focal therapy and the quality that you need for a focal therapy needs to be very high. But if you're using MRI scans for other purposes, maybe just the diagnosis or just the staging, it's probably much better than that. But as the consensus emerges on whether it's PSA testing or combined with MRI, once that consensus and a screening programme maybe is developed, how would you foresee take up? So, say, next week, suddenly we all agreed and there was a programme, but I read somewhere recently that in breast cancer screening, for example, there's huge variation in take-up of it, and that's a study in itself, and women from various ethnic backgrounds or income groups or locations don't take it up. I mean, I realise this is something long into the future and it's a nice problem to have if you have a screening programme, but would you see take up because of the time it's taken to arrive at a programme and that all the information that's come together maybe has been dispelled. Alan Doherty It's a great question and I'm sure there are precedents out there from previous studies. And my experience with a ProtecT study was that the pickup was actually quite high, remarkably high, and it was driven by GPs, who were sort of calling patients in to have it. You can tell by the way, if a charity is putting on a free PSA test, the queues go around the street. And of course, a lot of patients have urinary symptoms when they get to a certain age and it'll be playing on their minds, thinking, well, perhaps these symptoms are to do with cancer. And so the opportunity to go and get checked out would be very tempting, rather than to make an appointment and seem like they're worried well, we don't want to do that. So I think a PSA programme would be good and I think if we are going to do a trial on whether it's beneficial or not, it's got to include a focal therapy. Clare Delmar Or at least the information that this range of treatments is available and to take the fear factor away, as you said. Alan Doherty Well, I mean a sort of a proper government study, but the trouble with these studies, they take years to do and I've not heard of any potential screening studies in the pipeline. Alan Doherty Transparency of outcome has always been something which I think is not there, and it should be there because a lot of these treatments are skill based and it's very hard to interpret outcomes and so not enough work has been done on that. I think the other thing I'd be quite keen on is obviously people being counselled properly about the implications of what they're doing and that would be quite important. I think those things that would be the ones that I focused in on if I was setting up a screening programme. But really interesting, I mean, I can see a follow on interview coming up in the near future. Clare Delmar Further information on Alan Doherty and his clinical practise is available on our website, along with the transcript of this interview, as well as additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. In an era of celebrity overload, characterised by continual celebrity self-promotion through every media outlet imaginable, are we measurably influenced when they use their status to raise awareness about an issue like prostate cancer? Well, when prostate cancer affects them directly, evidence shows that celebrities can not only raise awareness about it but they can also impact the behaviour of those at risk. Five years ago this was described as the "Turnbull-Fry effect" after the celebrities Stephen Fry and Bill Turnbull, who both were diagnosed with prostate cancer and spoke publicly about it. Stephen Fry, together with his urological surgeon Ben Challacombe, published an interview about the doctor-patient relationship in a medical journal which made headlines and widened awareness about prostate cancer. The influential medical publication BJUI recognised the power of this and awarded the article the BJUI Social Media award in 2019, citing how the story "garnered worldwide attention due to the

profile of Stephen Fry and his 12.7m Twitter followers.” The same year Bill Turnbull a popular UK broadcaster, revealed his diagnosis and described his struggles with treatment, encouraging men to get tested for prostate cancer. The National Cancer Registration & Analysis Service investigated how the Fry Turnbull effect played out, and concluded: Our findings show a marked increase in the number of prostate cancers diagnosed from the time of Fry’s and Turnbull’s announcements of their own diagnoses. Celebrities publicising their cancer diagnoses may prove invaluable in influencing their peers (in this instance, similar age groups) to investigate whether they themselves could also be at risk. Further research could investigate which other factors could have an effect on help-seeking behaviour. Since then, in the wake of the Covid pandemic and a backlog in cancer referrals, the number of diagnoses have slowed, and more worryingly of those diagnoses a greater number are at a more advanced stage. So given where we are now, can celebrity-led messaging and campaigns help to drive more men to their GPs and help to stem the growth in late-stage diagnoses? Adding to the changes that have emerged in the last five years since the Turnbull-Fry effect played out is the surge in volume of stories and information in the media, challenging anyone trying to cut through effectively and influence behaviour. But in the last six months, we have seen several celebrity-led stories about prostate cancer that seem to resonate. These have focused on a particular message about prostate cancer, specifically sexual function, mental health and screening hesitancy amongst black men. Often regarded as “taboos”, these aspects of prostate cancer risk and treatment haven’t, until recently, been discussed so openly. Former Scottish rugby international Kenny Logan went public about his prostate cancer treatment in September last year. Over the ensuing months he was joined by his wife, also a celebrity, who joined in the campaign via her podcast which addresses physical and mental health issues affecting middle-aged people, which led to a number of media appearances as a couple discussing how Kenny’s prostate cancer treatment impacted he and his wife’s sex life. By early this year, Kenny Logan began to speak regularly and openly about the sexual impact of prostate cancer treatment, appearing in major news outlets like the Telegraph and Daily Mail. He said that he hoped his experience with prostate cancer will lead to more open discussions in the community, noting “men are particularly ‘notorious’ for suffering in silence and not scheduling regular check-ups with doctors.” Early this year former royal butler and reality TV star Paul Burrell went public about his prostate cancer diagnosis and treatment, emphasising the emotional toll that his treatment was taking on him: ‘I’m tired, I’m on hormone therapy, it’s robbing me of my testosterone so my beard isn’t growing as it should, I’m tired, and I’m getting hot flushes’ He went on to catalogue his experience with hormone therapy leading up to his surgery last month through a popular TV programme. ‘I get so emotional because of the hormone therapy, which will continue after the operation.’ He told viewers “So, I’m going to be in a mess for a very long time. Award-winning film director Steve McQueen produced a video last year about the higher risk that black men face in developing prostate cancer. Entitled “Embarrassed”, the video features four high-profile black actors, Morgan Freeman, Idris Elba, Micheal Ward and Chiwetel Ejiofor, who challenge the idea that discussing the illness with family and friends is something to be ashamed of. “Don’t let embarrassment stop you from having this important conversation,” Freeman says in the film. Bafta award-winning actor Chiwetel Ejiofor adds that he believes the film has encouraged positive conversation. “I’ve had a lot of messages from people saying, it reminded me I’ve got to get myself checked out,” he says. “And even though that the campaign is targeted at Black men, it opens up the conversation, and everybody wants to make sure that they’re okay and get checked out.” “This is not about weakness,” adds McQueen. This is about taking control of a situation and being healthy.” All of these celebrities have focused on issues about living with prostate cancer which seem to resonate, if not directly with men, with their families. We hear this from many of our patients, who tell us they have been influenced or even inspired by a celebrity going public on a very personal aspect of diagnosis and treatment. Prostate cancer is extremely common, and it’s estimated that 1 in 8 men will develop it during their lifetime. There’s no guarantee that you will or won’t be affected, but there are factors that can make a diagnosis of prostate cancer more likely. However, there are risk factors that can increase the likelihood that you will be affected. It mainly affects men who are over the age of 50, so many doctors recommend starting screening at this age. However, if you’re over 45 but have a higher risk of prostate cancer due to other factors, such as your ethnicity or family history, you may be eligible for earlier screening. The most common age for men to be diagnosed with prostate cancer is between 70 and 74 years. While the overall statistic states that 1 in 8 men will get prostate cancer in their lifetime, 1 in 4 black men will. Since your risk of developing prostate cancer increases with age, if you are a black man over the age of 45, it’s important to speak to your doctor about this and ask them about regular screening tests. Research from the U.S. shows that African American men are more likely to get

prostate cancer, develop the condition at a younger age and have more advanced disease when it is diagnosed. They are also more than twice as likely to die from prostate cancer than men of other ethnicities.

Genetics and family history

Genetics have been shown to be a key risk factor in the development of prostate cancer. The genes that you inherit from your parents can make you more likely to develop certain health conditions, including some cancers. You could be at greater risk of prostate cancer caused by genetic changes if:

- You have a first-degree relative — like your father or brother — who had prostate cancer
- If that relative was under 60 when they were diagnosed with prostate cancer
- If other members of your family have been diagnosed with breast, ovarian or pancreatic cancer

Just because you have family who has had prostate cancer, it doesn't mean that you are definitely going to develop the disease. If you are concerned about your genetic risk of prostate cancer, it's worth speaking to your doctor to see if you can start screening for the disease earlier. If not, making positive lifestyle changes could help lower your risk of getting a diagnosis of prostate cancer in the future. There is significant evidence to suggest that being overweight increases the risk of being diagnosed with advanced prostate cancer. And since lifestyle is something that you can control, making small adjustments to your diet and exercise levels to manage your weight could make a big difference to your health in the future.

Studies recommend that you:

- Eat a balanced, nutritious diet that is high in fruits, vegetables and lean meats
- Limit dairy foods, which contain calcium and are thought to increase your risk of prostate cancer
- Keep processed and red meat to a minimum
- Limit the amount of alcohol you consume to 14 units per week
- Get plenty of physical activity each week
- Give up smoking

Your doctor will be able to help advise and support you in making positive healthy lifestyle changes to decrease your risk of prostate cancer.

How to reduce the risk of prostate cancer

While there is no guarantee of being able to prevent prostate cancer, taking steps to control high-risk factors, such as those related to your lifestyle can help. It's also important to know the symptoms of prostate cancer so that you can spot it early if you do develop it. As with all cancers, the earlier prostate cancer is diagnosed and treated, the better your outcome is likely to be.

Symptoms of prostate cancer

The early warning signs of prostate cancer include:

- Difficulty starting to urinate
- Weak or interrupted flow of urine
- Urinating often, especially at night
- Difficulty completely emptying your bladder
- Pain or burning sensation during urination
- Blood in your urine or semen

If you are concerned about your prostate cancer risk or develop any of the symptoms listed above, don't hesitate to speak to your doctor.

What are the Different Stages of Prostate Cancer

What Are The Different Stages Of Prostate Cancer And What Do They Mean?

A diagnosis of prostate cancer can be devastating, but early diagnosis and selecting the right treatment can improve your prognosis. Not only can the right treatment have a higher success rate, but it can also help ensure the maximum quality of life after prostate cancer. This is particularly important since some types of prostate cancer treatment — principally those currently available on the NHS — can have long-term consequences that aren't commonly known. Learn more about the different stages of prostate cancer and what you can expect at each stage, including what treatments may be available to you.

What is a Gleason score?

As part of your prostate cancer diagnosis, you will be given a biopsy. This is where a small amount of tissue from your prostate is taken to be assessed under a microscope. When the cancer is detected, it is then graded. In prostate cancer, the Gleason grading system is used. Grading your cancer helps you and your doctor understand how advanced the cancer is, what it might behave like, what treatment you might be offered and your overall prognosis. This grading is done by looking at each sample of prostate cancer cells and rating them between 3 and 5 based on how quickly they are likely to grow or how aggressive the cells look. Doctors will then add together the two most common Gleason grades to come up with an overall Gleason score. This Gleason score will then determine which grade group your cancer will be given and what stage of prostate cancer you will be diagnosed with. Many people get confused between their Gleason score and their prostate cancer stage, but as with all other cancers, there are just four stages of prostate cancer. Find out more about the way in which prostate cancer is detected and diagnosed in the UK on our prostate cancer diagnostic process page.

What are the four stages of prostate cancer?

Your outlook and overall prognosis depend on the stage of cancer you have at the point of diagnosis. Here's what you need to know about each of the different stages of prostate cancer.

Stage 1

In stage 1 prostate cancer, the cancer is completely contained within the prostate gland. At this stage, almost 100% of patients will survive their cancer for five years or more after diagnosis. Surgery and radiation therapy are the standard NHS therapy choices for men with early-stage prostate cancer. However, patients with this stage of prostate cancer are also generally very good candidates for focused therapies such as HIFU and NanoKnife treatment, which aren't currently available on the NHS but have a similar success rate and a much lower risk of side effects. You can find out more about [early-stage treatment options](#) in our [best treatment for](#)

prostate cancer in early stages[1] blog post.

Stage 2 In stage 2 prostate cancer, the cancer has been found in more than half of one side of the prostate. Again, almost 100% of patients will survive their cancer for five years or more after diagnosis. Like stage 1, stage 2 prostate cancer is usually treated with surgery and/or radiation therapy. Hormone therapy may be used to treat stage 2 patients as it can help to shrink the cancer before radiation is applied. Again, these patients are usually good candidates for targeted therapies such as HIFU and NanoKnife which aren't currently available on an NHS treatment plan but can be arranged privately.

Stage 3 In stage 3 prostate cancer, the cancer has spread beyond the capsule of the prostate gland and may have spread into the seminal vesicles (the tubes that carry semen). Around 95% of men diagnosed with stage 3 prostate cancer will survive their cancer for five years or more after diagnosis. Patients with stage 3 prostate cancer have a few different treatment options. For example, surgery to remove the cancer is often followed by radiation therapy to eliminate any rogue cancerous or pre-cancerous cells. Patients may be offered hormone therapy which is designed to limit the growth of cancer everywhere in the body, even outside of the prostate. Some people may choose to have targeted therapies like HIFU or NanoKnife in conjunction with hormone or radiation therapy.

Stage 4 Stage 4 prostate cancer is a little more complex as it can mean one of several different things. Either:

- The cancer has spread to nearby lymph nodes
- The cancer has spread into nearby organs, such as the bladder or rectum
- The cancer has spread to other parts of the body outside of the pelvis, such as the liver or lungs

In stage 4 prostate cancer, around 50% of men will survive their cancer for five years or more after diagnosis. Patients with stage 4 prostate cancer are most often given hormone therapy, which is sometimes combined with chemotherapy or radiation. Surgery is rarely effective since the cancer has already spread significantly.

What is the TNM staging system? You may also hear your doctor refer to something called your TMN stage. TMN stands for Tumour, Node and Metastasis. The TMN staging system can be used to indicate the size of your tumour, its location and whether it has spread to either your lymph nodes or another part of your body — something known as metastasis.

- T – Tumour** The number next to the T describes the size and spread of the cancer, with T1 being the smallest and most contained, and T3 where the tumour has spread outside the prostate and may be growing into organs or tissue nearby.
- N – Node** The number next to the N describes whether the cancer has spread to the lymph nodes, with N0 meaning no it hasn't and N1 being where there is cancer in one or more lymph nodes. Patients may occasionally get an NX result which means there isn't any information about nearby lymph nodes, or they aren't able to be assessed.
- M – Metastasis** The number next to the M described whether or not the cancer has spread to another part of the body. Again, M0 is where the cancer hasn't spread to another part of the body, M1 shows that it had, and MX means inconclusive results.

Your treatment options will depend on your TNM result. Our team of prostate cancer experts will be happy to help you understand your diagnosis and which treatment options will be most effective for you.

Focal therapies are an effective way of treating early to moderate-stage prostate cancer.

HIFU Prostate Cancer Treatment Pros and Cons: What You Need To Know

HIFU Prostate Cancer Treatment Pros and Cons: What You Need To Know Prostate cancer is one of the most commonly diagnosed cancers in the UK — and while a diagnosis of prostate cancer can be frightening, the good news is that it is very treatable if it is caught early. Exactly what that treatment will look like will depend on your individual circumstances, but you will have a say in which treatment you choose. This is important, because what's not talked about enough is what life looks like after prostate cancer. Because — even after prostate cancer is treated, even if you become cancer-free — there are longer-term effects to consider. But we say that being cancer-free alone isn't enough if you are forced to live with a lesser quality of life after prostate cancer. Fortunately, there are prostate cancer treatments that have a far less significant impact on your quality of life.

HIFU stands for High-Intensity Focused Ultrasound — a focal cancer therapy with over 20 years of clinical use on more than 50,000 patients. It is most effective in treating medium to large-volume prostate cancers in the lower part of the prostate gland, where over 75% of prostate cancer occurs. As a soundwave-based therapy, HIFU is non-invasive, meaning that no incisions are made and there are no wounds to heal. The treatment uses a pair of high-intensity ultrasound beams to heat cancerous areas of the prostate, destroying the cancer cells. Cutting-edge 3D MRI fusion technology is used to guide the treatment, which is performed under general anaesthetic to ensure maximum comfort. A high success rate combined with minimal side effects makes HIFU treatment a popular choice for men with medium to large-volume prostate cancers. What this means is the treatment is focused purely on the cancer cells and leaves surrounding healthy cells untouched. 98% of HIFU patients are fully continent after 2 weeks. Urinary incontinence is one of the taboo side effects of conventional prostate cancer treatments. This is because cancer medications like chemotherapy can cause nerve damage, irritation and even vomiting that puts stress

on your bladder, making leaks more likely. However, since HIFU targets only the cancer cells, the risk of urinary incontinence is significantly reduced. 95% of HIFU patients maintain erectile function. Erectile dysfunction is the other side effect that remains taboo after conventional cancer treatment. Statistics from Prostate Cancer UK state that 76% of men who are treated for prostate cancer experience erectile dysfunction. One study has shown that just 16% of men who had a radical prostatectomy were able to obtain the quality of their pre-surgery erections again. HIFU treatment is focused only on the cancer cells, limiting the impact on surrounding tissues and making erectile dysfunction considerably less likely. This means that you don't need to stay overnight and can go home the same day — sometimes as soon as just 90 minutes after your procedure. A minimally-invasive procedure means a faster recovery. Since there are no incisions and no wounds to take care of, recovery from HIFU is faster than most conventional NHS prostate cancer treatments, with most patients feeling 100% within 3 days of their procedure. Preserve your future treatment options. HIFU doesn't exclude the option of radiotherapy or surgery down the line if it's needed, and it can be repeated if necessary. The only real disadvantage of HIFU treatment is that it's not currently available on the NHS, except under limited clinical trial conditions. In fact, treatment options on the NHS are limited and all have unpleasant and debilitating side effects. At The Focal Therapy Clinic, we offer the latest and most advanced prostate cancer treatments to our patients, including HIFU. However, the side effects associated with HIFU are minimal and temporary when compared to NHS treatments. These include: A short-term need to wear a catheter. Temporary urinary symptoms and a small risk of contracting a urinary tract infection. Blood and seminal fluid in your urine while the tumour breaks down. Decreased ejaculatory fluid which could impact your fertility. However, most men experience no side effects at all. The only other thing to remember is that HIFU treatment may not be right for you based on your individual needs. That's why our experienced and knowledgeable team of specialists assess every patient comprehensively before they recommend a specific treatment. HIFU has a very high success rate with reports that HIFU can be as effective as surgery or radiotherapy but with fewer effects. A landmark study by Imperial College London found that following HIFU treatment, the cancer survival rate was 100% at five years. The research also showed that the risks of side effects like urinary incontinence and erectile dysfunction were lower than NHS treatment options, at just 2% and 15% respectively. HIFU prostate cancer treatment is generally recommended for patients who have medium to large-volume prostate cancers in the lower part of the prostate gland where over 75% of prostate cancer occurs. Where the prostate gland is relatively large or the tumour is located at the anterior of the prostate, NanoKnife focal therapy may be more suitable. However, the best way to find out if you are a suitable candidate for HIFU treatment is to schedule a consultation with one of our leading consultant urologists. If preserving quality of life is one of your priorities after prostate cancer treatment, focal therapies are the solution.

Treating Early Stage prostate Cancer in 2023

Introduction

This article aims to provide patient-focused information on modern treatments for prostate cancer which is confined within the prostate gland (Localised). Precision diagnostics, especially the availability of imaging tools including MRI scans and PSMA PET scans and image-guided biopsies are changing the treatment of localised prostate cancer. We aim to provide men with localised prostate cancer with a solid understanding of the options available to treat prostate cancer based on their diagnosis and the increasing availability of non-invasive prostate cancer treatments in addition to well-established radical prostate cancer treatments. This article does not cover treatment options for advanced prostate cancer which has spread beyond the prostate gland.

Quotation "For men who have been diagnosed with prostate cancer, there is tremendous hope that they'll be able to live out their disease with fewer problems than their fathers or grandfathers did in the past" Mr Marc Laniado, Urological Consultant at The Focal Therapy Clinic

Definition of Early Stage Prostate Cancer:

Prostate cancer is a type of malignant tumour that develops in the prostate, a small walnut-sized gland located just below the bladder in men. Early-stage prostate cancer is defined as prostate cancer with a Gleason score which is no more than 7 and which is still localised within the prostate gland. (T2N0 stage)

Precision Diagnostics and Prostate Cancer

The diagnosis and treatment of prostate cancer continue to be revolutionised by the advent of modern imaging techniques including mpMRI scans and PSMA PET CT scans coupled with precision prostate biopsy strategies. These precision diagnostics have enabled clinicians to identify where prostate cancer is situated within the prostate gland. Targeted therapy aims to destroy cancer cells while sparing adjacent healthy tissue using a range of non-invasive treatments. This is called Focal Therapy. Targeted therapy or Focal Therapy has been clinically proven to offer equivalent cancer control to the established radical treatments with minimal impact on the quality of life in terms of rapid recovery, maintained erectile function and urinary and bowel continence. Statistics of Prostate Cancer

Incidence Prostate cancer is the most common cancer affecting men in the UK. Every year about 50,000 men receive a diagnosis of prostate cancer and 11,000 will die early from the disease. Of the men diagnosed approximately 50% will have early-stage localised prostate cancer, (Clinically described as T stage 1 or 2) which can be managed with little impact on life expectancy. Men with prostate cancer with a Gleason grade above 7 or stage T3 or T4 face a reduced life expectancy. In these cases established treatments including robotic surgery, combination hormone and radiotherapy treatment and chemotherapy treatment are needed. A major UK clinical trial reported in 2016 (the ProtecT trial) provided the following data on the outcomes for 1,643 men with early-stage localised prostate cancer receiving alternative treatments. This trial focused on results from Active Surveillance, Surgery and a combination of Hormone and Radiotherapy treatments. The results of this clinical trial and others combined with the increased diagnostic precision afforded by modern MRI scans, PSMA Pet scans and precision prostate biopsies is driving a re-appraisal of treatment options for men with localised prostate cancer. Increasingly the focus is to achieve cancer control but also to minimise side effects and damage to men's quality of life. Clinical trials carried out in the UK have established that the urinary and erectile function results from Focal Therapy treatment are similar to those from Active Surveillance. In the NHS to date, the number of men being offered minimally invasive alternatives to well-established therapies is low. However, at The Focal Therapy Clinic we provide the very latest in minimally invasive treatments for men who wish to consider this option. We are committed to providing a service which is founded on the highest levels of clinical evidence and patient experience. Our team of world-renowned consultants have decades of experience and offer a number of cutting edge treatment options tailored to the individual. The prostate is a walnut-sized gland located beneath the bladder and surrounding the upper part of the urethra – the tube that carries urine from the bladder. The gland is a part of the male reproductive system that makes most of the semen that carries sperm. The prostate gland surrounds the urethra, the tube that carries urine and semen out of the body. Prostate Cancer Prostate cancer is essentially caused by damage to the DNA of a normal prostate cell. These damaged cells form tumours that can be benign but often become malignant and cancerous tumours. Prostate cancer often grows very slowly so there is normally time to explore all of your treatment options before making a decision. In localised prostate cancer, the lesions are confined within the prostate gland and can be treated, often in a way which preserves the gland and its functionality. In more advanced cases prostate cancer treatment becomes more intense and radical treatment is needed to destroy the prostate gland and the area around it.

Risk Factors for Developing Prostate Cancer The exact causes of prostate cancer are unknown, but several risk factors have been identified. Black men are twice as likely as white men to receive a diagnosis of prostate cancer and usually at a younger age. Men whose father or brother had a prostate cancer diagnosis have a doubled risk of receiving a diagnosis. 13% of clinically significant prostate cancer is found in men between 50 and 60 and 87% older than 60 with an average age at diagnosis of 66. Diet and obesity are believed to increase risk with various authors commenting on the consumption of dairy and red meat.

Diagnosing Prostate Cancer Prostate cancer diagnosis usually starts with the use of a blood marker called PSA which provides an early indication of risk. In cases where the PSA level is above a level of 3 or 4, the patient is then placed on the Prostate Cancer Diagnostic pathway. This starts with a special prostate specific MRI scan which is effective at identifying areas within the prostate gland which may harbour clinically significant prostate cancer. If you compare that to standard TRUS biopsies, which we know to be about 30%, it's a completely different league." Dr Clare Allen, Uro-Radiologist at The Focal Therapy Clinic The MRI uses magnets to create an image of the prostate gland and the surrounding tissues. These images allow the radiologist to identify areas of suspicion which will need a biopsy to investigate further. Prostate biopsy strategies have been significantly improved by the movement from trans-rectal to transperineal biopsies which have a much lower risk of causing infection as well as significantly improved accuracy and diagnostic power. Transperineal prostate biopsy procedures are carried out under image guidance from an ultrasound probe placed in the rectum with needles inserted into the prostate from the skin just below the scrotum. This allows the urologist to access all areas of the prostate gland accurately and to take biopsy samples from those areas which were suspicious on the MRI scan. "A high-quality mpMRI scan combined with a targeted biopsy allows us to know the location and grade of your prostate cancer. We can then treat it with minimal damage to surrounding organs and reduced side effects." Mr Raj Nigam, Urological Consultant at The Focal Therapy Clinic This diagnostic process, powered by the use of MRI scanning, allows prostate cancer to be identified much earlier and more accurately than previously and also gives urologists a previously unobtainable understanding of the precise location and severity of cancerous cells within the prostate gland. For men with prostate cancer with an intermediate risk

prostate cancer, Gleason score 4+3=7 a PSMA PET CT scan may be taken before a decision on any treatment option. The PSMA PET CT scan is an imaging test used to detect prostate cancer cells throughout the body. It gives reassurance that the prostate cancer cells have not spread beyond the prostate gland. Benefits of Early Detection of Prostate Cancer Men with prostate cancer that are detected early with a definitive understanding of the location and extent of the disease have treatment options which were not available before the era of precision diagnostics. An accurate understanding of disease severity and location has made it possible to offer men non-invasive treatment options which were previously inconceivable. Suitability for treatment options Suitability for each of the prostate cancer treatment options is determined by a detailed clinical review of MRI scans, biopsy results and overall health but also takes into consideration the values and personal priorities of the man. This review is done in a multidisciplinary team meeting where a range of clinical specialists including urologists, radiologists and oncologists work together to assess each man's clinical circumstances and the treatment options available to them. The objectives are always to ensure that the primary objective of cancer control can be achieved with the least possible side effects for the man. The treatment options available for early stage prostate cancer which is confined within the prostate gland (localised) are, in order of severity Active Surveillance Focal Therapy Surgery Hormone and Radiotherapy treatment IV. These include side effects such as erectile dysfunction and incontinence where a man is unable to control urinary or bowel functions. For this reason, men may choose to delay treatment until there is confirmation that the disease is progressing and that treatment is necessary. Active surveillance is a management strategy for low-risk prostate cancer that involves monitoring the disease without immediately undergoing treatment. It is a way to avoid the side effects and costs of treatment without having an impact upon lifespan. The Active Surveillance monitoring protocol involves regular prostate-specific antigen (PSA) tests, MRI scans and transperineal targeted prostate biopsies to monitor any potential progression. The benefit of Active Surveillance is to reduce the risk of side effects from over-treatment and allow a man to delay treatment until it becomes necessary. The drawback is that Active Surveillance requires a significant commitment on behalf of men and clinicians to maintain this monitoring protocol over time to minimise the risk of progression towards dangerous life-threatening metastatic prostate cancer. Some men find that the Active Surveillance protocol can become a source of significant anxiety over time. 35% of men diagnosed in the UK annually are placed on the Active Surveillance Protocol for a period. Approximately 50% of men on the Active Surveillance protocol proceed to radical treatment within 3 years of starting the protocol. B. Focal Therapies Focal Therapy is a term for treatments which involve a partial ablation of the prostate gland focusing on killing prostate cancer cells and minimising the impact on healthy prostate tissue. Focal Therapy is enabled by precision imaging using MRI and sometimes PSMA PET scans to confirm where the prostate cancer cells are located and that they are confined within the prostate gland. These are followed up by transperineal image-guided biopsies of the prostate which can both determine the presence of cancer in the areas identified by imaging and the absence of cancer cells in the rest of the prostate gland. Focal Therapy is a treatment for men with early stage and intermediate stage prostate cancers which are confined within the prostate gland (Gleason 3+4=7 or 4+3=7. UK Clinical Trials have established that Focal Therapy provides cancer control equivalent to surgery at 8 years but with a minimal recovery period and almost no impact on erectile function or urinary or bowel continence. Criteria for Focal Therapy Suitability Large volume Gleason 6 Gleason 3+4=7 and 4+3=7 MRI identified lesions which are concordant with biopsy results Patient has a preference for Focal Therapy Patient accepts the need for ongoing monitoring Once it has been established that a man meets the suitability criteria for Focal Therapy then a decision is needed about what type of Focal Therapy treatment to offer. There is constant innovation in the field of Focal Therapy treatments however the major treatments in regular clinical use at this time are - High Intensity Focal Ultrasound (HIFU) - Cryotherapy - NanoKnife (IRE) - High Intensity Focused Ultrasound (HIFU) HIFU has been in use for the treatment of prostate cancer since the late 1990s. It is approved for clinical use in the USA and Europe and there have been over 50,000 procedures carried out and many clinical trials have been carried out. HIFU Focal Therapy is carried out under a general anaesthetic when an ultrasound probe is inserted into the rectum and high-intensity ultrasound waves are directed at the prostate cancer under image guidance. The Ultrasound waves are targeted toward cancer cells which are heated to 80°C to 100°C resulting in cell death. The whole process is carried out using sophisticated 3D imaging technology which integrates the results of MRI scans and Biopsies to ensure that targeted cancer cells are killed and that healthy tissue is spared. HIFU is performed in a day case setting with men going home with minimal discomfort a few hours after treatment although they do need to have a catheter in place for approximately 5 days. Once

the catheter has been removed almost all men have full control of their urinary function and 95% of men who had erections sufficient for intercourse before the procedure report no problems at 6 weeks after treatment. Cancer control at 8 years is comparable to surgery or radiotherapy treatments with 10 % of men needing treatment for recurrence. HIFU is the preferred treatment option for men whose cancers are located in the parts of the prostate gland which are close to the rectum. - Cryotherapy Cryotherapy which involves freezing areas of tissue to cause selected cell death has been used clinically for many years for the treatment of skin, breast and cervical cancers. Cryotherapy in the prostate gland is carried out under a general anaesthetic and involves the placement of cryotherapy needles around the prostate cancer cells to be killed under guidance from the ultrasound imaging probe placed in the rectum. Freezing is achieved by injecting cooling argon gas through the needles to form ice balls and risks to critical structures from the cold temperature are minimised by use of warming fluids in the urethra. Cryotherapy is a complementary treatment to HIFU in that it is effective at treating 25 - 30% of prostate cancers which are more distant from the rectum. Cryotherapy is especially useful in treating men with recurrent cancer after failed Brachytherapy radiotherapy procedures as its effectiveness is not impacted by residual radioactive seeds. A drawback of Cryotherapy is that temperature control is more complex and larger treatment areas are needed to ensure full cancer control leading to a small increase in the risk of side effects such as urinary incontinence and erectile function compared to HIFU. It has achieved clinical acceptance and rapid adoption in the areas of pancreatic and liver cancer. NanoKnife is a non-thermal treatment which is effective at killing cancer cells by using strong electrical fields to create permanent nano-sized pores in the membranes of cancer cells. This results in cell death within seconds and leaves a well-demarcated region of ablation with a sharp boundary between treated and untreated areas and minimal inflammation or damage to nearby nerves or blood vessels. NanoKnife is carried out under a general anaesthetic and the electrical current is directed by needle electrodes which are placed using sophisticated 3D imaging under ultrasound guidance following the recommended treatment plan developed by the uro-radiologist and the urologist. An advantage of NanoKnife is that it is relatively simple to administer with a normal treatment time of less than 1 hour and very rapid recovery. Early clinical data indicate high effectiveness at killing cancer cells with rapid recovery and minimal side effects but more time is needed for longer-term clinical trials to be completed. NanoKnife is increasingly seen as an ideal complement to HIFU treatment in the treatment of Focal Prostate Cancers and it is likely to replace Cryotherapy in the primary treatment of focal prostate cancer tumours which are not located close to the rectum. C. Surgery - Robotic Prostatectomy Surgery to remove the entire prostate gland and surrounding tissues, "Radical Prostatectomy" is one of the most established treatments for prostate cancer. According to the National Prostate Cancer Audit for England and Wales 5,000 men had a radical prostatectomy in 2021 compared to 14,00 who had hormone and radiotherapy treatment. Surgery is effective at cancer control and is the established standard of treatment for men whose prostate cancer has not spread beyond the region of the prostate gland. It is effective at curing prostate cancer confined within the prostate gland or where there is a risk of extra-capsular extension. Surgery is routinely offered to men who are healthy enough to undertake the procedure and who have an estimated life expectancy of 10 years or more. Over the last decade, there have been continuous innovations in surgical techniques that improve continence and erection outcomes for men. These include the Da Vinci robot has given the surgeon greatly improved precision and led to a reduction in the length of hospital stays to 3 versus 6 days and a reduction in blood loss. Retzius-Sparing techniques can reduce the impact on the bladder and reduce incontinence problems leading to a faster recovery of urinary continence. Neurosafe techniques help to reduce the impact on the nerves controlling erections reducing the risk of the loss of erectile function. Clinical data shows that surgery is highly effective at controlling prostate cancer with 98% still alive at 10 years after treatment and 75% showing no rise in PSA readings. Men take on average 6 to 10 weeks to recover from the surgery and while all are impotent and incontinent immediately after surgery there is improvement for the majority of men within the first year. The ProtecT clinical trial mentioned above showed that 10 years after surgery urinary problems impact 71% of men and erectile problems 66% of men. These rates are significantly higher than would be anticipated through the normal ageing process. The Active Surveillance cohort of the ProtecT trial showed that after 10 years urinary problems impact 39% of men and erectile problems 45% of men. D. Combination Hormone /Radiation Therapy In the UK the dominant treatment for prostate cancer is a combination of hormone and radiotherapy treatment. (to suppress testosterone levels and External Beam Radiation Treatment (EBRT)) This is the standard of care for men who - have localised disease but are not fit enough to undergo surgery - have high Gleason score cancer - have cancer that has spread beyond the prostate gland (T3 or T4)

According to the National Prostate Cancer Audit for England and Wales 5,000 men had a radical prostatectomy in 2021 compared to 14,00 who had combination hormone and radiotherapy treatment. Combination hormone and radiotherapy treatment offers an improved prostate specific survival rate at 10 years cure rate compared to radiotherapy alone but these treatments do carry side effects. For early stage prostate cancer Hormone Therapy (androgen deprivation therapy) is normally given for 3 – 6 months before radiation treatment but is not continued afterwards. This suppresses testosterone levels in the body which reduces the size of the prostate gland and makes prostate cancer cells more vulnerable to radiation treatment. Men on Hormone Therapy can expect a reduction in libido and erectile function and a risk of hot flushes, sweating, weight gain, depression and brain fog. Radiotherapy's short term side effects include tiredness and discomfort around the bottom which may include diarrhoea and rectal bleeding. Longer term there is a risk of erectile issues and a small risk of bowel continence issues. Currently IMRT (Image guided radiotherapy) is dominant but further improvements are being introduced including the use of Gels to minimise the risk to damage to the rectum and Stereotactic Radiotherapy which reduces the length of treatment. Cancer control rates for prostate cancer have been the subject of many clinical trials and men with early-stage localised prostate cancer can expect a 10 year survival rate equivalent to that of surgery or focal therapy of over 99%. The ProtecT clinical trial mentioned above showed that 10 years after combination hormone and radiotherapy treatment urinary problems impact 38% of men, erectile problems 48% of men and bowel problems 5% of men. The rates for erectile function and bowel problems are higher than would be anticipated through the normal ageing process. Active Surveillance cohort of the ProtecT trial showed that after 10 years urinary problems impact 39% of men, erectile problems 29% of men and bowel problems 2% of men.

Understanding Your Risk Group The first step in choosing the best treatment for prostate cancer is understanding your risk group. This is typically determined by a combination of factors, including the stage of the cancer, the PSA level, the biopsy results, and other relevant health conditions. Understanding your risk group is important because it helps determine the most appropriate treatment option.

Quality of Life Considerations Another important factor to consider when choosing a treatment for prostate cancer is quality of life. For example, active surveillance may not involve any immediate treatments, but it does require regular monitoring and biopsies. Focal Therapy is easily tolerated with minimal side effects for men who are detected early. Radical prostatectomy, on the other hand, can lead to urinary incontinence and erectile dysfunction. The Europa Uomo study which was reported in 2022 provided useful information about the quality of life implications of radical prostate cancer treatments 5 years after treatment for almost 3000 men. Another question asked the men 5 years after radical prostate treatment at an average age of 71 years to comment on their perception of sexual problems 5 years after treatment.

C. Consultation with a Specialist The final step in choosing the best treatment for prostate cancer is consultation with a specialist. This can be a urologist, radiation oncologist, or medical oncologist, depending on your specific needs and treatment plan. A specialist can help you understand your risk group, the available treatment options, and the pros and cons of each option. They can also help you understand the expected outcomes and side effects of each treatment.

Summary of the article The article discussed the various treatments available for prostate cancer, starting with early-stage prostate cancer and progressing to intermediate stages. The article also emphasized the importance of understanding one's risk group, the potential side effects of each treatment, and the need to consider quality of life when making treatment decisions.

Importance of early detection and treatment Early detection and treatment of prostate cancer is crucial in ensuring the best outcome. Regular screening tests, such as the prostate-specific antigen (PSA) test and biopsy, help to identify prostate cancer in its early stages, which increases the chances of successful treatment. By detecting the cancer early, individuals can choose from a range of treatment options and avoid more aggressive treatments that may have a greater impact on their quality of life.

C. Impact of Precision Diagnostics Advanced diagnostics, MRI and PSMA scans combined with precision biopsies, have made it possible to understand the location of prostate cancer and to enable improved decisions about treatment options for men. They have also facilitated the development of minimally invasive Focal Therapy treatments which offer many men with organ confined disease a minimally invasive and low side effect treatment option. They have also supported increased sophistication for surgery and combination hormone and radiotherapy options which are improving cure rates and significantly reducing side effects.

Sex after Prostate Cancer Treatment : What You Need to Know Sex after Prostate Cancer Treatment : What You Need to Know Active Surveillance and Focal Therapy preserve male sexual function Radical prostate cancer treatments damage male sexual function 76% of men rate their sexual function as poor 5 years after radical treatment Significant penile rehabilitation is

needed after radical treatment Intimate communication with wives or partners can help to preserve relationships Prostate cancer is the most common form of cancer found in men in the UK, with over 47,500 men diagnosed each year. These men have fully curable prostate cancer with a variety of treatment options available to them. The first question many of them ask after understanding that their prostate cancer can be cured is "How will prostate cancer treatment affect my sex life ?" In this article, we will explore the link between prostate cancer, decisions about treatment options and a man's sex life, his level of sexual desire and the impact on intimacy and relationships with partners. This report was the result of a detailed survey of 2,900 men with an average age of 71 who had been first diagnosed with prostate cancer at an average age of 66, 5 years earlier. It was reported anonymously and is regarded as the most reliable report on this subject at this time. Prostate cancer treatment damaged the sex life of 73% of men Prostate cancer and sexual health can be difficult and sensitive topics to discuss. So, whether you or someone you know has been affected by prostate cancer, we hope that this article will provide the information and support you need.

The Link Between Prostate Cancer and Sexual Function

The male reproductive system is a complex network of organs and tissues that work together to produce and transport sperm, as well as facilitate sexual function. The primary organs of the male reproductive system are the testes, which produce and store sperm, and the penis, which is responsible for sexual arousal, and ejaculation. Established whole-gland, Radical Prostate Cancer treatments offered to men in the UK cause:

- Erectile dysfunction: the inability to achieve or maintain an erection sufficient for sexual intercourse.
- Reduced libido, or a decreased interest in sexual activity, is a side effect of combination hormone and radiotherapy treatment.
- Loss of fertility: fertility is lost due to the loss of the ability to produce semen or to ejaculate.

Men experience feelings of anxiety and shame related to their sexual function which can impact their relationships with their partners. Clinicians often over-emphasise cancer control and underestimate the psychological and emotional importance of a healthy sex life to men and their wives or partners. Many prostate cancer patients who have localised prostate cancer would choose to trade off a small increase in cancer risk in return for the ability to maintain an active sex life with their wives or partner. "A lot of men have said to me over the years that they would rather be sexually potent... sexually active, than not being sexually active and having their cancer cured." – Lorraine Grover, Psychosexual Nurse Specialist

Treatment options for prostate cancer vary depending on the stage and type of the disease, as well as the overall health of the patient.

Prostate Cancer Treatment and reduced Sexual Function

Prostate Cancer is a disease of older men and it is important to be aware that about 40% of older men have impaired sexual function by the age of 71. This can be attributed to factors such as diabetes, heart disease, stress and anxiety and general ageing. Results of the Europa survey of 2,940 men with an average age of 71, 5 years after treatment for prostate cancer are shown below. The men were asked about their sexual function and quality of life after prostate cancer in a series of questionnaires. 5 years after radical prostate cancer treatment 76% of men rated their sexual function as poor and only 10% of men felt that their ability to function sexually was good or very good. The extent of this impact is rarely fully explained to men before they decide to proceed with radical prostate cancer treatment and has been shown to lead to significant levels of post-treatment regret. Given the significant impact on sexual function and quality of life from radical prostate cancer treatment, the question is how to advise men before their treatment decision and how to help men after treatment to accept penile rehabilitation to minimise their loss of sexual function and to engage in intimate communication with their wives or partners to minimise relationship damage.

Sexual Impact of the Prostate Cancer treatments options

Based upon the Europa Uoma study we have unbiased survey information on the sexual impact of prostate cancer treatments 5 years after treatment.

Active Surveillance

The Active Surveillance cohort did not have any treatment and therefore their level of sexual function can be considered normal for their age group. For men with early-stage prostate cancer which is unlikely to become clinically significant Active Surveillance is preferable to radical treatment. (Gleason score 3+3=6 or small volume 3+4=7) This is especially true for men who are older and where the likelihood of their prostate cancer developing to become clinically significant and having any impact on their quality of life or mortality is low. These men do need to continue to monitor their prostate cancer to ensure that it does not progress through PSA tests, occasional MRI tests and a biopsy if there is evidence of significant progression then they will proceed to the definitive treatment. Active Surveillance should be considered as the first treatment in order to ensure the best quality of life.

B. Focal Therapy

Modern Focal Therapy treatments for prostate cancer were not reviewed in the Europa Uoma study. Focal therapies which rely upon precision imaging and diagnostics are easily tolerated day-case procedures with minimal impact upon sexual function. In clinical trials conducted in the UK more than 95% of men with adequate function before Focal Therapy

treatment had no sexual problems 6 weeks after treatment. Men can have sex or masturbate once the catheter is removed but will notice that they produce less semen than before and may experience infertility. Focal Therapy treatment for men with localised prostate cancer has equivalent success in controlling prostate cancer to surgery or combination hormone and radiotherapy treatment. Potentially up to 55% of men who are diagnosed with prostate cancer in the UK are eligible for Focal Therapy options. Focal Therapy offers a middle way between Active Surveillance and Radical Prostate Cancer treatments. Focal Therapy provides excellent cancer control at 8 years with minimal impact upon sexual function or urinary continence.

C. Surgery and Robotic Prostatectomy In the NHS the established standard of care for younger men with localised prostate cancer is Robotic Prostatectomy using the high-precision De Vinci Robot system. Prostate surgery is a significant invasive operation which takes between 6 and 10 weeks to recover from. In the Europa Uomo survey, after 5 years, 38% of men were still using 1 pad a day and 20% of men felt that dripping or leakage is a moderate or big problem for them. The Europa Uomo study has shown that 62% of men with good function before treatment will lose it permanently and that less than 10% of men will have a quality of erection as good as before treatment even with the use of Viagra/Cialis tablets. After surgery, men have no erectile function however 50% of men who had a nerve-sparing procedure can hope to recover erectile function sufficient for intercourse within 6 months of treatment. Men will notice some shortening of their penis and will no longer ejaculate semen but can have a Dry Orgasm. Men will no longer be able to have a child naturally and there is a risk of some urine leakage during orgasm. Radical prostatectomy is an effective in terms of cancer control however it is invasive and has a major impact on urinary incontinence and sexual function. The Europa Uomo study shows that at 5 years after Robotic Prostatectomy 55% of men report that the loss of sexual function is a major or moderate problem in their lives.

D. Hormone Therapy and External Beam Radiotherapy Treatment A combination of Hormone therapy and External Beam Radiotherapy treatment is the standard of care for men whose prostate cancer has progressed beyond the prostate gland or who are not robust enough to withstand surgery. The combination of Hormone Therapy (Androgen deprivation therapy) with Radiotherapy has been clinically proven to improve survival rates. Hormone Therapy lowers the expression of testosterone dramatically leading to a reduction in the size of the prostate before radiotherapy. It is normally given for 3 to 6 months before radiotherapy treatment and may be continued for some years afterwards in cases where there is a concern about a risk of extracapsular extension. This therapy promptly leads to a loss of libido and can cause muscle wastage, reduction in vitality and energy and mental alertness. Men need a rehabilitation exercise programme afterwards if they wish to recover their muscle strength and vitality. External Beam Radiotherapy is typically given over 30 days or so with more modern SBRT protocols providing higher doses over a shorter time frame. After the treatment men will suffer fatigue but will typically recover within 3 to 6 months. Urinary problems are rare and bowel irritation and continence issues have been greatly reduced in recent years. Men can have sex or masturbate after their treatment but most will need some time to recover their libido. Men may recover erectile function within a few months however many will see a gradual decline in function during the first 15 months after treatment due to radiation-induced damage to the nerves which control erectile function. The Europa Uomo study shows that at 5 years sexual problems after Hormone and Radiotherapy treatment are a major or moderate problem for 45% of men.

Penile Rehabilitation after prostate cancer treatment After radical prostate cancer treatment, all men will experience some degree of erectile dysfunction due to nerve damage or other factors related to the surgery or their combination of hormone and radiotherapy treatment. Penile rehabilitation is a form of sex therapy that aims to minimise damage to penile tissue and penile size following prostate cancer treatment to help men to recover some of their erectile function. Frequently men are overly optimistic that they will not experience treatment-related adverse effects or, if they do, they tend to assume that their recovery will be quick and unassisted or that erectile dysfunction treatment will be readily available and easy to use. They experience distress when they learn of the extent of physical rehabilitation required and many men abandon the use of erectile treatments even when effective in producing an erection, as treatments are often not easily integrated into couples' sexual lives. Penile rehabilitation involves a combination of medication, penile injections, vacuum pumps, sexual stimulation and/or penile exercises performed regularly by the man. The goal is to improve blood flow to the penis and to keep penile tissue oxygenated and stretched in order to rebuild penile tissue and minimise penile shrinkage. Medication + Cialis and Viagra are oral drugs that have been a major help to men with erectile dysfunction ED issues. These medications help men to have an erection when aroused and are compatible with most couples' sex lives. After prostate cancer treatment it may be necessary to take these medications for

many months. This is necessary to have sex or masturbate but also to maintain long-term penile function and health. A constricting ring can be applied around the base of the penis to allow the erection to be maintained for sex. For maintenance of penile health after surgery or when on hormone therapy men need to use the Vacuum Pump to achieve erection and deflation for 10 minutes every day. Vacuum Pumps are very safe to use but not all men or couples are comfortable with them or find that they can be integrated into a fulfilling sex life. Injections + Men can be provided with access to penile injection treatments using a tiny needle to inject medication into the base of the penis. These injections are effective at generating a natural-looking erection within 5 or 10 minutes that will last for approximately 1 hour. A sexual therapist can teach a man how to make injections into the side of the penis with a tiny needle. Similar to Vacuum Pumps, Injections can be used to help to maintain penile health during the period when inflamed nerves are recovering after radical prostate cancer treatment or when men are on hormone therapy. This needs to be done 3/4 times a week until the nerves have recovered or the hormone therapy has worn off. Penile Prosthesis Surgery + Penile Prosthesis Surgery is an option for men for whom other treatments are not effective or do not fit into their sexual life. The majority of men choose an inflatable option so that they can easily control the timing of their erections. All men will experience some deterioration in sexual function after radical prostate cancer treatment. Coping with the deterioration in sexual function after radical prostate cancer treatment is a challenging and emotional experience for men but also for their wives or partners. If action is not taken it can lead to a breakdown of relationships as men react by withdrawing from intimacy and losing confidence and motivation. The core strategy for coping and reducing harm from these changes is to maintain an open and honest dialogue with wives or partners ideally starting before the decision on treatment options is made. This helps to reduce feelings of shame or isolation and allows for the exploration of new ways to share intimacy. Prostate Cancer Support groups and online forums are available that provide a safe space for men and their partners to share their experiences and connect with others who are going through similar challenges. These groups can offer a sense of community and support, as well as provide practical advice and strategies for coping with changes in sexual function. By taking an active and collaborative approach to manage sexual side effects, men and their partners can significantly reduce the impact on their relationships. Fertility after Prostate Cancer For men and couples who wish to have children in the future prostate cancer treatments pose significant issues as after treatment it will be difficult to conceive naturally. Radical Treatment of the prostate gland will make men infertile as the whole gland has been treated. Focal Therapies are likely to impact fertility and the ability to conceive naturally as the volume of semen produced will be reduced and there is a risk of damage to the seminal vesicles. For men and couples who wish to have children after prostate cancer treatment procedures such as sperm freezing or testicular sperm extraction before treatment are recommended. Make sure you speak to your surgeon and express your desire to explore fertility-preserving treatment options before you start prostate cancer treatment. Men and their wives or partners need to understand the trade-offs between minimising the risks of advanced prostate cancer and the quality of life implications of radical prostate cancer treatments for men with organ-confined prostate cancer. Men need realistic information about the likely impact of radical prostate cancer treatment on their sexual function so that they can take action to minimise its impact upon their quality of life. By speaking openly about these issues with a partner and healthcare professionals and by researching actively themselves, men can take an active role in choosing the right treatment option for them based on their clinical diagnosis understand the trade-offs between prostate cancer treatment and a healthy sex life, reduce the risk of relationship breakdowns, explore ways to maintain intimacy. Busting myths around prostate cancer Living in an era of information overload is challenging; and in the case of healthcare the sheer quantity of information ranging in quality is overwhelming at best and harmful at worst. Our patients tell us some incredible things that they've been told and advised in their journeys to our clinic. Last week Prostate Cancer UK raised this question on social media: "What myths do you hear most often about prostate cancer? What do people say that winds you up?" The answers included "The PSA test does more harm than good" "It's a good cancer to get" "It's an old man's disease" This inspired us to go through patient notes and share some of the myths our patients have heard, and which have been successfully busted in their experience with us. Prostate cancer will ruin your sex life This "warning" was recounted by former TFTC patient Tim in our recent blog, whose father had endured hormone therapy for his prostate cancer and encouraged his son to seek alternative treatment if possible. Brian did exactly that and, following NanoKnife treatment last year, maintains healthy sexual function. Brian and his dad sum up the reality of prostate cancer and sexual function – prostate cancer treatment can, and often does, negatively impact sexual function. But non-invasive treatments such as focal therapy --- suitable for men

with localised prostate cancer – will treat cancer leaving sexual function intact. A recent European study showed the harsh reality of invasive treatment for prostate cancer treatment, concluding “The outcomes of the unique, patient-driven EUPROMS study revealed the significant and non-negligible impact of prostate cancer treatment on sexual function” Prostate Cancer campaigner Elvin Box speaks openly and honestly about the impact his prostate cancer surgery has had on his sex life, and urges men to be aware of these effects and to be tested early so they can avoid radical treatment. The best chance of avoiding the risk of a ruined sex life from prostate cancer is early detection and noninvasive treatment. For many men, radical treatment for prostate cancer can be avoided through regular PSA testing, a diagnostic pathway led by MRI including precision fusion biopsy. Those found suitable can undergo noninvasive focal therapy, whose beneficiaries experience high levels of satisfaction and low levels of regret as compared to those undergoing radical treatments – evidenced in a recent multicentre study. Those who have undergone radical treatments can benefit from advice and support from sexual health professionals like Lorraine Grover and bloggers such as Recovering Man. Prostate cancer will put you in nappies for the rest of your life. This concern is what drives many men to our clinic, and the reasons why it doesn’t have to be the case are similar to the ones outlined above for sexual function. Radical treatments for prostate cancer will impact continence, but this can be avoided with noninvasive treatment such as focal therapy. All men should be counselled about the possible impact of prostate cancer treatment on their continence, and men who are impacted should be directed to specialists who can help. PSA testing is ineffective. Before the precision diagnostics we use now were available, the risks of overdiagnosis from a simple PSA test were high and felt by patients and clinicians alike as “blind” biopsies led to too many men having their lives harmed through prostate surgery. It was also acknowledged that an elevated PSA did not indicate cancer per se, and often indicates non-cancerous inflammation or infection of the prostate. Now that the diagnostic pathway has changed so significantly, and the evidence for focal treatments are building, the risks of overdiagnosis and overtreatment from a simple PSA test have reduced considerably. The MRI pathway is now well established and has demonstrated it can reduce the number of both lifetime biopsies and overdiagnosis by approximately 50%, according to a recent study published in JAMA. Just this week Prostate Cancer UK has announced a new approach to PSA testing based on this argument, presented visually here:

Your doctor always knows best. While your doctor is almost certainly a well-trained and committed professional who bases decisions on evidence, s/he doesn’t necessarily have access to all evidence, and doesn’t know you as well as you know yourself. The majority of our patients come to us for a second opinion, often following treatment recommendations and sometimes diagnoses that have been questioned by our clinicians and which didn’t feel right with patients. You’re an old man at 70. Most men in the UK at 70 can expect to live another 12 years, based on current life expectancy data. The old adage “you’re as young as you feel” is beginning to build evidence as we enter an era where one’s biological age – as distinct from one’s chronological age – is becoming measurable. So, for example, a man who has a chronological age of 70, or has lived for 70 years, may have a biological age of 50 as measured by biomarkers which in turn are influenced by lifestyle factors which include diet and exercise amongst a range of other factors. And it’s important to realise that not everyone in healthcare subscribes to this view and we have seen age discrimination occur, even in the persistent tendency to describe prostate cancer as an “old man’s disease”. NanoKnife, enhanced patient choice and the case for prostate cancer screening. Adding NanoKnife to our clinical offer of focal treatments to patients has been eye-opening on a number of levels. Not only has it revealed both clinician enthusiasm and patient satisfaction, but it has reinforced our commitment to improving the early detection of prostate cancer and has accelerated our drive to improve access to screening. Two recent Focal Therapy Clinic patients and their consulting urologists offer insights. Brian Bishop underwent NanoKnife treatment in May 2022 with TFTC Urologist Marc Laniado. Aged 77, Brian lives an active life and upon being diagnosed with localised prostate cancer, was briefed comprehensively by Marc on his treatment options. Brian spoke to us recently about his experience and expressed how his decision to opt for the NanoKnife over prostatectomy or radiotherapy was a “no-brainer”.

“Marc described everything in detail and I had absolutely every confidence in him” said Brian. “Because of the location of the cancer, Marc felt that NanoKnife was preferable to HIFU and that he felt it would be successful – and it has been”. “The post-procedure MRI scan showed complete eradication of the cancer, and a blood test three months later showed that my PSA level had returned to normal. Obviously I was delighted with the result and I could see that Marc was also delighted with it as well – win-win all around basically”. Asked how he would advise men with a diagnosis similar to his, Brian commented “Well, if you’re deemed suitable for the procedure, it really is a no-brainer. I think, to go down this line first is the only way if you want to

minimise your possible after effects. I mean, the procedure was minimally invasive, it was quick, as I say, a day case in hospital, totally painless. I've actually come out of a dentist after a filling and felt more discomfort than I have with this, so totally painless. And in my experience, I've had no lasting after-effects whatsoever". Tim Haskey is another TFTC patient who, at 54, actively searched for a second opinion hoping to find an alternative to the treatments he had been offered upon diagnosis. Prior to his diagnosis, Tim had a high level of awareness about prostate cancer and the effects of treatments for it, as his father, aged 82, had been diagnosed years earlier and was undergoing hormone therapy. Like many men, Tim arrived at diagnosis asymptomatic, having requested a PSA test from his GP at an annual review for another condition. The result led to an MRI and biopsy with a diagnosis of Gleason 6 localised prostate cancer, and he was given the options of removing prostate or "doing nothing." Tim describes his father's response to his son's diagnosis: "He told me it would ruin my sex life and to seek every option possible". And so he did and found TFTC and Consultant Urologist Alan Doherty who reviewed Tim's imaging and following MDT with the TFTC clinical team determined that Tim was a suitable candidate for focal therapy. Given the location of the cancerous lesions on his prostate, NanoKnife was selected as the optimal treatment. Tim believes strongly that men must be advised of all treatment options, and that early detection is essential especially now that "new technologies in imaging and non-invasive treatments are effective and won't compromise quality of life". It's this belief that is driving him to fundraise for Prostate Cancer UK through a sponsored walk at Easter. If you'd like to support Tim, the link to do so is [here](#). TFTC Consulting Urologist Marc Laniado has been practicing focal therapy for almost two decades with a range of modalities, and he is very keen on what NanoKnife offers to both patient and clinician. He spoke passionately about its impact in a recent OnFocus podcast. Asked about his views on growth in the use of NanoKnife, Marc gave three insights into why he believes growth is inevitable. First, he pointed to the increase he's seeing in patients with anterior lesions – those presenting at the front of the prostate gland – which are ideally suited for NanoKnife treatment. He describes how an 80-20 rule has applied in the past, with 80% of lesions presenting at the rear (posterior) of the gland, and 20% at the front. "But since we've introduced MRI scans to diagnose prostate cancer, we're finding many more men who have cancer at the front of the prostate. These men often weren't diagnosed for many years," he says. Why not, he's asked. "they weren't diagnosed because we did transrectal biopsies through the back passage, so only ever sampled the back of the prostate. But with the advent of MRI and transperineal biopsies, which enable us to sample the front of the prostate more effectively, we're identifying more men with cancers at the front of the prostate. Hence the number of men potentially suitable for NanoKnife or similar technologies will increase." Second, Marc believes that the continual improvements in the precision of imaging and biopsies allow for better margins in ablation, improving outcomes and safety for patients. Third, as more men become aware of less toxic treatments for prostate cancer they will hopefully be incentivised to come forward for screening. "Early diagnosis gives men more treatment options," he says. Alan Doherty, Consulting Urologist at the Birmingham Prostate Clinic and the Focal Therapy Clinic, is another advocate for the benefits of NanoKnife, from a clinical practice perspective as well as patients'. A newcomer to the procedure, Alan has been impressed with the precision, speed and impact of the IRE approach to focal therapy. "For a clinician it gives us a high level of control around the ablation area, and its impact is almost immediately measured in post-treatment MRI" he says. "This gives us as close to a tangible result as possible with a non-invasive procedure." Alan believes that adding NanoKnife to the range of focal treatments available to men with localised prostate cancer will increase the number of men undergoing them who benefit from good outcomes with minimal side effects. Like his colleague Marc Laniado, Alan feels this will have a positive impact on early diagnoses of prostate cancer. "In my view this will inspire more men to come forward for screening", he says. A reduction in the "fear factor" of prostate cancer treatment would undoubtedly motivate many men to seek testing. The reality is that the clinical advancements that are increasingly making focal treatments safe and effective and support its implementation also support the rationale for early testing. We have the tools for highly precise diagnoses of prostate cancer, enabling highly precise treatments that are well tolerated with minimal side effects. With an early, precise diagnosis men can avoid radical procedures and undergo curative treatment that maintains their quality of life. This is the message that motivates former patients like Brian and Tim to speak openly about their experience with prostate cancer and, in Tim's case to take on fundraising challenges. It's also what drives clinicians like Marc and Alan to embrace and master these tools and treatments. Do you have comments you'd like to share on precision diagnostics, focal treatments and improving early diagnosis of prostate cancer? NanoKnife is giving more choice to patients Marc Laniado, Consultant Urologist at with The Focal Therapy Clinic and a leading innovator in

imaging led diagnostics and targeted treatments for prostate cancer is today's OnFocus guest. Marc has been a vocal advocate for the rights of patients to be informed about their treatment choices from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital. He's also a dedicated practitioner in optimising treatment choices for patients, and has built a reputation in identifying and delivering the right treatment for each patient, based on precise diagnostics and comprehensive discussion about lifestyle, aspirations and relationships. He's here today to speak with me about a relatively new treatment -- IRE focal therapy, also known as the NanoKnife -- that he's been offering to patients and how he sees this developing in future.

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Marc Laniado, consultant urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a vocal advocate for the rights of patients to be informed about their treatment choices from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital. He's also a dedicated practitioner in optimising treatment choices for patients and has built a reputation in identifying and delivering the right treatment for each patient based on precise diagnostics and comprehensive discussion about lifestyle, aspirations and relationships. He's here today to speak with me about a relatively new treatment, IRE focal therapy, also known as the NanoKnife, that he's been offering to patients and how he sees this developing in the future.

I know we haven't talked in a little while, so happy New Year and I guess I can still say that in February.

Clare Delmar So we're all very excited about NanoKnife, and I've spoken to a number of your patients, so I'm really interested in hearing about it from you. And I guess the best way to start our conversation is to put it in the context of focal therapy, which you've been providing to patients for, I mean, I'm going to say a decade.

Marc Laniado Using HIFU treatments anyway and I've been treating men for prostate cancer and diagnosing it for over 20 years. So one of the things we've talked about before is how the sort of portfolio, if I can call it that, of modalities or various forms of focal therapy are really expanding and I mean, possibly even accelerating in the last few years. And there's a lot of attention and a lot of excitement around NanoKnife, which you have embraced wholeheartedly.

Marc Laniado Well, as you identified, NanoKnife is a new treatment, so I've treated hundreds of people for focal therapy using HIFU, and in the last year I've adopted the NanoKnife procedure for men. So currently we're treating about three or four men every month, possibly five men a month by NanoKnife to deal with prostate cancer, particularly in certain locations of the prostate. And to date, we've treated about eleven patients entirely by using this technology and as I said, we have patients coming through every month and actually an increasing number of patients are wanting it as it becomes known that we can offer this treatment as one of the ways of dealing with localised prostate cancer.

Clare Delmar Yes, that's one of the things I want to ask - what are the common features in terms of both the clinical disease and the lifestyle choices of the patients who are a) suitable for NanoKnife treatment and b) excited about undertaking it?

Marc Laniado So most of the men who come to see us to talk about focal therapy are men who are still young at heart. They're still active, vibrant, living life, perhaps to its full, hopefully to its full, exercising, cycling, playing golf. And it's been a big shock to them in many ways because they want to live their life to the best that they can. And so most of the men we see for this tend to have relatively smaller cancers perhaps than the large ones, which need, will definitely need radical treatment. So they're men who have an area of the prostate that has prostate cancer so not the whole amount and they typically have intermediate grade cancers as well. So it's what are called ISA grade group two or three or also known as Gleason score three plus four or four plus three equals seven. So that's the intermediate group and sorry for using technical language, but they're men who have, as I say, these small intermediate risk cancers which often, are said, perhaps suitable for treatment or perhaps for monitoring. And so now these men are also being told well, you have a cancer potentially we can treat it radically or we can monitor it and watch it and see what happens and intervene later. And they're being offered the treatments or ways of managing the prostate by active surveillance because the active treatments themselves have quite significant side effects, as most of us well know. So radiotherapy can induce changes to the bladder and the bowel, giving rise to diarrhoea and having to pass urine very frequently and urgently, as well as quite significant fatigue. Surgery - even if you do surgery very well, which many of us do obviously, it can still have side effects with problems of erections commonly. So if you're a young man, 50s or 60s, with cancer that's been told said to be intermediate in risk and you still want to enjoy a sexual relationship, it's quite a difficult decision then to decide whether to take the risk of active surveillance or go ahead with treatment and take the risk of having that treatment.

Clare Delmar

Indeed. So, you've talked a lot about HIFU, which is you've been providing for decades, as you said. How does the NanoKnife differ both in terms of - this is a big question - but in terms of the energy source that's actually ablating the cancer that you've just described on the patient's prostate gland and secondly, are certain types of cancers of the prostate more amenable to NanoKnife treatment versus, say, HIFU? Marc Laniado So ablation means destruction or killing of cells, and we can achieve that by several means. It heats the tissues to 55 degrees or more, and no carbon based life form can survive that temperature for more than a few seconds or more. A series of electrical currents, a direct current, are passed through the cells between electrodes, and the electricity breaks down the cell membranes of the cancer cells, which results in the cells dying. And the benefit of this technology is that it tends to spare the surrounding matrix, which supports the cells. So, for example, the tissue structure is important for continence, and the nerves and other structures around tend to be preserved more effectively than by, say, HIFU or cryotherapy, which is when you freeze the prostate. HIFU, high intensity focused ultrasound, is performed by placing a probe in the back passage to pass ultrasound energy through the rectum, whereas Nanonife is performed by putting probes or electrodes through the skin between the anus and scrotum called the perineum to surround the tumour. So about 20% of the cancers you have tend to be at the front of the prostate, one in five, whereas HIFU is probably best suited for cancers at the back of the prostate close to the rectum. So we can use the location of the cancer to help decide which might be the best treatment for the patient if he wants to have focal therapy. Marc Laniado The evidence is judged on clinical trials, and the clinical trials are assessed by the National Institute for Clinical Excellence, NICE, in this country and various other bodies throughout the world. They've been several systematic reviews and meta analysis which show that the treatment works in the sense that we know that we can ablate the tumours, we can destroy the tumours, and we know that the patients have a good PSA reduction and most people do not need additional treatment within about eight years. What we don't have, we don't have traditional randomised controlled trials where one therapy is pitted against another, in which men are literally they're randomised to, say, surgery or radiotherapy or NanoKnife or HIFU or cryotherapy. And what's pretty clear is that the side effect profile of NanoKnife and HIFU compared to standard treatments is much better tolerated. Marc Laniado Between NanoKnife and HIFU, it seems that the preservation of erections is better with NanoKnife. It might be related to the energy, but it also could be related to the selection of patient men who have cancers at the front of the prostate. Marc Laniado I don't think it's entirely clear whether it's just down to the technology, but certainly there's no incontinence. Most men preserve their erections, although there may be a dip immediately after treatment, most men preserve their erections at one year. Most men are very attracted to that, to be able to deal with the cancer and yet preserve normal quality of life. One is that, as I said, NanoKnife is really ideally suited for cancers at the front of the prostate. And since we've introduced MRI scans to diagnose or find prostate cancer, we're finding many more men who have cancer at the front of the prostate. Marc Laniado Yes, they weren't diagnosed because we did transrectal biopsies through the back passage, so only ever sampled the back of the prostate. But with the advent of MRI and transperineal biopsies, which enable us to sample the front of the prostate more effectively, we're identifying more men with cancers at the front of the prostate. Hence the number of men potentially suitable for NanoKnife or similar technologies will increase. And furthermore, although there is no actual screening programme in this country, in the United Kingdom, for prostate cancer at this time, we're certainly seeing that more and more men are keen to find out if prostate cancer is present. And so more men are presenting with early prostate cancer, cancers that are right at the very beginning and actually are most amenable to treatment. These are the men who have often been told to go on to active surveillance because they're small tumours and the benefits from radical prostatectomy or radical radiotherapy relative to the side effects is not thought to be great. That's because the side effects of the traditional radical treatments are so toxic or potentially so toxic. So when we have a new way of managing cancer or treating cancer which has much less side effects, more men are going to say actually yes, I have to have this treatment on the basis it's less likely to cause problems. You have the least amount of open quote collateral damage, close quote, most likely to be a lower grade and so more sensitive to treatments that can kill it. Then you may have to treat areas include the nerves also it may become inherently more resistant to the treatment you deliver or it could already have metastasized at that and we often we don't find that out for many years. In conclusion to your question, yes, I absolutely do think that NanoKnife will increase as a treatment option for men for prostate cancer and I will be doing much more of that in my practise. I want to pick up on what you said just now about you mentioned about presenting early and you mentioned even coming forward for screening, knowing that there and I wanted to kind of connect this between focal therapy and screening because it's

interesting to note that while this so called supply of focal therapy treatments has been increasing, we've discussed that HIFU and we didn't talk about cryotherapy, but that's out there and now obviously NanoKnife. But the demand seems to be moving in possibly a slightly different direction, not because fewer men are developing prostate cancer, but more men are presenting with more advanced disease and maybe less likely to be suitable for focal therapy. And then what I'm wondering is if this raises the issue of cancer backlogs and better screening and do you see then a correlation between screening? Because then you get, as you said, early presentation and then as you also said, more suitability for treatments like focal therapy which as you said, are less toxic and very effective. There are many people still waiting to be assessed with COVID and the problems associated with that. We know in our local area that there's a huge number of undiagnosed patients who eventually may come through but haven't been found so far. But over time hopefully that will disappear and we will find we're back to our normal way of doing things. Yes, I do hope that with better recognition of the potential for dealing with early prostate cancer in an easy way, that more people will come forward to have the test and more people will go into the treatment measurements that allow them to have these therapies and hopefully be free of cancer going forward. I mean, do you think that men are put off coming forward because they're afraid of the outcome of not just obviously having cancer, but also because they have heard that the treatment itself is, as you say, so toxic? Marc Laniado I think even today in the news, I was reading an article about the young man in his 50s. He was terrorised at the thought of having the treatments and a test which might be painful and unpleasant. But he was put off by the thought of urinary incontinence, loss of erections, bowel problems, all those issues which people have heard about when they look into the potential outcomes of what happens if you're diagnosed with prostate cancer. But I think if we recognise that actually it's not quite so bad as it was and that, again, it's much easier to deal with a problem when it's small than when it's large. Clare Delmar Of course Marc Laniado ... more people become accepting that we should be moving forward with this. I mean, it beggars belief that we're still very reticent about diagnosing and treating prostate cancer in the United Kingdom. We're quite different to many other countries in the world where there is a much more proactive approach. You do need to have a properly performed MRI scan and then properly collected prostate biopsies and to be sure about the location and the type of cancer that's present. Otherwise everything else that becomes we can't manage prostate cancer with the least amount of side effects and the best benefit unless we have a good diagnostic pathway. Marc Laniado And that has been lacking in much of this country, especially up north unfortunately, but it is improving. We are seeing more MRI scans and we're seeing better biopsies, but there's still a huge room for improvement. We're still not seeing quite the benefit that we could by properly implemented MRI scans with the right protocols and radiologists to know how to interpret them, and then biopsies, which are actually definitely directed to the abnormality, which also leads on to treatment too. I mean, the other thing I didn't perhaps talk about is about image fusion for focal therapy. We know that biopsies are much better if you can look at the MRI scan, see where the tumour is and direct the biopsies to there. Similarly with the tumours, if you use the MRI to direct your treatment to the abnormality on the MRI, you're much more likely to get a good result. A doctor would look at his screen with the MRI images and look at his ultrasound machine to his side and they think, right, I'm going to merge these two images in my brain and I'm going to direct the needles or the therapy into this right area. Actually, it makes logical sense that if you can use a computer system or an AI system to digitally fuse the MRI scans with what you're looking at in real time, the ultrasound in real time, you're much more likely to be able to direct your biopsy or your treatment into exactly the right area and hence also create a better safety margin. Because not only do you have to treat the cancer, plus you have to create a margin around it. And computers are much better able to draw those areas that need to be treated than the human brain can. So I think in time, as these additional technologies get embraced by urologists or other people delivering treatments or making diagnoses, we'll see the precision of the treatment will be much better, the benefits will be higher and the side effects will be less. But I have to say this has been fascinating and I really want to thank you for your time and we'll be really excited to see as patients come forward, the ones that have, I know, have spoken to me about how extremely pleased they are with everything, the whole process from beginning to end. A transcript of this interview is available on our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. "My Experience with NanoKnife" Brian Bishop joins OnFocus to discuss his experience with NanoKnife treatment for prostate cancer. Brian is 77 and lives in Virginia Water since retiring from a career in the airline industry, and was diagnosed with prostate cancer in May 2022. A few months later

he was treated by TFTC Consultant Urologist Marc Laniado with a form of focal therapy that uses electric current to ablate cancerous tissues, also known as the NanoKnife. Clare Delmar Hello and welcome to On Focus, brought to you by The Focal Therapy Clinic where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, and too often ignored. Joining me today is Brian Bishop, who is 77 and lives in Virginia Water since retiring from a career in the airline industry. Brian was diagnosed with prostate cancer in May 2022 and several months later was treated by Focal Therapy Clinic consultant urologist Marc Laniado with a form of focal therapy that uses electric current to ablate cancerous tissues, also known as the NanoKnife. Hope I can help anybody that...

Clare Delmar Yeah, well, you're like a pioneer here in having had the NanoKnife treatment, so we're very keen, and I'm sure our listeners are very keen to hear what you've been through. I was referred to consultant Marc Laniado by my GP following a routine blood test which came back showing an abnormally high PSA reading. The first consultation with Marc consisted of a physical examination of my prostate and he referred to that as suspicious and referred me for an MRI scan. The MRI scan showed two areas of cancer in the prostate which fortunately was contained, it hadn't spread from the prostate and he then decided to refer me for a biopsy or book me in for a biopsy. What were the options that you were considering for treating the prostate cancer that was diagnosed?

Brian Bishop Okay, well, basically because the cancer hadn't spread beyond the prostate, the focal therapy would be quicker, carry less risk of possible after effects than other procedures such as prostatectomy or radiotherapy, NanoKnife in particular, because it would be more accurate in targeting the position of the cancer within the prostate. I believe that the cancer was in quite a... certainly one of the cancer areas was in quite an awkward place of the prostate.

Clare Delmar Okay, and did Marc go through with you, first of all, how focal therapy worked, but secondly, the different ways to undertake focal therapy, the different sort of energy sources that are used to ablate the areas?

Brian Bishop Well, no, it was described in general terms or he described it in general terms as laser ablation. Brian Bishop Which would target the areas of the cancer without damaging surrounding tissue. And as a hospital day case, the most important thing would not preclude further treatment in the future if I required it.

Brian Bishop Yes it was because I didn't want to sort of close the doors on any future treatment if I needed it.

Clare Delmar Was any other treatment recommended or it was always going to be focal therapy? And he described the possible side effects or after effects of both of those procedures and basically it was a no brainer to have the focal therapy because that obviously carried the least side effects and because of the cancer, he said he felt that it would be very successful. So you felt that you had a pretty substantial briefing on the sort of trade off, if you will, between sort of getting rid of the cancer but also preserving your sexual health, your urinary health, even your mental health.

Brian Bishop Very much so and he described everything in detail and I had absolutely every confidence in him. A blood test three months after the procedure showed that my PSA level had returned to normal. Obviously I was delighted with the result and I could see that Marc was also delighted with it as well - win win all around basically.

Clare Delmar As you said before, when you're describing how it was presented to you, you went in as a day case patient, is that correct?

Brian Bishop Yeah, I checked into the hospital at 07:00 in the morning and I was home by about 07:30 at night. And I mean, did you have a sense of this being something that was not at all experimental but something that was actually very leading edge in terms of prostate cancer treatment? I didn't actually know the difference at that stage between NanoKnife and say HIFU, but I was told afterwards that he was using the NanoKnife procedure because of the position, the awkward position of the cancer in the prostate and he felt that that would be more accurate. So you knew about that that had to do with the location of the lesions...

Brian Bishop That's right.

Brian Bishop Yeah, that actually came to light when I got onto my insurance company to give them the procedure code and they questioned the code. I was thinking at that stage it was the HIFU, but they questioned the code and said that they required more information from the consultant, which he gave them. One of the cancer areas was very close to the urethra and he didn't obviously want to damage that, so that's why he felt that the NanoKnife procedure would be more accurate in dealing with it.

Clare Delmar Okay, so you really went into this with a pretty full sort of base of knowledge? And in fact, even on the day of the procedure, I think he had a couple of consultants observing in the theatre, observing the procedure as it was so new, they wanted to witness the procedure being carried out.

Brian Bishop I knew nothing about it, of course, at that stage, but I certainly didn't object. So it sounds like you would recommend this procedure to other men with a similar diagnosis. I think, to go down this line first is the only way if you want to minimise your possible after effects. I mean, the procedure was minimally invasive, it was quick, as I say, a day case in hospital, totally painless. I've actually come out of a dentist after a filling and felt more discomfort than I have with this, so totally painless.

Clare Delmar And also,

you felt very confident in Marc and the advice he gave, and you went in sort of fully understanding why and how it was going to work? Well, first of all, I just want to say thanks for sharing this information and it's wonderful news that this all went so well for you and hopefully we'll get a chance to talk to you again. But it's been extremely generous of you to join us and I want to thank you once again, Brian.

Clare Delmar

A transcript of this interview is available in the programme notes on our website, along with links to more information on NanoKnife and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

The NPCA Annual Report 2022: some questions answered, many questions raised

The National Prostate Cancer Audit is the first clinical audit of the care men receive following a prostate cancer diagnosis. Its specific objectives are to investigate:

- Service delivery and organisation of care in England and Wales
- The characteristics of patients newly diagnosed with prostate cancer
- The diagnostic and staging process and initial treatment planning
- The initial treatments that men received
- The experiences of men receiving care as well as their health outcomes 18 months after diagnosis

Overall and disease-free survival

Its annual report is a summary of these investigations, published in long form and short form, and provides comprehensive data on key indicators such as number of men diagnosed. The report also presents recommendations based on NICE guidance and clinical practice, and progress on these is tracked across annual reports. While the report is comprehensive and offers solid evidence for healthcare leaders, policymakers, clinicians, industry leaders and campaigners, when it comes to patients the report probably raises more questions than it answers.

Patients who come to the Focal Therapy Clinic are primarily interested in three things: side effects from prostate cancer and its treatment; support for side effects; and accessing non-invasive treatment such as focal therapy. Information on these areas is limited in the NPCA annual report.

Information on side effects is addressed though a recommendation to ensure that men who are offered prostate cancer treatment are "made aware of the side effects including: loss of libido, problems getting or keeping erections, loss of ejaculatory function, a worsening of sexual experience, urinary incontinence and/or bowel side effects." This recommendation references NICE Guideline [NG131], 2019 1.1.12 which advises healthcare professionals to "Tell people with prostate cancer and their partners or carers about the effects of prostate cancer and the treatment options on their: sexual function physical appearance continence other aspects of masculinity. Support people and their partners or carers in making treatment decisions, taking into account the effects on quality of life as well as survival. Very little follows on; a note about no change in percent of men "experiencing at least one genitourinary complication requiring a procedural/surgical intervention within two years after radical prostatectomy" and nothing about sexual function.

In terms of specialist support for side effects, another recommendation is to "empower patients to ask to be referred to specialist support services if they are experiencing physical or psychological side effects during, or following, prostate cancer treatment. These should be offered early and on an ongoing basis, in keeping with national recommendations." This recommendation references NICE Guideline [NG131], 2019 1.1.11 which advises care providers to "ensure that mechanisms are in place so people with prostate cancer and their primary care providers have access to specialist services during the course of their disease." This is further referenced by NICE Quality Standard [QS91], 2015 QS4: which advises that "men with adverse effects of prostate cancer are referred to specialist services."

The report presents no data to measure occurrence or impact of these recommendations so we cannot measure or assess if, when, where and to whom they are being implemented. We've discussed sexual, urinary and mental health aspects of patients' prostate cancer journey with patients and specialist support providers alike, who all agree that this is lacking comprehensively across the country.

In terms of focal therapy, the report provides no information, despite the availability and accessibility of data contained in a repository known as the HEAT Registry, which provides comprehensive information on men who have undergone HIFU focal treatment. This resource has been used in multiple studies which have begun to build the evidence base for focal therapy. Last year a seminal study demonstrated the impact of HIFU focal therapy over a 15-year period. "Cancer Control Outcomes Following Focal Therapy Using High-intensity Focused Ultrasound in 1379 Men with Nonmetastatic Prostate Cancer: A Multi-institute 15-year Experience" undertook an analysis of 1379 patients recorded in the HEAT Registry from 13 UK centres (2005-2020). Five or more years of follow-up was available for 325 (24%) patients. It concluded: "Focal HIFU in carefully selected patients with clinically significant prostate cancer, with six and three of ten patients having, respectively, intermediate- and high-risk cancer, has good cancer control in the medium term." And HIFU isn't the only story. New focal therapy modalities are also being introduced such as NanoKnife, currently undergoing a trial called PRESERVE (Pivotal Study of the NanoKnife

System for the Ablation of Prostate Tissue), adding to the number of patients choosing and undergoing focal therapy. Anyone looking at the NCPA would think that focal therapy doesn't exist. We would like to see the NCPA complete the audit by including information on focal therapy – specifically cases undertaken and a recommendation that all men are provided with information on all treatment options available to them. Too many men tell us they were not informed about the availability or even existence of focal therapy, and investigated alternatives the information themselves, often under considerable stress and anxiety. Men with localised prostate cancer deserve better. Have you been denied specialised support for side effects of prostate cancer treatment, or focal therapy? Seeking alternative treatment to maintain quality of life

Graham Pipe, a recent patient at the Focal Therapy Clinic who underwent HIFU treatment with Consultant Urologist Tim Dudderidge following a diagnosis of localised prostate cancer, joins OnFocus to discuss the process he went through to seek an alternative treatment which would maintain his active lifestyle. Age 70 and recently retired from a career as a Chartered Building Surveyor, Graham describes himself as Young at heart who loves travelling abroad and is married 47 years to the love of his life, who is a model.

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men who are diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Graham Pipe, a recent patient at the Focal Therapy Clinic who underwent HIFU treatment with consultant urologist Tim Dudderidge following a diagnosis of localised prostate cancer. Age 70 and recently retired from a career as a chartered building surveyor, Graham describes himself as young at heart, who loves travelling abroad and is married 47 years to the love of his life, who is a model. It's just good to be able to be able to talk to you and share my experience because I hope it's going to help other guys. Why don't you start by telling me and our listeners what was your initial diagnosis and the treatment recommendation that you were given at that time? I then had the usual MRI and then a transperineal biopsy, which was, to put it mildly, the most unpleasant experience I've ever had, far worse than anything that I experienced having the actual cancer removed.

Clare Delmar Can I just ask you quickly, is that because it was under a local anaesthetic as opposed to a general? I didn't know what was involved until I actually arrived there and having signed all the papers as usual, I went into the room and then I discovered what they were going to do. Graham Pipe Obviously after the healing, which took quite a few weeks, I had a phone call with the diagnosis, which was then followed up by a letter and pretty flat, the phone call was just very factual and included a lot of medical descriptions that I didn't fully understand, even though I had sort of Googled and investigated quite a lot. But the only recommendation given both by phone and the letter was a radical prostatectomy or radiotherapy. I did ask if there was any other choices, but they said that this was what they would recommend.

Clare Delmar Okay, so then why did you seek an alternative approach and how did that lead you to the Focal Therapy Clinic? One of my wife's cousins died of it when he was in his forties because it had spread to his liver or bladder. I had a biopsy probably about 10-15 years ago, which proved fine, but it was always in my mind. So I was very much aware of the problems relating to it and the very unfortunate and very common side effects. Me being me, no way did I want any of the side effects of either incontinence or impotence. So if there was anything that I could do, any procedure that was available and recommended, I wanted to look at. So that's what set me on that line, because I still feel young, though my body occasionally tells me I'm not.

Clare Delmar And so when you raised those concerns with your urologist that initially gave you the diagnosis and the treatment recommendation, was there a response to that? The only bright part of it was, and I wish I knew her name they assigned me a clinical nurse who phoned me, and she was actually really good, really lovely. But she did find out about them and came back to me and actually said that, yes, I could be referred to one of the few hospitals that actually do these procedures. But it was far too late then because I had already agreed to go with Tim Dudderidge at the focal therapy clinic. I mean, in addition to him offering you a different approach to your diagnosis and subsequent treatment, how did he build your confidence in focal therapy? Graham Pipe I was thinking about that because I first of all spoke to Brian Lynch on the phone. Now that's something I'm not used to in business or many other ways to have that prompt attention. What I found with Tim, who already - me being me - I researched him thoroughly to make sure he wasn't a charlatan. He was a man who just knew that he knew what he was talking about and had nothing to prove to himself or me. That might sound strange, but it's that that instilled the confidence in me, that he knew what he was doing. So when he said that, yes, I was an ideal candidate for focal therapy and that he could say there was a very high likelihood that my urinary problems would go and I would not have them again. Obviously, there was that small amount of doubt, but up to that

point, as you would appreciate, I was very fearful and worried because I thought, well, will I be a suitable candidate? So when at the consultation he said yes, we can, you've got an excellent chance of full recovery and beyond, lots of my worry went. I have absolutely no incontinence of any description and I'm fully sexually active without any side effects of any sort. I just want to pick up on what you said about the monitoring through MRI and the PSA testing. I mean, your journey clearly has been a blend of both NHS and private care through the focal therapy clinic. Because it's something that a lot of men will be facing and contemplating and don't fully understand, and I'm just wondering if you can offer just some either some red flags or some things that people ought to be looking out for and be mindful of.

Graham Pipe The difficulty is my experience, obviously, with the NHS, whenever it was for all the time, except the clinical nurse, was very poor - communication and everything else. **Graham Pipe** There may be a history to that, which actually I'm aware of, but once I got involved with the focal therapy clinic, everything changed. He had two staff, I think Kirsten and Natalie, that I dealt with, were incredibly helpful, guided me through all the procedures and everything else I needed to do. I knew that the procedure itself and even after the procedure, I'm not likely to get much pain. But the only thing I wasn't looking forward to was the catheterization, which I actually hated. But I would recommend that, assuming that, as in most cases, the initial contact will be with the NHS, that you ask the consultant or whoever is giving you the diagnosis lots of questions and to ask them to explain it in layman's language so you can understand whether or not there's a serious problem or whether it's a less serious problem. Because I was presented with a less serious problem, which became clear once I started researching it. And then being presented with the radical options, obviously it was considered, as it would appear to them as being a very serious thing with no other option. You need to ask questions including, of course, if a radical procedure is recommended, as in my case, that you then ask if there's any other alternatives and mention is focal therapy an alternative? There's only six or seven hospitals currently in over 130 NHS trusts which I believe are actually offering these procedures. And then they will be able to find out when talking, for example, to the focal therapy clinic, whether or not they are a good candidate, so to speak.

Clare Delmar Yes, I mean, the criteria for actually selecting patients for the procedure is quite rigorous, as you know, and involves quite a lot of discussion, involves an MDT. So I think it's an interesting question about what you would recommend to other men who have a similar diagnosis. You mentioned, for example, that your wife was involved in your conversations, even in some of the research that obviously drove you to achieve what you finally did undergo. Is there anything around partners or other aspects that you think you would want to recommend to someone in your situation?

Graham Pipe My wife and I communicate a huge amount about virtually everything, but a lot of men don't like to talk about this. **Graham Pipe** I want to encourage all men to be honest about it because if they can't deal with this before they have a procedure, then it's too late for many of them, with a dramatic effect on their lifestyle.

Clare Delmar Well, that's extremely helpful and I really want to thank you for coming today and chatting to us about it. Would you be willing to chat to other patients who might contact us, having listened to this interview? Because obviously I've got my own experience and I'm a firm believer in what Tim and his colleagues do for obvious reasons.

Clare Delmar Well, first of all, it's great news to hear that you've had such a wonderful recovery and I want to thank you once again for joining us and we look forward to possibly speaking again in the future.

Clare Delmar A transcript of this interview is available on the programme notes on our website, along with links to more information on diagnosis and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Prostate Cancer Treatment Focal Therapy: Fight prostate cancer with unmatched, targeted precision Non Invasive Surgery No Radiation No Hormone Therapy Non Invasive Surgery No Radiation No Hormone Therapy FEES £250 Consultation From £14,000 Procedure HIFU and NanoKnife treatment based upon advanced diagnostics. Focal therapy options such as HIFU and NanoKnife get rid of prostate cancer while leaving the rest of your body alone. As pioneers in this technology, the Focal Therapy Clinic offers safe and effective treatment that results in high cure rates, reduced side effects, and quick recovery times. Located in multiple locations across the UK, our team has successfully treated more than 500 focal therapy patients in the UK with world-class technology. The Right Time, the Right Treatment, at the Right Place It's hard to be diagnosed with prostate cancer. If you have early-stage or intermediate stage cancer, why settle for traditional radical treatment approaches that are invasive and have unwanted side effects?

BENEFITS OF FOCAL THERAPY Minimally-Invasive Technology Compared to traditional prostate cancer treatments, such as active surveillance, radical prostatectomy and radiotherapy treatments, the Focal Therapy Clinic offers: HIFU Focal Therapy Soundwave-based treatment Read More NanoKnife IRE Focal Therapy

Needle-based treatment Read More Both Focal Therapy treatments target and treat the cancerous areas without damaging the rest of your body – leading to less risk of urinary incontinence and erectile dysfunction. CANCER CONTROL UNMATCHED PRECISION REDUCED SIDE EFFECTS Minimal risk of incontinence Preservation of erectile function NON INVASIVE SURGERY NO RADIATION NO HORMONES Outpatient procedure Rapid recovery CANCER CONTROL OUTPATIENT PROCEDURE RAPID RECOVERY MINIMAL RISK OF INCONTINENCE PRESERVATION OF ERECTILE FUNCTION Request a Call Back WHY THE FOCAL THERAPY CLINIC? World-Renowned Doctors and Expertise The Focal Therapy Clinic is home to the world's most experienced focal therapy clinicians. In fact, after the one-year follow-up, all patients report zero incontinence and problems with erectile function. Minimally-invasive treatments, HIFU Focal Therapy and NanoKnife IRE Focal Therapy are recommended for men with up to intermediate localised prostate cancer. You might be a suitable candidate if your prostate cancer is: Early-Stage Localised Intermediate Stage Recurrent Am I suitable? The Focal Therapy Clinic multidisciplinary team (MDT) of urologists, oncologists, and uro-radiologists work together to develop the best possible prostate cancer treatments. The Focal Therapy Clinic can provide the world-class care you need to beat prostate cancer and reclaim your quality of life. Request a Call Back from Focal Therapy Clinic Today PRECISION TREATMENT For Prostate Cancer Focal Therapy is a general term for minimally invasive treatments for men with early-stage localised prostate cancer. These treatments have been pioneered and advanced in the UK by clinicians committed to offering men precision treatment options that effectively control their cancer and preserve their quality of life. The Focal Therapy Clinic offers patients HIFU Focal Therapy, and NanoKnife IRE Focal Therapy. More About HIFU Focal Therapy More About Nanoknife IRE Focal Therapy "Where appropriate Focal Therapy provides effective cancer control with minimal impact upon sexual potency or urinary continence." Mr Marc Laniado, Consultant Urologist at The Focal Therapy Clinic Download Free Info Pack Click here We are delighted to be selected as a finalist in the Health Outcomes category in this year's Laing Buisson's Healthcare Awards <https://laingbuissonawards.com> Download Free Info Pack <https://vimeo.com/394228009> SUITABILITY FOR FOCAL THERAPY EXPLAINED Focal Therapy is a general term for non-invasive techniques such as High-Intensity Focused Ultrasound (HIFU) and NanoKnife IRE. It has been shown to be as effective in controlling prostate cancer as radical treatments but with less side effects. Despite the general acceptance and use of the term in the media, the annual week of awareness that is promoted internationally and the ongoing public campaigning led by admirable organisations such as the Movember Foundation, "Men's Health" continues to mean many things to many people, without a coherent narrative essential to generate real impact in outcomes related to, well, men's health. This is as much about behaviour and cultural norms as it is about healthcare provision, and as observed by an eminent professor from Ireland's Royal College of Surgeons, these are starkly relevant when presented against the behaviour of women in regard to their healthcare: "Compared with females, males have lower rates of help-seeking behaviours, including lower usage of health care services and consulting with health professionals. Many men fail to get medical attention when sick or in pain and often present at health services in a more advanced stage of disease." Indeed, mass media does little to alter this behaviour. Googling "Women's health" generates top listings that focus on information about women's bodily functions and approaches to health and health prevention, typified by images like this: A google image search on "Men's health" delivers this: There's nothing wrong or misleading about this image or the message it's conveying, but it is representative of a bias toward fitness – and competitive fitness – versus overall health, something that the media perceives most men can comfortably talk about amongst their peers. But does it reflect what men want, or need, to know to improve or retain their health? In the flurry of new year media on health and wellbeing, the Times offered Seven Midlife Health Tips every man over 50 should know. Along with "lose the paunch", "walk further and faster every day" "protect against heart disease" and "have three consecutive alcohol-free days a week" is "protect your prostate": "About one in eight men in the UK will be diagnosed with prostate cancer in their lifetime, according to the charity Prostate Cancer UK. "Being overweight, not exercising enough, drinking too much, being black and having a family history of the disease all increase a man's risk ... If you have risk factors or any symptoms, such as changes in the way you urinate, you should consult your GP. All men over 50 are entitled to a free prostate-specific antigen (PSA) blood test, and Prostate Cancer UK advises anyone with a higher risk to speak to their GP from the age of 45." We applaud the Times for offering this advice and integrating prostate health with other aspects of men's health. Taking an interest in prostate health as part of overall health builds the confidence and knowledge necessary to make sound, informed choices and to effectively self-advocate if prostate cancer develops in future. Do you

have views on how men's health is promoted or provided?

HIFU Treatment for Prostate Cancer

HIFU treatment for prostate cancer is a minimally invasive, localized treatment for prostate cancer using high-intensity focused ultrasound (HIFU). HIFU is a very precise treatment for prostate cancer that kills the cancer cells but does not affect healthy tissue. It is also known as focal therapy, high-intensity focused ultrasound or HIFU treatment. HIFU for prostate cancer is a minimally invasive, highly effective treatment with few side effects and precise accuracy. It is a desirable choice for those with localized prostate cancer, instead of more drastic approaches such as robotic prostatectomy or hormone/radiation therapy.

HIFU Treatment

The use of high-energy sound waves, Ultrasound waves, means that HIFU focal treatment focuses the heat on a specific area of the prostate with great accuracy making it a less invasive, yet effective option for treating localized tumors within the prostate. Real time imaging during treatment allows doctors to pinpoint where to deposit the high-intensity ultrasound energy with extreme accuracy and precision, making it possible to preserve healthy prostate tissue while destroying cancer cells. HIFU treatments are administered by specially trained physicians who specialize in focal therapy for localized prostate cancer, meaning that patients can rest assured they are receiving the best care available. Patients should not hesitate to ask questions or raise any concerns about the procedure during their consultation appointment. Focal HIFU treatment has been studied in both clinical and laboratory settings, and research conducted over the last 25 years. These studies and clinical trials have shown that high-intensity focused ultrasound (HIFU) is effective at eliminating cancer cells while preserving healthy tissues. High-intensity focused ultrasound (HIFU) has been shown in clinical trials led by UK University hospitals to be very effective at treating prostate cancer. At 8 years after treatment prostate cancer control is equivalent to radical robotic prostatectomy but with minimal side effects from treatment.

The HIFU Procedure

The HIFU procedure is done on an outpatient basis, meaning the patient does not have to stay overnight in the hospital. The patient is under a general anesthetic for between 2 and 3 hours but will be able to walk out the hospital within 90 minutes of the end of the procedure. The total recovery period for high-intensity focused ultrasound treatment is less than 7 days, much shorter than that of a radical prostatectomy or other more invasive treatments.

Benefits of HIFU Treatment for Prostate Cancer

HIFU treatment for localized prostate cancer has several advantages compared to traditional treatment options. HIFU treatment offers high precision and accuracy due to real-time imaging technology that allows doctors to precisely target the affected area. Clinical Trials completed in 2021 show that HIFU treatment for prostate cancer provides excellent cancer outcomes at least equivalent to radical prostatectomy at 8 years. HIFU treatment is minimally invasive, which means less risk of complications and a much shorter recovery time when compared with more invasive treatments such as robotic prostatectomy or radiotherapy. HIFU treatment is not associated with the side effects normally associated with radical and traditional treatments for prostate cancer. Clinical trial data show that the risk of urinary incontinence is less than 1% and the risk of erectile dysfunction is less than 5%.

Cost of HIFU Treatment for Prostate Cancer

HIFU Treatment for Prostate Cancer is available in the private sector at a number of locations. The all inclusive cost for HIFU treatment for Prostate Cancer ranges from £14,000 to £18,000 depending upon the hospital chosen. At the Focal Therapy Clinic network the all inclusive cost of HIFU Treatment for Prostate Cancer is £14,000. <https://www.thefocaltherapyclinic.co.uk/wp-content/uploads/2022/12/HIFU-Treatment-for-Prostate-Cancer.mp4>

NanoKnife for Prostate Cancer Treatment: What You Need to Know

1. Introduction

NanoKnife IRE prostate cancer treatment is an exciting addition to the array of Focal Therapies now available for the treatment of prostate cancer. Prostate cancer is the second most common form of cancer in men in the UK with 47,000 cases annually and 11,000 reported deaths annually. Prostate cancer is normally detected in men over the age of 50 with a significantly increased risk for men of African Caribbean descent. Treating prostate cancer involves a precision diagnostic process and a careful balancing between the need to destroy cancer cells whilst preserving healthy cells with the least impact on a patient's quality of life. When detected early, prostate cancer can be treated with a variety of therapies, focal therapy for prostate cancer up to the intermediate grade and confined within the prostate gland and for more advanced cases, robotic prostatectomy/surgery or hormone and radiotherapy treatment.

NanoKnife treatment targets and destroys tumours while preserving healthy tissue. This relatively new, Focal Therapy option is growing in popularity as more clinical studies demonstrate its effectiveness in treating and curing hard-to-reach prostate cancer. Nanoknife is used in the treatment of tumours that may otherwise have been deemed unsuitable for HIFU Focal Therapy for prostate cancer. In this article, we discuss the basics of NanoKnife treatment, including its benefits and risks, what to expect during treatment and its availability in the UK.

II. The importance of understanding all of your treatment options

When faced with a Prostate

Cancer diagnosis, it is important to discuss and understand all treatment options available before making an informed decision about which therapy is right for you. Always the critical point is the grade and extent of each patient's disease and their priorities. NanoKnife therapy can greatly reduce recovery time and side effects on the prostate's important functions related to sexual health and urinary control compared to traditional treatments such as radiation and surgery.

III. What is Prostate Cancer Nanoknife?

NanoKnife Therapy is a minimally invasive Focal Therapy option for prostate cancer which is early to intermediate stage and is confined within the prostate gland. NanoKnife is based on a technology called Irreversible Electroporation (IRE) which uses very short pulses of electricity to create tiny/nano holes in the cell walls of prostate cancer cells. This process is irreversible, meaning that once the cells have been destroyed they cannot regenerate or repair themselves. Irreversible Electroporation (IRE) employs a series of precisely short electrical pulses which pass through tiny needles, acting like scalpels to target and destroy tumours. The precise placement of the needles is made possible by the use of 3D MRI Imaging Tools enabling surgeons to target the pulses to effectively kill prostate tumour cells in exactly the right area while leaving healthy cells unharmed thus avoiding erectile dysfunction and urinary incontinence. This permits urologists to achieve a 97% eradication of prostate cancer cells within the targeted area and to minimise impacts on the prostate's important functions relating to sexual health and urinary continence.

IV. Benefits of NanoKnife Focal Therapy

NanoKnife surgery offers a minimally invasive alternative to more traditional cancer treatments such as surgery or radiation and has benefits relative to more established Focal Therapies in treating hard to reach tumours. NanoKnife treatment is quick, taking only 40 to 60 minutes to complete, and patients can go home the same day. There is no need for an overnight hospital stay or pain relief, so recovery time is significantly reduced compared to traditional treatments. In addition, NanoKnife surgery (IRE) offers a high degree of precision in targeting cancerous cells while leaving healthy tissue intact, with 97% of cancerous cells destroyed in the tumour. This helps to preserve sexual function and urinary continence, which are often adversely affected by other treatments. NanoKnife Therapy using Irreversible Electroporation (IRE) has some advantages compared to Focal Therapy techniques such as HIFU which uses heat or Cryotherapy which uses freezing. These therapies are effective in the main part of the prostate gland and can treat significant tumour volumes but they can be difficult to apply with precision in some critical areas of the prostate gland. NanoKnife surgery is highly effective at treating smaller hard-to-reach tumours which are very close to critical structures controlling the important functions of the prostate gland. These are the nerves which control erectile function and the sphincter which regulates urinary continence. Extensive clinical trials have shown that Focal Therapies have an equivalent rate of cancer control at 8 years compared to radical treatments (85%) however they have much lower side effects with minimal impact on erectile function (95% success rate) and almost no issues with urinary continence once the catheter is removed after 4 to 6 days. NanoKnife technology has not yet had as many Clinical trials as the other Focal Therapies however those that have been completed have provided support for very strong cancer control rates with over 97% in the area treated at 5 years with excellent success in preserving sexual and urinary functions. A further significant benefit of NanoKnife treatment is that if the initial treatment is unsuccessful it can be repeated.

V. Who is a Candidate for Nanoknife Treatment?

Focal Therapy in general is restricted to patients with clinically significant prostate cancer with a PSA score of 20 or less, a Gleason score of 7 or less and whose prostate cancer is largely confined within the prostate gland. In cases of extensive disease spreading across and/or beyond the prostate gland and/or high-grade cancer with a Gleason score above 7 the more radical treatment options of surgery, brachytherapy or hormone/radiotherapy treatments are recommended. Which Focal Therapy treatment option is best for a patient is determined by the location and extent of their prostate cancer based upon a rigorous review of the results of their magnetic resonance imaging (MRI) scans and their precision biopsy and histopathology results. This review is conducted first by the urologist and then reviewed in a Multidisciplinary Team meeting including oncologists, urologists and radiologists reviewing each patient's clinical results in detail and agreeing on the possible treatment options in each case. After this, the patient will be informed of the team's recommendations by the urologist and a final decision will be made in consultation with the patient.

High-Intensity Focused Ultrasound (HIFU) Therapy

is the preferred choice for larger volume prostate cancers in the main part of the prostate gland but for smaller prostate cancers occurring in hard-to-reach parts of the prostate gland, NanoKnife (IRE) is a very attractive and preferred treatment option.

VI. How is the Nanoknife Procedure Performed?

The NanoKnife (IRE) surgery is performed as a day-case surgery taking between 40 and 50 minutes. Based upon the result of the MDT meeting the Radiologist will have used the information in the MRI scan along with the histopathology report to

provide the urologist with a detailed 3D map of the prostate showing the area to be treated in detail. The patient is brought to the theatre and put under general anaesthesia to ensure that they experience no discomfort and crucially that they do not move during the procedure. The urologist will guide the thin needles/electrodes into position using the 3D map provided by the Radiologist under Ultrasound Image Guidance. Once satisfied with positioning the urologist will then apply the electric current using the NanoKnife (IRE) technology. Once the procedure is completed the electrodes are removed and the patient is returned to the recovery area. Patients will be woken after about 20 minutes and can usually leave the hospital within an hour or so of the treatment completion with little or no discomfort albeit with a Catheter in place for between 4 to 6 days.

VII. Accessibility and Cost

NanoKnife (IRE) Therapy for prostate cancer is a relatively new treatment for Prostate Cancer. In the United Kingdom, it is available only on a restricted basis in the NHS under a clinical trial setting. In the UK's private health sector, it is more widely available and its costs are covered by the major insurance providers. The Focal Therapy Clinic offers NanoKnife (IRE) Therapy in Southampton with Mr Tim Dudderidge, in London with Mr Marc Laniado and Mr Raj Nigam and in Birmingham with Mr Alan Doherty. The Focal Therapy Clinic works with the esteemed uro-radiologist Dr Clare Allen of UCLH for all of its treatment planning. The Focal Therapy Clinic package price for NanoKnife (IRE) therapy is £15,000. <https://www.thefocaltherapyclinic.co.uk/wp-content/uploads/2022/12/Nano-Knife-Treatment-for-Prostate-Cancer.mp4>

Sitemap

A Chatbot's view on prostate cancer

Amidst the many major news events of the last few weeks was the launch of Chat GPT on November 30. A chatbot developed by US-based OpenAI, it's causing a stir amongst investors and technologists, and is even being talked about as a replacement for Google. It's also giving anyone who takes part in its current beta test an opportunity to engage with an AI around pretty much any topic. We registered for the beta test and chatted with ChatGPT about lots of things, including some topical issues related to prostate cancer. Here are the highlights of our "conversation".

TFTC: How do we improve treatment for prostate cancer?

ChatGPT: "There are several ways that treatment for prostate cancer can be improved:

- Early detection:** Early detection is key to successful treatment of prostate cancer. The earlier the cancer is detected, the more treatment options are available and the better the chances of successful treatment. This is why it is important for men to undergo regular screenings for prostate cancer, especially if they have a family history of the disease or are at higher risk for developing it.
- Personalized medicine:** Personalized medicine involves tailoring treatment to the specific needs of the patient, based on factors such as the type and stage of the cancer, the patient's age and overall health, and any other medical conditions the patient may have. This can help to improve the effectiveness of treatment and minimize side effects.
- New and emerging treatments:** There are always new and emerging treatments for prostate cancer being developed, such as targeted therapies and immunotherapies, which may be more effective or have fewer side effects than traditional treatments. It is important for patients to discuss all treatment options with their healthcare team and to stay up to date on the latest research and developments in the field.
- Supportive care:** Supportive care, such as pain management and symptom control, is important for improving the quality of life of patients with prostate cancer. This can include medications to manage pain and other symptoms, as well as techniques such as relaxation therapy and mindfulness meditation to help patients cope with the physical and emotional challenges of cancer treatment.

TFTC: How do we improve screening for prostate cancer?

ChatGPT: "There are several ways that screening for prostate cancer can be improved:

- Increasing awareness:** One of the most important ways to improve screening for prostate cancer is to increase awareness of the importance of regular screenings. This can involve education campaigns to inform men and their families about the importance of screenings and the risks and benefits of different screening tests.
- Improving screening tests:** There are several different screening tests available for prostate cancer, including the prostate-specific antigen (PSA) test, digital rectal exam (DRE), and transrectal ultrasound (TRUS). Research is ongoing to improve the accuracy and reliability of these tests, as well as to develop new screening methods.
- Risk assessment:** Risk assessment is an important part of screening for prostate cancer. By identifying men who are at higher risk for developing the disease, it is possible to target screening efforts more effectively and improve the chances of early detection. Risk assessment tools are available to help healthcare providers determine a patient's risk for prostate cancer based on factors such as age, family history, and other medical conditions.
- Shared decision-making:** Shared decision-making is the process of involving patients in the decision-making process about their healthcare. This can be particularly important when it comes to prostate cancer screening, as there are different options available and the decision to undergo screening can be a complex one. By involving patients in the decision-making process, it is possible to improve the quality of care and increase patient satisfaction.

TFTC: Is prostate cancer an old

man's disease?CHatGPT: "Prostate cancer is a type of cancer that affects the prostate gland, which is a small, walnut-shaped gland located in the pelvis of men. The risk of developing prostate cancer increases with age, with the highest incidence occurring in men over the age of 65. However, it is important to note that prostate cancer can occur at any age and it is not limited to older men. Men of any age can develop prostate cancer, and it is important for all men to be aware of their risk and to discuss screenings and prevention with their healthcare providers."TFTC: How will sexual health be impacted by prostate cancer?CHatGPT: "Prostate cancer and its treatment can potentially impact a man's sexual health in several ways. Some possible impacts on sexual health may include: Erectile dysfunction: Erectile dysfunction, or difficulty getting or maintaining an erection, is a common side effect of prostate cancer treatment, particularly for men who undergo surgery or radiation therapy. This can be caused by damage to the nerves and blood vessels that are involved in the process of achieving an erection. Decreased libido: Some men may experience a decrease in their desire for sex or a decrease in their ability to become aroused after prostate cancer treatment. This can be caused by a variety of factors, including fatigue, anxiety, and changes in hormone levels. Difficulty reaching orgasm: Some men may experience difficulty reaching orgasm or may not be able to reach orgasm at all after prostate cancer treatment. This can be caused by damage to the nerves that are involved in the process of orgasm. It is important for men to be aware of these potential impacts on sexual health and to discuss any concerns with their healthcare team. There are various treatments and therapies available that can help to manage sexual dysfunction after prostate cancer treatment. It is also important for men to communicate with their partners and to be open about their needs and concerns."

So there you have it – what a chatbot can tell us about prostate cancer. AI is with us, however we choose to engage with it – and expect to see more in 2023. But don't take our word for it – go have a conversation with Chat GPT during your holiday break – all you need to do is register here. Happy Holidays from all of us at the Focal Therapy Clinic! The Future is bright for Innovations in Prostate Cancer Treatments This episode's interviewee is Arvin George, Assistant Professor of Urology at the University of Michigan School of Medicine in the USA. A Urologic Surgeon specializing in the diagnosis and management of genitourinary cancers, Professor George's research interests include minimally invasive and image-guided treatments, functional prostate imaging and focal therapy for prostate cancer, and he has published widely in these areas. He is also a practicing consulting urologist who has been a leading voice globally on focal therapy and whose contributions to building the evidence base for it have been invaluable to advancing the practice and making focal therapy more accessible to a wider group of patients. Arvin George's publications: <https://www.researchgate.net/scientific-contributions/Arvin-K-George-2144216305>

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Arvin George, assistant professor of Urology at the University of Michigan School of Medicine in the USA, a urologic surgeon specialising in the diagnosis and management of genitourinary cancers. Professor George's research interests include minimally invasive and image guided treatments, functional prostate imaging and focal therapy for prostate cancer and he's published widely in all these areas. He's also a practising consulting urologist who has been a leading voice globally on focal therapy and whose contributions to building the evidence base for it have been invaluable in advancing the practise and making focal therapy ultimately more accessible to a wider group of patients. Arvin George is here today to share his insights from his research and his clinical practice. I'm really excited at this opportunity to think and chat about some of the new horizons in prostate cancer treatment. I mean, starting as a consultant urologist, you've lived, you've practised, you've researched internationally, so how did you end up becoming a focal therapy global specialist based in Michigan? Arvin George I've really had the opportunity to work with innovators in the field of urology since the beginning of my training. And whether it be minimally invasive surgery or image guided treatments like different focal therapies, I was kind of guided in that direction to pursue that innovative path and what's new and where can we have the greatest impact on the field? And I saw early on the potential for focal therapy to impact not just the field but patients lives in a positive way and it's been a constantly changing environment and an exciting field where we've really been learning and growing every day. And so I think that I've been really excited about pursuing both focal therapy as a research and a clinical interest as well. Clare Delmar And you've been quite involved, to say the least, in building the evidence base, as I suggested earlier. Do you feel that the evidence base now for focal therapy is sufficient for widespread adoption? Arvin George That's a tricky question

to answer because I do think that there's a number of factors that we need to take into consideration. But I would say that in an overall sense, I would say my answer to that would be I don't think we're ready for widespread adoption, but I do think that we are ready for selective judicious adoption. And what I mean by that is that while I'm extremely enthusiastic about focal therapy as a field and its potential, my major concern is that the success of these new treatments are really... they're highly dependent on identifying the right patient. And if you don't choose the right patient for the right treatment, and that goes for surgery to remove the prostate or radiation, it goes for all treatments that we employ in medicine. If we don't choose the right patient for the right treatment, then our expectations are going to be misaligned with what the patient's goals of care are. And so we need to be really careful to be able to implement this responsibly and ensure that both patients and providers understand what the best practises are in this space, which of course, they continue to evolve. But I think it can be offered as the standard of care in select patients when, of course, they're followed very carefully and their outcomes are recorded, either ideally within a clinical trial, but outside of that within some sort of registry, so that we can learn from our experience and ensure that we're doing the right thing for patients.

Clare Delmar And you talked a few minutes ago about being intrigued by innovation and that's how you eventually wound up in this area of research and practise. And focal therapy has certainly been a real product of innovation in imaging as well in some of the new and applied energy sources that are used to actually undertake focal therapy and in radiological reporting, just examples. Do you feel that these are areas of innovation that are playing out in helping to advance focal therapy? I would say the amount of progress that has been made over the last ten years or so in prostate cancer specifically has been impressive. And at all ends of the spectrum, whether it be in advanced prostate cancer when the prostate cancer has gone outside of the prostate, there have been a tremendous amount of innovations. When we look at prostate imaging, I do feel that imaging in general is really the pulse of any field. And as we start to have improvements in imaging, specifically prostate cancer imaging, our treatments kind of coincide with that progress and we make significant strides in terms of treatments. Prostate MRI is being widely utilised now and I would say ten or so more years ago, it was really in its infancy, especially with regards to adoption outside of expert centres. We have new PET scans with novel different radio tracers that can target prostate cancer very directly. There is the advent of diagnostic treatments which both serve in a diagnostic role, to both identify where a cancer is, but also can treat it at the same time. And when we talk about you mentioned the different energy sources that are used, that's also been a field that's just exploded historically. We've had maybe high intensity focused ultrasound or HIFU and cryotherapy, but since those seem to be now, I wouldn't say they're contemporary treatments, but we have a lot of newcomers on the block, whether that be irreversible electroporation, or it could be radio frequency ablation, microwave ablation, nanoparticle directed laser ablation, conventional laser ablation. I think we just need to really understand where they all fit in that puzzle of what's best for the patient.

Clare Delmar And just keeping on the theme of innovation, what other areas of innovation are evolving that you think might eventually make focal therapy far more accessible? And by this I mean not necessarily the energy sources and the imaging, because we can talk about that for a long time and that continues to evolve, as you rightly say. But I'm thinking things like social innovation and how men are messaged about their health through digital media or public service awareness campaigns. And I think that part of that - the fact that PSA is not particularly specific to prostate cancer only has helped us identify prostate cancer earlier, but it has also maybe led to going down a slippery slope of biopsies and treatments that may not benefit men in the long run. And so I think that at least in my own experience, I've seen men, and not just men, but their family members and spouses and other people who are close to them, take a much more central role in becoming their own advocates. There's so many mediums by which we can communicate now, whether that be on social media, whether that be on the news, whether that be through podcasts like this, for example, or videos on YouTube. There are so many places where both patients and physicians can kind of consume this information. Now it can become a double edged sword because like with anything, we want to ensure that we're getting this information from credible sources that are objective, that always have the patient's best interest in mind. And I think that's probably the greatest challenge, making sure that we get the right information out there through objective sources. I don't want to say mislead patients, but don't give them a false sense of security because any individual treatment is not a panacea.

Clare Delmar I agree with you, and I know in fact, there has been research done on degrees of misinformation through digital media and again, it's a difficult one to control. Have you had experience where a patient has actually presented you a lack of information or perhaps some misinformation that you've actually had to challenge when you've recommended a treatment option for example? Have you

come across any patients who come into your care and actually have a fixed way of thinking that you've had to challenge? Arvin George I have actually, I would say in the focal therapy space there is very limited objective information that's out there, whether that is vetted by organisations or professional societies. And so with that it becomes difficult to come across some of this objective, reliable information that's there. And because this field is changing so quickly, what we think about two, three years ago may be very different than what we think about today. And so if I'm thinking about specific examples, I would say, for example, I do cryo ablation, but most of the information, if patients were to seek it out themselves, is predominantly on whole gland cryo ablation. And the outcomes and the patients experience is very different from whole gland versus a focal cryo ablation. And then I would say the other example is that it's very hard to keep up to date with some of these contemporary evidence or data that's available and we can sometimes be biased by historic data where we were learning. I feel sometimes it takes me as long to counsel a patient and tell them, hey, you are a good candidate for this novel treatment, even though it may not be the standard of care versus I have other patients where I have to take as much time to convince them that they're not a good candidate focal therapy. And it's important to take the time to explain that so that they understand fully the reasoning behind that, so that they can choose what's the right treatment for them. Clare Delmar I think that's actually really important because they're the ones who are the so called self advocates that you described earlier and they're very enthusiastic and they've probably done a lot of their research and come to you because they want to experience your approach. And as you say, so much of this is about the right selection, the right treatment for the right person at the right time. But would you find that someone like that who is self advocating and is knowledgeable is then easier to well, easier may not be the right word, but they're willing to listen to you and abide by what your recommendations are? But I think in prostate cancer it is supremely important because certainly we're looking for cancer control. But with the natural history of prostate cancer, I think that we have the opportunity to offer less and less invasive treatments that can also ensure that patients are able to maintain a very high quality of life rather than offering them a treatment that can significantly impact their quality of life with a questionable benefit from a cancer perspective. Clare Delmar And does that seem, in your experience, to be the main reason why people come to you and to discuss opportunities for focal therapy because they are aware that there's a quality of life impact? I think that of all the questions that still do exist regarding focal therapy, I think the one thing that has been completely settled is that the outcome, the functional outcomes with regards to quality of life, whether that be sexual function or urinary function, in terms of urinary leakage and urinary symptoms, bowel function, that is proven beyond a doubt in my opinion. I think that we clearly know that you're going to do better from both a logistic and side effect perspective with focal treatment. And now we're really focusing on how can we achieve the best cancer outcomes for these patients Clare Delmar and presumably for more patients? Clare Delmar So what would be your message of hope for men as they age and they navigate the possibility or the reality of developing prostate cancer? Arvin George Yeah, well, I'll tell you what I start every one of my new consultations with and I start by saying that before we get into it, I tell them you are going to live a long and healthy life. But for the most patients who is confined to the prostate and it does require some sort of treatment, I tell them you're going to see your grandchildren, you're going to see your children graduate from university or you're going to see them get married, just to take the tension off. Because I think we know a lot about the biology of prostate cancer and when somebody comes in for a new consultation, they are extraordinarily anxious and understandably so. You've been labelled as a cancer patient and it's very difficult as a patient to understand that there are differences between different cancers and we're so fortunate that prostate cancer can be very effectively treated. And I would say in terms of a message of hope, I would say that our advances in the prostate cancer space have been exponential in the last few years and I feel that that trajectory is going to continue that way. And we are gathering additional studies in the evidence base to help support it and really solidify focal treatments and even newer treatments in focal therapy that are on the horizon that will make it make cancer treatments both more effective and also help them in being able to maintain the lifestyle that they want to maintain. Clare Delmar Well, that is very helpful indeed and it's wonderful to hear it from someone like yourself who's actually really leading a lot of those advances and I hope our listeners will look at your work, which I will put on our programme notes. And I want to thank you so much for joining me today, because you've shed a lot of light, and it's really important to men who, as you say, get a diagnosis, and they and their partners and their families experience a lot of stress. Clare Delmar A transcript of this interview and links to more information about Professor Arvin George and his work are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and

additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Thank you for your interest in The Focal Therapy Clinic. Please find the download link to your Free Info Pack below. Click here to download our brochure. Imagine two men, Joe and John, each diagnosed with localised prostate cancer and aged 70 years. John is retired, sexually inactive, and suffers from a range of conditions that prevent him from engaging in physical activity. Not surprisingly, Joe tells us he “doesn’t feel seventy” and has never felt better in his life, while John complains of “the challenges of ageing”. We are frequently approached by the Joes of this world, who feel as though they’ve been “written off” on the basis of their age, because often it’s age which is a defining factor in how they are treated. Whether this is fair or just is not the point – and many clinicians do indeed assess their patients’ cases on evidenced quality of life and life expectancy criteria, and not just age itself. No matter how broadly or comprehensively we incorporate age into patient assessment, we all measure it in one way – the amount of time, usually in years, that we’ve been alive. This approach to measuring age is changing, however, and when it comes to diseases like prostate cancer -- where ageing is a significant risk factor -- how we measure age could have an impact on how we manage prevention and treatment of the disease itself. There is a growing community of researchers and healthcare practitioners who believe that the process of ageing can and should be actively managed to extend “healthspan” (the amount of time we are living in good health) as well as lifespan (the amount of time we are living). At the core of this so-called longevity science is the distinction between biological and chronological age. Chronological age is the number of years you’ve been alive, while biological age refers to how old your cells and tissues are based on physiological evidence. If you’re especially healthy and fit for your age, your biological age may well be lower than your chronological age. But if you’re sedentary, chronically ill, or in poor physical condition, your biological age may be higher. The key is while chronological age is fixed, biological age is not, and can be actively managed through lifestyle changes and, increasingly, an array of interventions. There is a growing body of research which suggests that biological age is more accurate than chronological age for predicting morbidity from age-related diseases such as dementia, breast cancer, and colorectal cancer. While there is an emerging consensus on the distinction between chronological age and biological age, measuring biological age is not simple or straightforward and, indeed, has generated considerable debate and discussion amongst researchers, clinicians and patients. However, embracing the concept of biological age on an individual level could have significant impact on behaviours, attitudes and practices that drive personal health. Knowing that biological age can be altered through diet, exercise, mental and emotional well-being may motivate people to manage these more actively. This may lead to improved self-advocacy when it comes to engaging with healthcare professionals who, in turn, will be better informed when considering treatment options for their patients. There is much developing in the field of ageing and considerable debate and even controversy around new approaches to “manage” age. But it is also a very exciting arena for rethinking attitudes and practices as our society ages and is beginning to generate some objective measures that will only empower future patients with age-related conditions. Prostate Cancer UK Clinical Champion Pilots Intervention Programme Consultant Urologist Tim Dudderidge, who works with TFTP and is based at University Hospital Southampton, joins OnFocus today. Tim is an innovator in focal therapy and has co-investigated most of the clinical trials and studies that have built the evidence base for focal therapy and advanced its adoption and practice. He has recently completed his appointment as Clinical Champion for Prostate Cancer UK, and he’s here to discuss what he learned and what implications this might have for patient care. The poster Tim developed for patient self-referral to receive PSA testing. Hello and welcome to OnFocus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Joining me today is consultant Urologist Tim Dudderidge, who works at the Focal Therapy Clinic and is based at University Hospital, Southampton. Tim is an innovator in focal therapy and he’s co-investigated most of the clinical trials and studies that have built the evidence base for focal therapy and advanced adoption in practice. He’s recently completed his appointment as clinical champion for Prostate Cancer UK and he’s here to discuss what he learned and what those implications are for patient care. I mean, you’ve just completed this wonderful year, you and, I guess you’ll tell us in a second, a number of other clinicians. So let’s just start by sharing with us how was your experience as a Prostate Cancer UK clinical champion? Tim Dudderidge Well, I saw this programme, it’s actually an 18 month programme and I first saw it advertised and thought it was a great opportunity to get a project that I had in mind off the ground. And so I applied and was successful and joined a group of... a mixture of people actually,

urologists, clinical oncologists, radiographers, radiologists, some nurses. A really wide spectrum of people all working in prostate cancer and we all had an idea, and some of the ideas were the same about trying to develop services in our hospitals and in our areas. And Prostate Cancer UK really wanted to try and get a group like that together who all were on a journey and to give us some leadership training. Actually, a lot of it was quite familiar to me because it wasn't my first rodeo, but actually it was great to go on this journey and have the licence of Prostate Cancer UK to really support my project. So for me, it was an opportunity to use that process of personal development as a launchpad for this particular project and actually, I was very lucky that it really allowed the project to work and so I'll tell you all about that.

Tim Dudderidge When this opportunity came up we were just in the middle of coming out the COVID kind of hiatus in a lot of clinical services and we were noticing a big gap in cancer referrals for understandable reasons, the health service in disarray focusing on this COVID challenge. And we went very quiet in the prostate cancer service, relatively, and we knew there were men going missing and so we wanted to deal with that challenge. It's also historically been the case that there's been a bit of a gap in opportunistic testing for prostate cancer. And the men who tend to get tested, they've either got health insurance or they're made aware of prostate cancer through their networks, or they read the newspapers. And what you find is that there's a big socioeconomic divide between the typical man coming forward who doesn't have symptoms who has opportunistically found his prostate cancer, and the men who don't have that sort of education, who maybe wait till they got quite severe symptoms, often when they've got locally advanced disease or metastatic disease. And perhaps we can do more to try and make it a bit more equitable situation for access to prostate cancer investigation. We have these kind of multiple things going on and my feeling was that, okay, we can't impose a new screening programme yet because we don't have the evidence, perhaps, to really support the imposition of a test on people at a certain age like that exists for breast or cervical cancer. And we already have a situation where the NHS supports a free PSA test if you want one, if you've been well informed. And I just thought that we have to have an intervention that made things fairer when we generated interest in PSA testing as a result of this, not everyone will be interested, but if they are, we shouldn't have barriers for them to get the test. Even getting men to go see the doctor is a barrier, when they get there, there's a variability in opinions about PSA testing and people might get put off even when they've made a choice. And what we came up with in my project proposal was an idea that we would publicise the idea about prostate cancer awareness. There are charities doing, including Prostate Cancer UK, but smaller local charities, and so we would not be doing anything particularly new in that respect. But what we would be doing is providing, if you like, well balanced prostate health information, which is sort of locally relevant in terms of what you do next. And what you would do next in this project was contact the hospital and be able to directly get into the hospital system and get a blood test.

Tim Dudderidge One of the major differences that we can say, just come to us, we'll sort it out. And a specialist team of nurses will just arrange everything and then give you some advice afterwards about what to do. And often this is either being done by GPs who have the protocols to follow, but they're not dealing with prostate cancer day in, day out and they're very busy with other important things. Nor is this a situation where you've got amateurs, if you like, the very enthusiastic patients who form a group and then they buy themselves some PSA tests and they organise it that way, that goes on a lot as well, and then you don't have any expert advice coming out of that. So we developed then a whole lot of material to advise people about their urinary symptoms, depending on how bad they were affected about their PSA result and a number of outcome letters were generated. But importantly, if you had a risky PSA level, you'd be fast-tracked into the two week wait clinic without your GP having to be troubled with this process. They were keen for us to do this, to try and deal with this big gap in...

Clare Delmar Yeah, well, you probably relieved them of some burden that they were already feeling. Because while I understand the gap, and certainly from a resource point of view, going to hospital usually suggests you have symptoms already.

Tim Dudderidge Well, this whole idea that I started out with, I put into a PowerPoint presentation and luckily, at the time there were also other people worried about this. And so the Cancer Alliance, Wessex Cancer Alliance were interested and they said, this meets with some of our kind of targets and what we've been asked to do. I presented to a number of... the whole of the south of England Cancer Alliances and discussed the idea with them. And they were like some were interested, some not so interested, but there was kind of eyebrows being raised and other things, similar projects were being done as well by other people, but all people doing at their own different way. And so we had some publicity and we went through radio, TV, like Trust events and GP events and we got a bit of momentum. So basically, throughout the course of this year, we've had a pretty large number of people coming through who would not otherwise get tested. So probably about a quarter of them with no

symptoms at all but the others with varying degrees of symptoms. We got funding to get some staff, one of them has just started, the other one starting the new year, but otherwise this has been done by sort of, the department's absorbed the activity and we've had about 500 or 600 people now come forward for testing. They were probably not quite double that, but a large number of people who made inquiries and maybe read the information decided it wasn't for them. We had, during the COVID in the beginning of the year, we had some of the COVID facilities testing outside in a big car park, the drive-through thing, so that helped. And what we're seeing is that this is a way of drawing men into education about their prostate, and the men who feel that they want to proceed are proceeding. And we've generated so far, I think, from the group of 465 that I looked at, 64 of those cases ended up needing a two week wait appointment so that's quite a high conversion rate in many ways. We haven't analysed to get the data about how many important cancers were within that group. We're going to analyse all of this and we're presenting to a Health Service Journal meeting in the spring and we're hoping to have enough resources locally to run a pilot in a GP surgery, where we'll eventually in a twelve month period run through every man in the risk group. 45, if they've got family history or they're black, or 50 to 70 otherwise, and basically go through that risk group and present them with a please click here for the information. So that is approaching not a screening test with PSA, but what I'm calling eventually what we call a National Prostate Health Intervention Programme. And I think the nuance is different there because we're not saying you should have this test, we're saying you should have this information. And I think that's, first of all, far less dangerous thing to be putting around because people worry about the harms of screening. And actually, it would take some of the concern that people have about screening programmes out, because people can be informed about the pros and cons and make their own decisions... Clare Delmar And make their own choice. Did you notice even anecdotally or have you collected the data of these, I think you said 500 men or so who came forward. Were there any dominant demographic groups, any particular profile to the people who did come forward? Were you reaching those people that you suggested earlier who we're actually not being informed? I'd say it's probably just as many with mild as severe LUTS, but the majority with some degree of urinary symptoms. I think there are a lot of symptomatic men out there who are perhaps worried about cancer, but in actual fact, it's the ones you know, you don't have symptoms which are perhaps harbouring just as many cancers. So we need to make sure that message comes across well because whenever you speak to journalists, they always say, so tell us again about the symptoms of early prostate cancer - well there aren't any. Clare Delmar Yeah, I mean, another question is informing them about prostate disease and prostate health, but equally, did people come forward because this was an opportunity to avoid a wait for a GP appointment? Like, did the fact that you have these waits right now for primary care services help your project? Tim Dudderidge So I think we will be picking up some of the men who might otherwise come through their GP. And the GPs are well aware of this service and I've even noticed our service being advertised on their GP surgery websites. And so for them, it does offer a chance to pivot men who might otherwise be seen face to face directly. It may be that that is the best way of dealing with it, you know, is actually for such a formulaic process these men have to go through, which is read the information, symptom score and then if they need to, they want to, have a blood test. It requires a high volume and high skill in this area activity which can be done by nurses or other health care workers. Going forward, how this will benefit patients in future, you think once you get it piloted and begin to collect some data and some evidence, do you think this is something that you could see being rolled out? Tim Dudderidge Yeah, I mean, I think my objective for the next year are to obviously get these staff in and trained up and grow our capacity. I think there are certain bits of the IT I want to improve so that we can have a micro website that actually handles the information and PSA requesting side of things automatically, allowing more time for the sort of more detailed conversations that patients might want with the nursing team that we're building. And then to maybe have a programme in a pilot site in a GP surgery where we proactively target the men in their database within the risk group and try and see if you did that proactively how much work is generated for a certain population of men and therefore what staffing would you need if you wanted to run this on a citywide basis? There are 8000 men in their primary healthcare databases who have not had a PSA test, who are over 50. Some of those over 70, we might be able to may not proactively target them, which would fall in line with guidance. But I thought we would generate about 35 two week wait appointments per week if we were to go out and really push this. Clare Delmar Yeah, no, indeed, but it sounds like a fabulous programme and I look forward to hearing more about it. Because it's a really important intervention, as you say, but just pivoting, I mean, to the programme itself, I know there was a whole group of professionals, as you said earlier, were there other projects that other champions that you met in the programme that pursued that particularly

impressed you as well? Tim Dudderidge Well, I think interesting is a lot of people are trying to push to develop local anaesthetic, transperineal prostate biopsy services. A lot of people still doing transrectal ultrasound guided prostate biopsies and they wanted to come and try and see how they can overcome barriers to deliver that. There were a lot of people, there was one very interesting project looking at improving the sexual health support for men with advanced prostate cancer. Obviously, we think about this a lot with prostatectomy and getting their erections back, but what about men on hormones who have metastatic disease? A lot of men trying to improve the diagnostic pathway and improving their imaging processes and straight to test. So there's a lot of interesting projects out there, actually, and it's great to see how much enthusiasm there is for improving the prostate cancer services. Do you feel that programmes like these are really key to progressing these new areas of clinical practise? But what's really amazing is, for a very prestigious charity like Prostate Cancer UK, they've got a lot of recognition and clout and just turning up to a meeting and saying, I'm the Prostate Cancer UK champion and this is my project, people just listen. I think the charity is very cleverly got now a group of people who all really feel a sense of camaraderie with the charity. As a group, we communicate very well with each other, and they're looking for advisers, and they're building a big advisory community to help the charity. And they're doing a similar thing with patients as well, to basically have a really strong group of people who can advise the charity on how to move forwards. And so whenever they've got an idea, they'll go to their patient group, they'll come to the clinician group, and that way it keeps the charity pointing in the right direction. So it is continuous and final question, I know you said you proposed this project with some materials, I think you said it was on a PowerPoint, but is there a place where some of the research you've done on this project exists that listeners could go find? I produced a poster for my programme recently so I'm certainly happy to share that but I would say we're going to have some meaningful outcomes from this in the middle of next year. There's plenty of information on the UHS website about the self referral programme and in fact it's on lots of the GP surgery pages around here as well, but we will certainly be able to offer a bit more insight into our results in the middle of next year. Clare Delmar Good, well we'll look forward to that and very exciting and congratulations once again on really launching something very interesting. A transcript of this interview and links to more information about Tim and his work are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy clinic. Making an impact on Men's Health We were delighted to be nominated and selected as a finalist in the Health Outcomes category for this year's Laing Buisson Health Awards, and last week's awards dinner was an opportunity to share a platform with some established and dedicated healthcare organisations, all making a significant impact on health outcomes across the country. We were clearly the "new kids on the block" having been established only three years ago, and many at the event asked us who we are and what we're about. The Focal Therapy Clinic was set up to provide state-of-the-art focal therapy to men with localised prostate cancer, driven by several core values and practices: • a continually improving practice of patient advocacy and patient engagement • innovative and dedicated clinicians who are world leaders in the development and practice of focal therapy • personalised care beginning with a rigorous and world-class MDT for all patients • a commitment to outreach and raising awareness of key issues facing men with prostate cancer, including inequalities based on age, race, sexual preference and geographical location These values and practices underpin what we increasingly regard as USPs in the provision of care for men with prostate disease, starting with our clinicians - individually and collectively world leaders in the practice of focal therapy with a dedication to patient care. Our MDT is widely recognised as state-of-the-art in its clinical and technological expertise, informed by qualitative patient information generated through deep patient engagement. And our commitment to outreach involves building a network of thought leaders, campaigners and researchers who are all dedicated to changing attitudes and advancing practice in diagnosing and treating prostate cancer. All of this is reflected through continually evolving online content, including podcasts and blogs which we regularly share on social platforms and with our network. Focal therapy is a non-invasive approach to treating cancer of the prostate using a range of energy sources, or modalities, which destroy cancerous tissue in the prostate gland. Because it treats cancerous tissue without removing the gland itself, it is often compared to advances in breast cancer treatment and called the "male lumpectomy". Its success is based on highly precise diagnostics which enable the clinician to understand the exact location, size and severity of the cancerous lesions on the prostate. Our practice has been focused on HIFU (High Intensity Focused Ultrasound) as a modality for ablating cancerous tissue in the prostate gland, and we have worked in

partnership with Sonacare, a leading supplier of HIFU medical equipment, to provide our patients with state-of-the-art technology for HIFU focal therapy. This year we have enhanced our approach and have added IRE, known as NanoKnife, to our focal therapy modalities. Our innovations in the diagnostic process for prostate cancer has underpinned clinical excellence in selecting and treating patients with focal therapy. This includes state of the art radiological reporting which enables clinicians to make an accurate diagnosis - no other clinic or practice provides the qualitative and quantitative level of reporting on prostate MRI than we do - it is considered the gold standard. Our MDT which has been developed online since the pandemic supports deeper levels of clinician participation which ultimately benefits each patient in their treatment recommendation. Our clinicians have discussed publicly how viewing radiology reports and imaging through this proprietary digital platform enables improved quality of discussion and review. Since our establishment we have given over 500 men a comprehensive understanding of treatment options based on a forensic review of their clinical case, which has reduced high levels of anxiety and supported confident decision making in each patient's care plan as they were often challenging established thinking and practice. 40% of these men proceeded with focal therapy, and all have had solid cancer control and no side effects. All have responded positively to follow up contact and many have discussed their experiences and outcomes in our podcast series. Innovation and technology play a significant role in our approach to patient care. Our clinical team have been and continue to be involved in clinical trials around focal therapy, giving them a deep understanding of challenges and opportunities in diagnostic and treatment technologies which they apply regularly in their clinical practice and which they describe in our podcast series which we share to a wide audience to educate students, researchers, primary care providers and prospective patients on state-of-the art clinical practice. The diagnostic requirements for each patient that is considered for focal therapy are based on advanced imaging technology and radiological expertise, eg MR/US fusion biopsies, and our radiology reporting is recognised as unparalleled. This is our standard practice and is key to making the optimal decision on patient care and to our success as a clinic. And finally, our approach to digital content and communication is enabling us to reach more and more prospective patients as well as clinical partners - manifested in our website content, podcast series and social media outreach. As an organisation we are committed to supporting our team and wider stakeholders who influence the prostate cancer patient experience. Alongside our clinical team is our patient advocacy team, which we support through training and continual engagement with clinicians. We also support the HEAT registry, an ongoing registry of all men who have undergone HIFU treatment and shared openly with researchers, policymakers and prospective patients. On a wider level we support and give voice to campaigns and campaigners focused on some of the key issues facing men with prostate cancer - these include health inequalities driven by age, race, sexual preference and geography; health literacy; and breaking taboos around prostate cancer and its impact on health and quality of life. Our overall aim is to attract, recruit, engage and treat men with localised prostate cancer so that their health and quality of life are optimised. This requires investment in expertise and technology, as well as a commitment to giving men and their loved ones a health literacy around prostate cancer - informing them of the clinical and non-clinical aspects of their disease including diagnostic processes, technology, and the side effects and taboos surrounding their sexual, mental and urinary health. Do you have questions about the clinic and its aims, values and practice? Men poorly informed about Prostate Cancer Treatment Last week, a study was published in the UK which had some astonishing findings about men and prostate cancer. Two especially stood out: One in three men over the age of 45 would put off seeking help for prostate cancer - because they fear every diagnosis is terminal. Research into 1,200 men, over 45, also found nearly two-thirds (62 percent) believe undergoing treatment for prostate cancer can result in side effects that could impact quality of life. Clearly men do not understand the prostate cancer treatment options potentially available to them and rarely get an independent second opinion on their prostate cancer treatment options. The report, commissioned by Genesis Care with the support of Prostate Cancer UK, further found of those who have received treatment, almost half (48 percent) wish they had known more about how the treatment could have been personalised to them. Of the men diagnosed with prostate cancer, more than half (58 percent) wish they'd known more about the treatment options available. More than a third (34 percent) believed if they had been better informed, they'd have chosen a different treatment pathway. Despite the prominence of prostate cancer - with one in eight men being diagnosed with the disease in their lifetime - nearly a third (31 percent) of men aren't sure what therapies are used. Nearly a fifth (17 percent) believe treatment for prostate cancer is comprised of chemotherapy alone. Commenting on the report's findings, the CEO of Prostate Cancer UK pointed out that recent advances in prostate cancer treatments have improved outcomes, "so it's important that

men understand their treatment options and feel empowered to make a decision that's right for them."This demonstrates the need for a second opinion on each man's prostate cancer treatment options over and beyond what may be available within their local NHS environment. Empowering men to make informed decisions. Decisions require information, confidence and commitment, and the disturbing findings of this report raise the question of how you empower men diagnosed with prostate cancer to make informed decisions? How do you make them aware of the need to access information beyond that available in their local NHS trust. Another way of looking at this question is through health literacy. The NHS defines health literacy as follows: Health literacy is about a person's ability to understand and use information to make decisions about their health. A user with low health literacy will generally struggle to: read and understand health information, know how to act on this information, know which health services to use and when to use them, look for an independent second opinion on their prostate cancer treatment options. Fear of Prostate Cancer Treatment Side Effects impacts screening. So how does health literacy impact men and their prostate health? An American study published earlier this year surveyed over 12,000 men, demonstrated a positive association between self-reported health literacy and the likelihood of PSA screening, and concluded that "while PSA screening can be controversial, health literacy may serve as a window into which patients are more likely to be proactive in their urologic care". Research at Harvard Medical School reinforces the UK study on health literacy and treatment decisions, demonstrating links between health literacy and treatment choice specifically for men with slow-growing prostate cancer. Understanding your treatment options. Men with early stage prostate cancers need to understand the modern focal therapy treatment options for prostate cancer which offer a less drastic alternative to robotic prostatectomy or hormone/ radiotherapy treatments. This is where an expert independent second opinion on their prostate cancer options can add value. Improving health literacy isn't confined to a particular age, race or location, and fixing it doesn't happen overnight. Even if there was a continuous stream of vetted information to all men supplied through a range of media channels, not all men are ready to or able to listen. It really is a case of the right information accessible at the right time, as decisions require both accurate and timely information and the confidence to take that information for self-advocacy. Fortunately there is a body of dedicated campaigners and organisations committed to providing the right information about prostate cancer to the right people at the right time and in the right place, and during this month of November the Movember campaign stands out as exemplary. As the research described here shows, it is sorely needed and a long haul. If you have questions about treatment options for prostate cancer, we'd love to hear from you. Joining me today is Almar van Loon, Director of Customer Success at Quantib, a technology company that creates products to support radiologists using artificial intelligence. Almar has a background in clinical radiology, and has worked with Quantib since 2018 as an application specialist supporting radiologists and other clinicians on improving their workflow. One of the products Almar has worked with extensively is Quantib Prostate, which uses AI to read prostate MRI scans, and he's here to discuss how this is impacting clinicians, and ultimately patients, in the diagnosis of prostate cancer. <https://www.quantib.com/en/solutions/quantib-prostate> Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Almar van Loon, Director of Customer Success at Quantib, a technology company that creates products to support radiologists using artificial intelligence. Almar has a background in clinical radiology and has worked with Quantib since 2018 as an application specialist supporting radiologists and other clinicians on improving their workflow. One of the products Almar has worked with extensively is Quantib Prostate, which uses artificial intelligence to read prostate MRI scans. And he's here to discuss with me how this is impacting clinicians and ultimately patients in the diagnosis of prostate cancer. Let's jump right in, because I think when you sort of hear people say AI or artificial intelligence, some people react with absolute wonder and excitement and a sort of tell me more attitude and others kind of, you know, retract with fear and intimidation. And I think the idea is that this is something that's very exciting, it could potentially really help prostate cancer patients, but we need people like you to shed some light on exactly what is happening. So if we can jump right in and if I can ask you how the work that you're doing with Quantib will help men with prostate cancer, can you explain that to us? What we do and what drives the people at Quantib is really leveraging that exciting power of artificial intelligence to streamline and enhance the radiologist workflow. So specifically, talking about prostate cancer and the issues we're seeing there in the diagnostic pathway, we see that our solution, which is deep learning based software for the reading of prostate MRI, is really aimed at helping the radiologist, which is of course, the medical specialist who reports on the MRI scans of the

prostate. And what you see in that field is that with the most recent changes in guidelines of European Association of Urology, prostate MRI is required before a biopsy is performed. And that is leading to an incredible increase in the number of prostate MRIs that are being acquired. And then on top of that, we have a growing interest in active surveillance - so following patients with suspicious areas of interest in the prostate using MRI, and the European Commission, who two or three weeks ago recommended to start population screening for prostate cancer, and the discussion there is also if you should include MRI. So one of the big problems is that increase of workload because that is leading to longer waiting times for patients to get their result. And with higher volumes, it means the amount of radiologists is not rising in correlation, so less experienced radiologists are starting to report on prostate MRI. And there the literature, the scientific literature, warns us for the fact that the less experience, or the lower the experience of a radiologist, the lower their ability is to detect prostate cancer in the hundreds of images that are acquired in one single MRI scan. And our software helps the radiologists to make their reporting process significantly faster, so enabling the radiology provider to reduce the waiting time for results for patients and their referring physicians. Next to that, the current clinical practise is to provide the radiology results in a dictated text report. And that means that the patient and the referring physician need to distil all the relevant information from a block of text. With our software, the radiologist goes through their reporting workflow, but next to their dictated report, also a standardised visual report is generated, enabling much easier communication between radiology and the urology department, or urology practise, but also enabling easier and faster communication between the treating physician and the patient or prospective patient. So in short, our work really helps patients to get results faster and increase the quality of communication between the radiologists and the urologist and his and her patients.

Clare Delmar Okay, so I want to go back to a couple of things you said, but I just want to sort of extend the question by asking how this will lead to improved diagnostics and ultimately more effective treatment for men with prostate cancer? So we have multiple ongoing projects, scientific research projects where you're trying to quantify the effect of using AI software in the clinical pathway. Campus Biomedico, one of the largest medical universities in Rome, showed with their team that a first year's resident, so not a medical specialist, but someone in training to become a radiologist using Quantib prostate, was able to read and report prostate MRI at the same level as an expert prostate radiologist using our AI software. So there you really see that you improve the detection in the diagnostic pathway, but you also want to verify that with the pathology results because of course the pathology results, the results that come back after biopsy are your ground truth. We work together with a big urology practise in Berlin, in Germany, affiliated with Charité University Medical Centre, which is one of the largest university clinics in Europe. So what they did normally in a regular clinical setting, the urologist performs a targeted biopsy on the targets the radiologist reported on and after that does an even broader systemic biopsy, so puncturing randomised areas in the prostate just to make sure that there are no cancer cells in other areas. What they did in this study is perform the targeted biopsies on the radiology report targets, but then use the output of our software to target that random biopsy. And in a cohort of 150 patients, this group found ten more cancer lesions that were not reported in the initial radiology reports. You really see that AI is not only making the workflow more efficient, but also enabling easier detection of prostate cancer lesions. On a more anecdotal level is that our users in a regular hospital setting, after the radiology report comes back, the treating physicians, the radiologists, the pathologists, etc. And what you see in practise, and you might laugh, is that these meetings can be very inefficient because for each patient, a radiologist has to put the images up, find the correct slices, and before you can even start to discuss the patient.

Almar van Loon What we get back from our users is that their meetings have become much more efficient because instead of putting all the images up, they just discuss the standardised visual report that also medical specialists without a background in imaging, so without radiology knowledge can easily understand and together make decisions on.

Clare Delmar Okay, there's a number of red flags that come up, including what's been the reaction in the radiology community and in the wider clinical community to your software?

Almar van Loon Yeah, that's an interesting follow up question because that is what I see in reality, and I've been in this field for now about five years, is the current situation is really different than the situation a few years ago.

Clare Delmar Okay Almar van Loon A few years ago you really saw that the clinical community had a fear of AI. And there's a relatively funny anecdote which shows that sometimes reality catches up with your quotes. Professor Geoffrey Hinton, which is kind of considered one of the godfathers of neural networks, which is a certain AI technique, stated that we should stop training radiologists because artificial intelligence could outperform them very soon. And that generated a lot of resistance to the deployment of artificial intelligence in radiology. But nowadays we actually see that people have gotten

over that fear and really see that AI is not there to replace the medical specialist, but really to work in synergy with the medical specialist to make them more accurate, to make them more efficient, and also to take over cumbersome tasks that they are now performing that can actually be performed better and more consistently by artificial intelligence. So that radiologists or other clinicians, of course, in that retrospect, get more time to spend on the more difficult cases or with their patient, etc. So now you really see that that attitude has changed, especially because our healthcare systems are facing great challenges on the financial side, staffing shortages and incredible growth in diagnostic exams. So the amount of radiology exams and images being acquired and you see that the healthcare field is now seeing the deployment as one of the viable solutions to deal with the ever rising number of exams and staffing shortages. So I really see the move right now from the early adopters in academia to real world clinical practise and that is an exciting time to be in. Clare Delmar So can you give us an example of where your system is being implemented and what lessons you're learning from its use in clinical practise? Our portfolio at Quantib is broader than just the prostate product, but focusing on the prostate product, currently being deployed mainly with a focus in the European Union where we have customers like Sapienza University in Rome, but also very nice mix of non teaching hospitals and private clinics in countries like Belgium, Norway, Switzerland, Turkey and Slovakia as example. And in the United States, we are now finalising the deployment at RadNet, which is one of the biggest radiology players in the United States, with over 350 imaging clinics in seven states, but also with other private providers in states like Florida and Texas and public hospitals in Pennsylvania. And for us what is really valuable in having such a broad range of deployment sites is that that mix of academia, non teaching hospitals and private clinics adds an incredible value to us as company. Enabling us as customer success team to summarise this feedback and relay it back to our development teams in our labs to develop new features for existing products that are really based on the actual clinical needs and problems customers experience so that you're really adding value to the clinical workflow. And that is only possible with such a mix of diverse deployment systems, because an academic hospital might have completely different needs than a private centre or a non teaching hospital. Clare Delmar Well, Almar, this is a fascinating area and I hope it's the beginning of a number of conversations. I mean, there's a lot to take in, but it's really fantastic to talk with someone like you who's been sort of at the coalface of it and is now dealing with it in clinical practise. Almar van Loon Thank you so much for inviting me, Clare, it was a pleasure speaking with you. Great questions and I hope we generated some knowledge and understanding about what AI can mean for patients in prostate cancer pathways. A transcript of this interview is available on our website, along with links to quantify prostate and further information on diagnostics and treatment for prostate cancer. Also included our additional interview stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Twice the Burden How fitting that during this final week of Black History Month, we came across the London-based poet Herbie Dunnan. Jamaican-born Herbie works as a teaching assistant and, in his spare time, writes poetry about the people, situations and feelings that he experiences in daily life. His forthcoming collection contains a poem that Herbie wanted us to share with people, and particularly those in the Black community, because it's about the excess burden of prostate cancer that Black men face. Herbie's motivation came from spending time with a friend who had recently been diagnosed, and he began to learn about prostate cancer and was struck by its disproportionate burden on black men. Prostate cancer I watched a video this morning about prostate cancer in black men It's a topic it seems a lot of us do not comprehend. They were enlightening us on the statistics which are really scary Open your ears please; and listen clearly. Ladies encourage your partners to look, listen, learn Take heed and get tested - it should be both your concerns. Have a talk with your doctor and see what they say They will put your mind at ease; come what may. Has prostate cancer inspired you or anyone you know to share the experience and and/or express feelings about it through poetry, music or art? NanoKnife at The Focal Therapy Clinic Our clinical team undertook its first procedures using the NanoKnife therapy for prostate cancer treatment, launching a new clinical programme at the Focal Therapy Clinic. TFTC Consultant Urologist Tom Dudderidge believes the new ablation approach will in time broaden the focal therapy offer, giving more patients access to precision treatment. "It's very exciting to use NanoKnife therapy for treating prostate cancers which are located in difficult to access regions of the prostate gland. The precision of NanoKnife allows us to precisely eliminate prostate cancer cells while preserving surrounding healthy prostate tissue giving good cancer control with minimal side effects" NanoKnife uses Irreversible electroporation (IRE) technology to precisely target cancerous cells using electric current to destroy them. According to the Journal of Medical Ultrasound, IRE induces cell death through the application of high-voltage current. NanoKnide (IRE) is effective at

treating prostate cancers which are hard to access with minimal impact upon surrounding tissue. Tim Dudderidge emphasizes this latter point: "Nanoknife has advantages over technologies such as cryotherapy. Its higher level of precision reduces the side effects often seen with cryotherapy especially with regard to urinary incontinence." TFTC Consultant Urologist Alan Doherty concurs on the effectiveness of Nanoknife "for reasons of simplicity and effectiveness, I think Nanoknife will become the dominant focal therapy for hard to reach prostate cancer tumours. We use MRI contouring to position the treatment electrodes so that we can be confident about treating the area of cancer while we preserve healthy tissue." NanoKnife Clinical Trial NanoKnife is produced by Angiodynamics, an American company which is currently running the PRESERVE (Pivotal Study of the Nanoknife system for ablation of prostate tissue in an intermediate-risk patient population) trial in the USA. It treated its first patients earlier this year after receiving FDA clearance, and has clear objectives for the trial: "This single-arm study will assess the safety and effectiveness of the NanoKnife device when used to ablate prostate tissue in intermediate-risk prostate cancer patients. The study is expected to conclude by March 2024 and enroll 118 patients in facilities across the United States." The Focal Therapy Clinic MDT At the Focal Therapy Clinic team meeting there is a detailed clinical review of each patient's case. At this meeting there is a discussion as to the clinical treatment options for each patient and the likely trade-offs associated with them. The clinicians then discuss this review with patients to arrive at a decision which meets with the priorities of each patient. The early experience at the Focal Therapy Clinic with the NanoKnife procedure has been successful in terms of treatment impact and minimal side effects and the effectiveness of the precision treatment as confirmed by MRI scans. TFTC Consultant Urologist Raj Nigam. "I look forward to seeing longer term results as more patients are treated, he said, adding "I'm delighted that we are contributing to understanding the role of Nanoknife in the Focal Therapy armamentarium." Tim Dudderidge. "we'll be starting this clinical programme very carefully, selecting patients that are most suitable and monitoring their results though the national registries we are setting up with colleagues." Are you interested in discussing Nanoknife treatment for prostate cancer? Developments in prostate imaging and why you should care Marc Laniado, Consultant Urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer, joins OnFocus to discuss prostate imaging and reporting. Marc has been a dedicated practitioner and vocal advocate for the rights of patients to be informed about their treatment choices from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital. He's here today to talk about the crucial role that imaging plays in diagnosing and treating prostate cancer, and why a minimal standard of imaging and reporting is essential to successful diagnosis and treatment. Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Marc Laniado, consultant urologist at the Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a dedicated practitioner and vocal advocate for the rights of patients to be informed about their treatment choices from his base at Frimley Health, where he's prostate cancer lead at Wexham Park Hospital. He's here today to talk with me about the crucial role that imaging plays in diagnosing and treating prostate cancer and why a minimal standard of imaging and reporting is essential to successful diagnosis and treatment. Clare Delmar So let's jump in and just for our listeners, I spoke a lot with Marc just quite recently, earlier this month at the Focal Therapy Masterclass at Imperial College, where there was so much exciting developments and advances were presented and a lot of the discussion was around imaging. And I think the reason we started the conversation was because the good news is that imaging now, prostate imaging, that is, multiparametric MRI imaging even more specifically, is now fully accepted. But I think the conversation we had was that one man's prostate MRI is not another man's prostate MRI. And the variability is something that I know you've been concerned about and that at the the Focal Therapy Clinic really pride ourselves on having a minimum standard. And I just wanted to throw out to you, we always talk about precision diagnostics and we say that that leads to nuanced care or less invasive care. Nuanced care is about giving care that's bespoke for the individual man you see, with his personal problems and issues and his specific prostate cancer. You take a typical man aged about 60 or 55, something like that, he's diagnosed with Gleason score 3+4=7 cancer, which is grade group two. So one of the commonest cancers to be found, PSA around six, he would have what's typically called fable intermediate risk prostate cancer or cancer prognostic two, group two prostate cancer. The cancer of that type can range from a small cancer in just part of the prostate to a large cancer enveloping the whole prostate. And so the treatment would need to be different depending on that type of cancer the

man has. His cancer could have been found through screening, or he could also have problems passing urine. So precision diagnostics is really about understanding the severity of the cancer, but also knowing much more about its location, the volume, the grade, its position than it was typically given in the past. So it's only with precision diagnostics where we know all these additional details, where we can say, okay, you've got your man with no other symptoms and you've got a small cancer, we can treat it perhaps just by ablating or destroying that small area of cancer compared to another man at the same age, same PSA, same Gleason score tumour. But his cancer may be occupying the whole prostate or most of the prostate, and he also has urinary symptoms and he would need nuanced care or precise care that's related to that, which would be treating the whole prostate and enabling him to pass urine. And his treatment would be perhaps surgical removal of the prostate or something similar. So the two men, although ostensibly with the same type of cancer, have completely different background scenarios and their cancers need different treatment. Yes, we need precise diagnostics so that we can give each man the individual care and treatment he deserves. Clare Delmar Okay, that's really helpful, and I imagine more contextual information and data on the patient is important too, but I'll come back to that. I just want to recognise once again, as I said in the intro, that you've really been at the forefront of focal therapy for well over ten years. How would you describe the changes in the prostate cancer diagnostics that you've worked with in that period? And if you go back to the very beginning, we used to diagnose prostate cancer by putting a finger in the back passage in the rectum and then putting a needle almost blindly through the rectum to try and sample the prostate and find out the cancer was there. So ultrasound first through the lower belly, but then in the back passage, when we could do that, we could then see for the first time, you could actually see how big the prostate is quite accurately. And by being able to see the prostate, we could put needles into systematic locations of the prostate. So rather than sort of randomly or wildly putting needles through the rectum into the prostate, we could direct them into certain parts more specifically. Only if there's a very large one, you might see it on ultrasound, but most of them were pretty much invisible. And then around 2000 and from there on, MRI became more prominent and soon became recognised in special centres that actually MRI can show where high grade cancer is located, specifically the higher grade cancers of larger volume, those cancers that might shorten a man's life or give him side effects as he gets older. And so armed with that information we were able to start directing needles into the right place in the prostate to find cancer. But that also had problems because we were putting needles through the back passage we often had infections. And then in latter years we've moved on from transrectal biopsies to doing transperineal biopsies. So now they're both safer, less risk of infection, but also we can reach all parts of the prostate. When we do things through the back passage, we can only really sample the back of the prostate, but now we can really take biopsies or samples from the front, the back, the sides with extreme accuracy. So even though in the past we had the MRI and we take the biopsies, we still had to somehow use our brains to merge the ultrasound images with the MRI images which is not as easy as it sounds, because when you're looking at the prostate in real time, it's moving around and changing shape, whereas the MRI is a static image, pretty much. So we then moved on to be able to use complex software, digital software that could then fuse the MRI images with the ultrasound in real time. So when we're scanning a prostate in real time, we can overlay the MRI images and see where the cancer is located then. We can know where cancer is located, where it's not located, we can know the exact grade and volume. So we've gone from really being able to just about say someone has prostate cancer to being able to say that you've got this specific volume, this specific grade and is located in these specific areas over the last 20 years or so. And so the fact that this imaging has been the most significant change and that's obviously translated both into biopsy as well as ultimately in treatment as well. So what do you think are the challenges of diagnosticians like yourself that you face with regard to imaging? So the challenge for most urologists and other people diagnosing prostate cancer is interpreting the MRI scan. And in the past when we were doing ultrasound, it was black or grey, grey, white and black and fairly easy. They're done also to look at blood flow, the stiffness of the tissues, what's called diffusion, restricted diffusion. And that for a urologist, can be challenging, but it can also be challenging for radiologists. And there's been huge variability across the country in the skills of radiologists interpreting MRI scans. But more than just that, it's not just that the doctors having issues, it's also been an issue with the scanning equipment. They vary both in resolution, the ability of the imaging to resolve or give clear images, but also how the images have been, how the MRI scan has been set up. Contrast is an agent or substance that's given to patients, which helps to see where the blood flow goes through an organ, like the prostate. We know that cancers often take up more blood flow than non cancers, so to see the prostate take up contrast, and where it takes up contrast can be

quite helpful for an imaging doctor, a radiologist or a urologist, to see where cancer might be found. And that may be fine if you're going to just treat the whole prostate, but if you want to give nuanced care, if you want to give really bespoke care to the patient, to the man, you really need contrast. So we see a huge variation in the scanners, the administration of contrast and the interpretation of the scans, and that poses major and significant changes to what can be offered to patients relatively so that they get the right treatment. I.e. for example, they have treatment if they have significant disease, but also not being told that they have no cancer and then be put onto active surveillance, i.e. monitoring, but then find out, okay, oh dear, sorry, we made a mistake, in fact, there is more significant disease than we thought. And now maybe either you missed the boat for a very simple treatment, or actually you really need very heavy major treatment and we may not be able to cure you anymore. So the variability in all these things does lead to confusion amongst people because men are told they can have active surveillance in many cases, they are told they can have surgery, can be told they need focal therapy, or can have focal therapy but in fact it may all be incorrect if the imaging hasn't been done well. Clare Delmar So the imaging really does make a significant difference in what kind of treatment is being offered and ultimately the quality of life. Yeah, I mean, has there been discussion about a minimal reporting standard or a minimal image capture standard or is that being discussed? I know that was touched on a little bit at the masterclass, but where do you stand on that? And there has been a classification system called PI-QUAL, which is about how good the imaging is and how reliable it is. And although the scale has been presented, it's not widely used unless the imaging is being reviewed at another meeting outside of where the imaging was performed. And then in terms of interpretation, there is no, for example, exam that people have to sit to be able to pass to say that they can report multiparametric MRIs of the prostate gland. But there are courses that radiologists go on and urologists also can attend where they can become skilled in interpreting the scans. And usually it involves a period of mentorship and close monitoring of the reports of the MRIs scans with subsequent prostate biopsies if they're done. There's no, if you like, standard across the country which people have to specifically pass to be able to say that they can report MRIs of the prostate. Clare Delmar I mean, do you think that something like artificial intelligence is the future, is the answer to more consistent and more detailed reporting of prostate images? Marc Laniado Well, the good thing about robots and computers and artificial intelligence is that they're not subject to emotion, they don't get tired and at least in theory, they do what they're told, so they will follow a specific path and not leave things out. So I think artificial intelligence has already made major inroads into many things that we do, it also make a major step forward, enabling us to have more consistent MRI reporting. And certainly, for example, it will consistently report normal prostates, what's a normal prostate. But also it will help flag up abnormal prostates, which need a skilled human who's very good at interpreting MRIs, to perhaps have a look at it and say what he or she thinks. But the MRI scans using artificial intelligence now can report to the standards of an average radiologist. Clare Delmar And finally, at the end of the day, people listening to this are going to care about, I'm a prospective patient, or I know somebody who is about to undergo a prostate imaging before they have a biopsy. What do you think men really need to know before they accept that they're going in for an MRI? If a patient was to ask what the PI-QUAL of a particular set of imaging is, they probably won't get an answer. So PI-QUAL refers to the standard of the imaging that's been performed, and sometimes that will vary within a patient. So, yes, it would be useful to know the typical PI-QUAL standard for a hospital or a scanner. But actually, if you are going to have focal therapy, contrast is incredibly important because it's the contrast scans after treatment that enable us to tell how effective the treatment has been. So if you get an MRI scan without contrast, that's a biparametric MRI, and then you want to have treatment following the treatment up afterwards, which requires contrast, is going to be perhaps not quite as good as if the patient had received contrast with the first scan. The trouble is, in most cases, you can't choose your radiologist and you can't choose your scanner, but it would be also helpful to know, was the radiologist who reported the scan a dedicated uro-radiologist, someone who reports routinely on prostate MRI? Was it a general radiologist or was it someone who just got, unfortunately lumbered with having to report that scan and isn't particularly used to doing that sort of reporting? A lot to take in, but I know it's something that's been hugely important, and it's even more important that patients understand how important it is. Clare Delmar A transcript of this interview is available on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk, and follow us on Twitter and Facebook at The Focal Therapy Clinic. North America gains from UK & European focal therapy Dr Rafael Sanchez- Salas joins On Focus Joining me today is Dr Rafael Sanchez-Salas, an emerging leader in the field of focal therapy for

localised prostate cancer. Trained as a urologist in his native Venezuela, Dr Sanchez-Salas led research on robotic surgery and focal therapy for over ten years at the Institut Mutualiste Montsouris Paris, and is now a member of the faculty at McGill University in Montreal where he is leading research on localised prostate cancer and minimally invasive approaches to its management. Dr Sanchez-Salas discusses how the researchers and clinicians in the US and Canada are now deploying the evidence and patient experience gained in the UK and Europe to advance focal therapy. Learning from the Masters The Imperial Prostate masterclass on Focal Therapy took place last week at Imperial College – refreshingly for the first time in person since 2019, and returning bigger and better. The faculty – both resident and visiting – is undeniably a collective of world leaders and pioneers in imaging and focal treatments for prostate cancer. TFTC Consultant Urologist Raj Nigam presented a session on MR/US fusion biopsies of the prostate, with an emphasis on the critical role that clear, detailed radiological reporting plays in successful precision biopsy. Raj was supported by TFTC radiological consultant Dr Clare Allen in demonstrating how state-of-the-art contouring of a patient's MR imaging provides the essential roadmap for precision biopsy of the prostate. The panel discussions and debates covered all the “hot” topics surrounding focal therapy's position and status in the treatment of prostate cancer, including screening, imaging, and building the evidence base for focal therapy. It was clear that while much has advanced since the last meeting, there is still much that is unknown and untested. What the presenters made clear are the things we absolutely do know Prostate cancer isn't going away and is increasing worldwide Screening for prostate cancer continues to be widely debated with new techniques and new bodies of evidence adding to and lengthening the debate Focal therapy continues to advance with patient selection regarded as an essential key to success, and approaches to selection continually improving, both quantitatively and qualitatively. Quantitative – genomics, biomarkers, imaging techniques and practice Qualitative – contextual patient information, lifestyle, aging Imaging continues to advance in its precision and acceptance, and is regarded by most as providing the foundation for the future of diagnostics and treatment. There were lots of takeaways from these presentations and discussions, but three stood out. The imaging-led pathway is here to stay: “The imaging phenotype is the future” according to Prof Mark Emberton, who argued that detection of prostate cancer is lesion-led, and that there has historically been “too much emphasis on histology” because most practicing urologists “grew up on TRUS” and that current risk stratification systems are antiquated. He believes that we are now in a new era and even described a case where he had treated a patient on imaging information alone – without biopsy. While Randomised Control Trials (RCTs) are the gold standard for clinical acceptance of new medical interventions, they present challenges for building evidence on Focal Therapy, often due to securing patient consent. Three recent trials comparing Focal therapy to Radical Prostatectomy and other treatment approaches were presented, each of which experienced >25% of participants refusing to undergo the invasive treatments. The conclusion was that “Unbiased RCT on focal ablation versus RP is difficult to realize due to the preference of patients for a less invasive treatment option”. Screening approaches continue to improve which provides some optimism for establishing screening programmes in future. Several new methods have been developed in the last few years which outperform PSA on a number of levels – these include alternative biomarkers detected in both blood and urine as well as new imaging techniques. All were considered in the context of benefits and harms as well as risk factors to patients and healthcare. Discussion ranged from an American perspective on the PSA test suggesting that this is a superior method of screening “but hasn't been used effectively”, to a case presented by the Imperial Prostate team on its image-based screening approach, called Prostagram, which they argue is superior on all counts – including diagnostic accuracy, patient acceptability, and cost-effectiveness. Whatever the views on screening modality, there was a consensus that screening for prostate cancer is beneficial and should be pursued. A poll was taken amongst delegates on the question “should there be a screening programme for prostate cancer” – and the results were as follows: Yes 60% unsure 30% no 10%. More info on the event can be found here <https://www.ipmasterclass.co.uk/> Would you like to learn more about advances in prostate imaging and focal therapy? HIFU Treatment Versus NanoKnife IRE Treatment Working with you to select the right treatment for you NANOKNIFE IRE VERSUS HIFU TREATMENT HIFU for easy to access parts of prostate 75% Nanoknife for difficult to access parts of the prostate Minimally invasive with few side effects The choice between HIFU and NanoKnife IRE treatment involves a careful review of each man's case. In general the location of the man's clinically significant prostate cancer will guide the decision. For some men however the decision is complicated by the fact that their prostate cancer may extend beyond a single zone. HIFU Focal Therapy delivered using the Sonacare HIFU system has been in clinical application for prostate cancer treatments for over

20 years. It is a well developed and clinically validated system for ablating Prostate Cancer tissue. HIFU Focal Therapy is most effective in the Peripheral, Central and Apical zones of the prostate gland. These areas are close to the rectum wall and are relatively easy to treat with High Intensity Ultrasound waves directed through a probe placed in the rectum. 70% - 75% of prostate cancers are located within these regions of the prostate gland. NanoKnife IRE is an established technique for the precise ablation of cancer tissues across the body. It is an especially effective ablation technique in the frontal (Anterior and Transition zones) regions of the prostate gland which are relatively far from the rectum and more difficult to treat precisely with HIFU. Many men who would have been considered unsuitable for Focal Therapy because their prostate cancer happened to be in a location that HIFU found difficult can now be offered NanoKnife. HIFU PROSTATE CANCER TREATMENT NANOKNIFE IRE PROSTATE CANCER TREATMENT <https://vimeo.com/639089349> THE DAY OF YOUR TREATMENT You will be asked to not eat anything for at least six hours before the HIFU/Nanoknife procedure. You should NOT drink anything for at least two to four hours before the procedure. On the day of the procedure, you will arrive at the hospital about 2 hours before your scheduled treatment time and will be met by the specialist nurse who will bring you to your room. After you have changed she will discuss the procedure itself including the urinary catheter, how you can expect to feel after the treatment and in the following days. At this stage you will meet with your consultant urologist who will discuss the procedure with you again and confirm that you have understood the proposed procedure. You will confirm that you wish to proceed by signing the legal consent form. Shortly afterwards the consultant anaesthetist will meet with you. The anaesthetist will explain the anaesthetic options available to you and make sure that your preferred option is both appropriate and safe. The anaesthetic will usually be a general anaesthetic (which puts you into a deep sleep during which you cannot feel anything). This is so that you do not move during the procedure, so that the HIFU/Nanoknife treatment is effective. Just prior to going to the operating theatre the specialist nurse may give you an enema to ensure that your bowel is unobstructed. After this you will be brought to the anaesthetic room where you will promptly be put to sleep. Both the HIFU and Nanoknife treatment use a probe, slightly larger in size to the one used when you had your first prostate biopsies taken, that is placed into the rectum (back passage) by the surgeon. During the HIFU treatment, the HIFU device is directed towards the prostate area so that the ultrasound waves can target your prostate gland through the rectum. HIFU treatment normally takes between one and two hours. The Nanoknife treatment is administered by a series of needles that are inserted into your prostate gland, through the perineum, surrounding the cancerous areas. Close Discover More More detail on the urinary catheter here An indwelling catheter can either drain into a bag attached to your leg, which has a tap at the bottom so it can be emptied, or they can be emptied into the toilet directly, using a valve. It is inserted into your bladder through your urethra which is a little opening through the penis. It is not usually a painful procedure but can be a little uncomfortable – a local anaesthetic gel is generally used to minimise any discomfort. Once inserted, indwelling catheters are held in place by inflating a small balloon at the tip of the catheter in the bladder with sterile water, either already in a pre-filled chamber within the catheter or by using a syringe, so it can't fall out of the bladder. You should empty the bag before it's completely full (around half to three-quarters full). Valves should be used to drain urine at regular intervals throughout the day to prevent urine building up in the bladder. The bag can be attached to your right or left leg, depending on which side is most comfortable for you. At night, you'll need to attach a larger bag. It should be placed on a stand next to your bed, near the floor, to collect urine as you sleep. Single-use night bags are usually used to reduce the risk of infection. The catheter itself will be removed after 5 or 6 days. This is usually done by a doctor or nurse at the hospital or at your local GP surgery however it is possible to learn how to do this yourself if you so wish. Close Discover More NanoKnife IRE Clinical Evidence NanoKnife IRE is a cutting-edge technique which has shown very promising results in a series of clinical trials, particularly in its superior preservation of continence and erectile function as compared to Radical Prostatectomy. In one study conducted in Australia between 2013 and 2018, 123 prostate cancer patients were treated with NanoKnife IRE, with a follow up of up to 6 years. CLINICALLY PROVEN OUTCOMES STUDY CONDUCTED IN AUSTRALIA BETWEEN 2013 AND 2018, 123 PROSTATE CANCER PATIENTS In one study conducted in Australia between 2013 and 2018, 123 prostate cancer patients were treated with Nanoknife, with a follow up of up to 6 years. Cancer control 97% were cured using NanoKnife IRE alone 15% had a recurrence within 5 years 3% needed to progress to full gland treatment within 3 years Urinary continence 99% had no issue with urinary continence after the treatment. Sexual potency *76% reported no change in erectile function NanoKnife Therapy for Prostate Cancer NanoKnife: Fight prostate cancer with unmatched, targeted precision FEES £250 Consultation £13,000

Procedure HIFU and NanoKnife treatment based upon advanced diagnostics. FEES £250 Consultation £13,000 Procedure "NanoKnife is a needle-based technology which allows us to reach difficult to reach cancers which would previously have been deemed unsuitable for Focal Therapy. Mr Marc Laniado, Urological Consultant at The Focal Therapy Clinic WHAT IS NANOKNIFE IRE THERAPY FOR PROSTATE CANCER? Treats difficult to reach cancers Day case procedure : rapid recovery Excellent cancer control No incontinence Preservation of erectile function NanoKnife is an exciting and relatively new Focal Therapy treatment for difficult to reach, intermediate prostate cancers. Nanoknife makes it possible to offer Focal Therapy to men whose tumours may otherwise have been deemed unsuitable for Focal Therapy. Unlike traditional cancer treatments such as surgery or hormone and radiotherapy treatment, NanoKnife therapy is minimally invasive, with a rapid recovery to normal routine and virtually no impact upon erectile function or urinary continence. Also known as Irreversible Electroporation (IRE), NanoKnife is an effective form of focal treatment recommended to treat early and intermediate-stage prostate cancer in difficult-to-reach parts of the prostate gland which are difficult to treat using HIFU. NanoKnife is a high-precision needle-based treatment. NanoKnife technology employs a series of short electrical pulses which pass through thin needles, acting like scalpels to target and destroy tumours. The precise placement of the needles is made possible by the use of 3D MRI Imaging Tools enabling surgeons to target the pulses to effectively kill cancerous cells in exactly the right area while leaving healthy cells unharmed thus preserving the prostate's important functions. Clinical evidence now shows that surgeons achieve a 97% eradication of prostate cancer tissue within the targeted area with almost no impact on healthy tissue and preserves sexual health and urinary continence. NanoKnife is performed under general anaesthetic and takes 40 to 60 minutes to complete. Patients can go home within a few hours with minimal pain or discomfort. Download Free Info Pack HIFU Treatment Versus Nanoknife / IRE Treatment Am I Suitable "NanoKnife is a needle-based technology which allows us to reach difficult to reach cancers which would previously have been deemed unsuitable for Focal Therapy. Mr Marc Laniado, Urological Consultant at The Focal Therapy Clinic Am I Suitable "Using precision diagnostics, we are able to pinpoint and treat the specific area of cancer. Traditional prostate cancer treatment is like using a sledgehammer to kill a flea." Alan Doherty, Urological Consultant at The Focal Therapy Clinic Am I Suitable What are the benefits of NanoKnife? The most obvious benefit of NanoKnife — and a leading reason why many prostate cancer patients use this minimally-invasive treatment — is the precision with which it can be performed especially in the front of the prostate gland, an area where HIFU can be difficult. The ultra-focused approach of this therapy makes it possible to avoid damage to any healthy tissues. This precision helps to reduce the two most unpleasant and debilitating side effects that are associated with many traditional prostate cancer treatments: urinary incontinence and erectile dysfunction. As a result, patients can feel less worried about experiencing embarrassing urinary leaks or difficulty maintaining an active sex life if they wish to. Other key benefits of NanoKnife therapy for prostate cancer include: Minimally invasive — non invasive surgery, no radiation, no hormone therapy Rapid recovery — most patients recover in just 2 to 3 days You'll be asleep while it is performed, so you'll have no recollection of the surgery A day (outpatient) procedure — you can go home the same day There is minimal pain and discomfort Preservation of urinary continence Minimal risk of erectile problems The treatment can be repeated if necessary You can still have radiotherapy or surgery if required Read Clinical Evidence Watch Patient Stories Getting NanoKnife therapy Getting any sort of cancer treatment can cause stress and anxiety, particularly if you don't know what to expect. Here is everything you need to know about before, during and after NanoKnife prostate cancer treatment. Before the procedure Before you can be admitted for NanoKnife therapy, our dedicated team will meet with you to confirm that this is the right treatment for you. You will have an initial consultation with your NanoKnife surgeon, where you'll discuss your cancer diagnosis and medical history, as well as your hopes and expectations for treatment. These could include MRI imaging and a biopsy to obtain more information about your tumour. Getting your body ready for NanoKnife therapy can significantly help with the success of the procedure and your subsequent recovery. Your surgeon will provide guidance on: The importance of following a healthy, nutrient-rich diet in the days before your surgery When you should fast and stop drinking ahead of going under general anaesthetic If there are any medications you should stop taking before treatment Anything else you need to do to prepare for your treatment It is essential to follow the guidance of your surgical team and ask questions about anything you aren't sure about. Your surgeon will also be able to tell you how long the surgery is expected to take and what you can expect from your recovery, as well as answer any other questions you have about this treatment. During NanoKnife surgery NanoKnife treatment is administered by a series of needles that are inserted into your prostate gland, surrounding the cancerous areas. First, you

will be put into a deep sleep with a general anaesthetic, which will ensure you don't feel anything or have any memory of your surgery. Once you are suitably anaesthetised, your surgeon will insert ultra-fine needles directly into the tumour. The number of needles can vary depending on the size of the mass, but most patients will have between four and five needles placed into the tumour. NanoKnife is performed using MRI imaging to ensure that these needles are placed with delicate precision.

NanoKnife recovery and aftercare Your recovery from NanoKnife surgery will depend on multiple factors, including your age, fitness level and the nature of your procedure. Your anaesthetic team will monitor you for several hours after your surgery to ensure that you are fit to be discharged. It can take up to 48 hours for the effects of the general anaesthetic to wear off, though you will still be able to return home the same day. You'll be fitted with a catheter as part of your surgery, and you will need to wear this for up to seven days. Standard surgical advice will apply once you return home, including making sure that you drink plenty of fluids and get sufficient rest. You will be advised to avoid heavy lifting or strenuous exercise for at least a week, and sexual intercourse until your catheter is removed and you feel comfortable. You may also be advised to avoid driving for up to 24 hours to enable the effects of the general anaesthetic to leave your system. It's important to follow all aftercare and follow-up instructions as provided to you by your surgical team.

NanoKnife side effects In comparison to NHS prostate cancer treatments, the side effects of NanoKnife are considered mild and short-lived. While you may have to wear a catheter for a few days, this is typically removed with no long-lasting effects. Other potential side effects include: Small amounts of blood and seminal fluid in the urine after surgery, as the tumour breaks down and is passed out of your body. Rarely, men may experience infertility due to decreased/absent ejaculatory fluid. A very small number of men may experience erectile dysfunction issues. However, most men will experience virtually no side effects at all. The cost of an initial consultation, which includes a review of your medical history and a second opinion on diagnosis and treatment options is £250 including VAT. This detailed consultation can be conducted in person or by video call and typically takes between 30 and 45 minutes. The cost of a NanoKnife procedure, including treatment, medicine and necessary aftercare usually starts at around £15,000 including VAT. Your consultant will be able to give you more detail and a specific quotation before you commit to having any treatment with us. It's also worth noting that your treatment may be covered by a private medical insurance policy if you have one. The cost of the initial consultation involving a review of your medical files and a second opinion on your diagnosis and treatment options is £250, including VAT. This detailed consultation can be conducted in person or by video call and typically takes between 30-45 minutes. The cost of the NanoKnife IRE procedure including treatment, medicine, and after-care is from £15,000, including VAT. Usually lasting between 30 and 60 minutes, it is a largely well-tolerated procedure that allows men to leave the hospital within 90 minutes of completion. Patients are able to return home within a couple of hours of having Focal Therapy treatment. The catheter is typically removed within 4-7 days and strenuous exercise is not recommended for 1 week following treatment. The risks and benefits of any procedure are different for everyone - your doctor will be able to explain in detail the risks that may affect you. However, the number of patients treated in the UK is low. The mission of The Focal Therapy Clinic is to make this option as broadly available as possible and to ensure that men have a good understanding of all their treatment options before they make a decision. This will be based on your MRI scan and biopsy results. Provided that your diagnostic results are of sufficient quality your consultant will be able to give you a definitive answer regarding your treatment options and suitability for Focal Therapy. Once you are comfortable that Focal Therapy is the right option for you, treatment can be arranged in a matter of weeks. One of the major benefits of Focal Therapy is that it does not preclude the subsequent treatment options of further Focal Therapy, surgery or radiotherapy. Around 74% of men will not need any further treatment for their prostate cancer after Focal Therapy. "Using precision diagnostics, we are able to pinpoint and treat the specific area of cancer. Traditional prostate cancer treatment is like using a sledgehammer to kill a flea." Alan Doherty, Urological Consultant at The Focal Therapy Clinic

Am I Suitable UK cancer services — a campaigner's experience Joining me today is Chris Lewis, founder and CEO of Chris's Cancer Community, an influential and impactful online community of cancer patients, recoverers, and those affected by cancer. The community has a significant online following (over 35k followers on twitter) and Chris has shared his unique and substantial knowledge on the daily experience of living with cancer with charities, government organisations and businesses both in the UK and internationally. HE is one of the most knowledgeable, insightful and honest campaigners I've met, and I'm delighted to chat with him today about the current state of cancer services in the UK and what members of his community are telling him about it. <https://www.chris-cancercommunity.com>

@christheeagle1 Clare Delmar Hello and welcome to On Focus, brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Chris Lewis, founder and CEO of Chris's Cancer Community, an influential and impactful online community of cancer patients, recoverers and those affected by cancer. The community has a significant online following, including over 35,000 followers on Twitter. And Chris has shared his unique and substantial knowledge on the daily experience of living with cancer, with charities, government organisations and businesses both in the UK and internationally. He is one of the most knowledgeable, insightful and honest campaigners I've met, and I'm delighted to chat with him today about the current state of cancer services in the UK and what members of his community are telling him about it. We spoke well, it's hard to believe it was a couple of years ago, didn't we, at the kind of summer of the pandemic, and lots has changed. So I guess I would just kick off by asking you what you see is the key trends that you've observed through your engagement with patients since the pandemic. So there are patients that I speak to daily that have been diagnosed pre-pandemic, and there are the ones that are being diagnosed since the pandemic. And I was obviously one diagnosed very much before the pandemic in 2007, and myself and others, most of us in that group actually feel grateful, if I can put it like that, for being diagnosed pre-pandemic. Because what I'm seeing now is that - not worse care, I can't say that - much more pressured care is now coming to the people that are new to the cancer diagnosis after the pandemic. By the way, I'm talking not just in the UK, I'm talking about globally as well, but specifically in the UK we all know the stories, and they're not fairy stories, they are reality. People are struggling to get their appointments with GPs and that, for most people, is where their cancer journey actually starts. But more and more so now, that's becoming A and E, which of course in itself is a very pressured environment. Chris Lewis Yeah, what I've noticed, as you know, I speak from experience, actually, because I run a prostate support group and I've done that for eleven or twelve years. For the group, we started doing Zoom meeting so that the group had somebody that they could refer to over that terrible period. But that was very challenging in more ways than one because we found the numbers dropped off quite considerably. Those that joined us on Zoom, most of them didn't find it particularly appropriate for their needs. I just mentioned about the GP situation, which is getting very tough, but also the time spent in hospital with health professionals. But there's a lot more to a cancer diagnosis, and particularly a prostate cancer diagnosis, than just letters and odd emails. Clare Delmar Are there any examples or stories of people you've engaged with around this that you might be able to share? And prostate cancer is one of those where the impact of various different treatments can be very different. There are surgery, there's chemo, radiotherapy and so many different options that are available to some - some only have one option - but there are various different options with various different side effects and various different impacts which can last for life after prostate cancer. The big thing that I'm finding really, is that people are not having these things explained to them well enough. Unfortunately, the people that are quiet and this is why I do the work that I do, because not everyone is like me and they're not forward and they're not speaking up. And I can't necessarily say that people always might get the treatment that they actually might require. And the discussions you have with members of your community often are aimed at just this point, aren't they? That's why the group that I do is once a month, and actually that's the one thing that I've kept up since I started all my work. But this is one area where I volunteer, because actually, online it's great, don't get me wrong, and I could communicate globally, but actually, when I see what's happening in my area, how the local GPs are dealing with things, how the local hospital are dealing with things, how the local health professionals are dealing with things, it makes it much more real. Chris Lewis When you're talking to patients eyeball to eyeball and they're telling us that they don't want to push for a blood test, a PSA test, their doctor's trying to put them off from it and that sort of thing you now. I mean, do you feel that even at that primary care level, and you mentioned PSA and specific to prostate cancer screening, do you think that there's more of that resistance to support men in that early ...? We know PSA is not the test, there isn't the test that exists for prostate cancer, but it certainly can be a good guide. And so many people have got genetic relationships where they've got their fathers and brothers and relatives that have had prostate cancer or breast cancer. You're very interesting point, because I think, again, in the case of prostate cancer specifically, the UK has been such a centre of advancement, both in diagnostics, obviously, around imaging, and in more precision led treatments like focal therapy, which we're involved with. Do you think patients appreciate this, that they're actually in this sort of centre of innovation for their disease? And do you think that's in any way something that would help them in sort

of seeking more information or do you think it's kind of less relevant?Chris Lewis Listen, progress in any cancer is absolutely relevant and we read a lot, particularly about prostate cancer, as you say. But if I'm honest with you, it doesn't seem, when I read it, I like to read what's going on and I like to see any possible progress. I mean, everybody is concerned with what's going on in their particular case, what is available to them. I don't mean this in a horrible way, if you like, but what may or may not be coming down the track in five or ten years time, actually, is if no concern to the people that are struggling currently. Clare Delmar We often get patients coming to us who have obviously had a diagnosis and a treatment offering or treatment recommendation, and on the latter bit, the treatment recommendation, they're worried, as you would expect, and then that's, of course, motivated them to go online or to talk to their friends or to just to seek further information. And so some of them who come to us are pretty well versed in some of these advancements and they want to understand (a) why they haven't been briefed on them, like back to a point you mentioned earlier. A lot of people do take to the internet and they read all sorts of things that actually, in many cases might not be appropriate for them anyway. There are so many different options now for prostate cancer, which is a great thing, but actually, we both know that not every treatment is available for everyone, and it's not always suitable for everyone. And of course, again, without opening this conversation up deeper, but at that point, if they were screened earlier, then you could look at more options, couldn't you? And in which case, the earlier you identify a man's prostate cancer, then the more options they tend to have in terms of treatments. And I'm sure that's something that comes up a lot in the conversations you have with your members. What do you see as the real good news in terms of cancer care, cancer diagnosis, cancer treatment? Clare Delmar Well, obviously I think our listeners are interested in prostate cancer, but, yeah, please do inform it by your other experiences. Chris Lewis I wish I could say it was a lot of good news, actually, Clare, but my experience isn't good news, and I've said this previously, that actually my experience of talking throughout to patients, to researchers, to clinicians, to CEOs, to most people involved in cancer, even politicians, right? I can only say that the cancer world in general has regressed by approximately ten years, in my opinion. Clare Delmar Do you think that the pandemic was primarily responsible for that, or have there been other factors? But to be fair, cancer was, in my opinion, falling off the edge a little before the pandemic came along. No country was really as good as it should have been for the amount of money and time invested into cancer care or cancer research in general. Our success rates, inverted commas, whatever you want to define success as, is nothing in relative terms to the time and money invested into it. And of course now all the hospitals are blocked, there's less money coming in, and cancer is no longer the priority it was. Clare Delmar I mean, it certainly is the headlines, and that's why I'm very interested in hearing your views, because you can obviously dig a lot deeper than what the average person reading the newspapers can see. And it's interesting and quite sobering to hear you say this, that actually those headlines are not that far off the mark, I guess, is what you're saying. To be honest, I'm glad to see them, because unless we know what the problem really is, we can't solve it. So all this waffle that we've seen on health care, all these wondrous things, actually, I class that as like a thunderstorm, what you do, you get a lot of noise and a bit of lightning, but actually, sometimes it's rare that the rain actually reaches the ground. And some of these sort of things that have been talked about in the media for some period of time, the actual reality is that before it reaches the man in the street, that's you and I, there's a lot of water to go under the bridge. Clare Delmar So Chris, what advice do you have for men who have recently been diagnosed with prostate cancer? Whatever... let's not discuss what stage, but a guy comes to you, he's heard about your community, and he says, Chris, what do you advise me to do? But to be honest, if we can't be responsible for our own health, we can't really expect others to be that way. And that really is another reason why I do this work, because the days of the letters come in, the appointments come in, just naturally happening. So I don't think we've got much chance of curing cancer while we can't even answer the phone. Clare Delmar But, I mean, you do find amongst your members that between you talking with them and them talking amongst themselves, that this can actually help to build a voice, build an advocacy role. Well, that is the good news, then, I guess, is people are taking a bit more control over their own care. And this, unfortunately, very sadly applies to most other countries with massive cancer issues, which is most other countries. You could get anything in America, of course you could if you had the money right, but actually, nowadays, the likes of you and I, basic people cannot get cancer care, even if you're paying for it. Australia, America, Europe, Germany, France, Spain, all of them, they have all different systems to us. So if you use just the figures in the UK, just the figures in the UK, we have 60 million people here and 30 million of us will be affected by cancer. Chris Lewis And so the fact that government are not bothered about it, the leadership of the NHS, they're just so flaky that they are controlled by the government anyway, so they can't do anything

about it. Clare Delmar And that's what your community really exists to support... Chris Lewis 100% Clare. I could talk with you about this for much longer, but I'm afraid our time is up and I think that's a good note to end on. And I hope that you do see more people coming through to seek the support that you give so generously. A transcript of this interview and links to Chris's Cancer Community are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Bill Turnbull and the Rise of Patient Self-Advocacy An inspirational campaigner and a meaningful legacy The death this week of Bill Turnbull, popular TV and radio presenter, is a blow to all who knew him whether in person or through his media work. It is especially felt amongst those whose lives have been impacted by prostate cancer, as Bill was an active and inspirational campaigner for screening and early diagnosis, having been diagnosed himself in 2017. Bill's name will forever be connected to prostate cancer screening, as his celebrity allowed him to join with fellow celebrity Stephen Fry, also diagnosed with prostate cancer, to launch a public campaign for early screening in 2018. This campaign had a significant impact on men coming forward for PSA tests, so much that the media called it the Fry Turnbull effect. The National Cancer Registration & Analysis Service investigated how the Fry Turnbull effect played out, and concluded: Our findings show a marked increase in the number of prostate cancers diagnosed from the time of Fry's and Turnbull's announcements of their own diagnoses. Celebrities publicising their cancer diagnoses may prove invaluable in influencing their peers (in this instance, similar age groups) to investigate whether they themselves could also be at risk. Further research could investigate which other factors could have an effect on help-seeking behaviour. Health care professionals often underestimate how people need motivation, inspiration and support when confronted by fear and uncertainty, which is what a prostate cancer diagnosis, or even the knowledge that one might be at risk of developing prostate cancer, invokes. Whether that motivation comes from a colleague, a family member or a more remote source like a celebrity doesn't matter - what matters is breaking through the fear, uncertainty and doubt, finding a voice and taking action. It's a deep commitment to this belief in shifting from victim to advocate that drives campaigners like Chris Lewis, Elvin Box and Tony Collier. In an era of constrained health services, self-advocacy is essential and the support these campaigners, and indeed celebrities like Bill Turnbull provide is essential to driving and sustaining self-advocacy for many. Bill's death has prompted a blizzard of news pieces about prostate cancer, reinforcing Bill's message about getting a PSA test. Have you been motivated or inspired by a celebrity or campaigner in seeking advice on prostate cancer? It takes two Partners and support networks in the prostate cancer journey

The majority of men who come to us with a prostate cancer diagnosis and treatment recommendation are motivated to seek out more detailed information and to explore alternatives by their relationships with wives or partners. Given the nature of the disease and the side effects of many forms of treatment, wives and partners are impacted in multiple ways and will experience their own emotional and physical challenges as a result of a prostate cancer diagnosis. There are likely to be significant changes to an intimate relationship as prostate cancer impacts the mental, sexual and urinary health of those diagnosed. Dennis Golden, CEO of Prostate Cancer Net, has experienced prostate cancer himself and has engaged with thousands of men as they go through initial diagnosis. He emphasises how important it is to bring partners into the process of acquiring information: "I think a big mistake guys make is that they receive a diagnosis, they don't know what to do with it and they freeze, and they decide they're not gonna share any information until they 'know more' and what happens typically is that it creates a very stressful situation in your home" There are resources for wives and partners – and it is mainly directed at wives (more on this later) and often limited in scope. In our view, men benefit most by hearing the experiences of other men and their partners and, most of all, having the opportunity to engage others when they are mentally and emotionally ready. In our patient community we've found that after the initial diagnosis of prostate cancer, a man's partner is often the main source of calm and stability in seeking further information and pursuing engagement with knowledgeable individuals and organisations. Jackie Reubin, wife of one of our patients Barry Reubin, spoke openly to us about her experience when Barry was diagnosed with localised prostate cancer. It was through Jackie's determination to seek a second opinion and explore a full range of treatment options that Barry found the treatment he needed and both he and Jackie have never looked back. Often conversations between partners focus mainly on the disease and its management and less on the side effects of treatment and what these mean in terms of tradeoffs and the impact on a relationship. And this is where professional counselling can really help a couple explore the tradeoffs between disease management and sexual health and what these mean to each

individual's sexual needs and identity. Specialist psychosexual nurse Lorraine Grover has spoken to us about the need for counselling at initial diagnosis, and emphasises how counselling supports the conversation between a man and his partner. She advocates for this as a matter of course for men newly diagnosed with prostate cancer and their partners: "A baseline sexuality and intimacy discussion is important and often enlightening to pre-existing issues. In my experience partners are really pleased to be able to have their voice heard." Pre-treatment education and post-treatment support for men and their partners are key to returning to sexual activity after prostate cancer, according to recent research. According to the study's lead, "If you educate them before treatment and support them after treatment, they return to sexual activity faster. The longer you go without it, the harder it is to come back to it." Elvin Box, a leading campaigner for open conversations about living with prostate cancer, spoke to us about his own experience with his wife when he was diagnosed. My 'period of instability' following the Op was horrific & Jude bore the brunt of my violent behaviour. Together WE nurture & tend to OUR good mental & physical health" Elvin has written extensively about the supportive role his wife has played in his experience with prostate cancer with honesty, humility and a great sense of humour. The majority of our patients are in heterosexual relationships, and increasingly we are hearing from men in non-heterosexual ones. Campaigner Martin Wells spoke to us earlier this year about his experience with prostate cancer as a gay man and emphasised the importance of developing a "prostate literacy" for men and their partners to communicate and make shared decisions about treatment and lifestyle impacts. Martin has founded two support groups to promote prostate literacy – Out with Prostate Cancer and Shaping Prostate Cancer Literacy. Progress since the Pandemic TFTC and Royal Surrey NHS Foundation Trust consultant Raj Nigam, joins On Focus. This episode features Raj Nigam, Consultant Urologist at the Royal Surrey NHS Foundation Trust and the Focal Therapy Clinic. Raj is an andrologist with a special interest in the impact of prostate cancer treatment on sexual and mental health, and has spoken several times with OnFocus about age-related implications of prostate cancer treatment. He's here today to discuss a range of issues that have evolved since the pandemic that are impacting how men with localised prostate cancer are being diagnosed and treated. True North project on prostate cancer <https://prostatecanceruk.org/about-us/projects-and-policies/truenth> Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Raj Niegum, consultant Urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy Clinic. Raj is an andrologist, with a special interest in the impact of prostate cancer treatment on sexual and mental health. And we've spoken several times before about age related implications of prostate cancer treatment. He's here today to discuss a range of issues that have evolved since the pandemic that are impacting how men with localised prostate cancer are being diagnosed and treated. Well, the last time we spoke, the pandemic was very much driving the behaviours of men and indeed clinicians and other hospital staff in terms of visiting a GP. Raj Nigam Yeah, I think that there's probably a slight shift, but it's not massive at the moment because I still think that we're in the aftermath, if you like, of the pandemic. There are a lot of men who resisted going to see their doctors or their accessibility to their doctors was poor and they've lived with vague symptoms for some time. And there were some who had their PSA checked at the beginning of the pandemic and then everything was left in abeyance. They either were not referred and they're now sort of going back into the mainstream, as it were. I've been talking to a number of men fairly recently whereby I've seen, oh, there's a two year gap between their PSA follow ups and then they explain that well, yes, they had one done and then they didn't follow it up. They had been having it followed up for two or three years and some of them, sadly, have had a massive jump in those two or three years, so we're not really seeing us back to normality. And of course, in the secondary care sector, a lot of hospitals are still very pushed in terms of doing prompt diagnosis and prompt treatment because of the waiting lists that have occurred. Clare Delmar I remember talking about that before and even just paying attention to the media, so to speak, that doesn't seem to have abated. I guess that kind of leads me to ask about second opinions because we have certainly seen at the clinic a marked increase in men coming seeking a second opinion on their prostate cancer diagnosis and their recommended treatment, both. Raj Nigam Yeah, I think that this is a reflection on increased or improved communication, both in digital means and by people willing to talk to their friends and relatives and so on, about treatments that are available. Within the public sector system there are two standard offerings and both of them are what we call whole gland approaches. As you know, we are focused very much on treating the prostate cancer where it lies and trying to preserve

other structures and neighbouring tissue which is unaffected by the cancer, which is a concept well understood in many other organs in the body, but hasn't really gained a wider acceptance in prostate cancer, but beginning to do so. And I think that, like I said, people asking for second opinions is a willingness to say, well, actually, yes, I do respect my local doctors and what they're saying, but they may be restricted in what they can offer. And so therefore, I'm going to try and find out from reputable sources what else may be out there. And of course, the Internet, we all know, can be a minefield, but there are established regular treatments which are being offered in the private sector and in other NHS hospitals, I hasten to add, which may not be available within their own locality. And it brings me to the point which I think I've made before, that NHS England has decreed that you have not consented your patient properly in terms of prostate cancer treatments, unless you have discussed all the options of treatment, including those that you do not offer yourself. And all too often we're seeing that last statement being not so much ignored, but not heeded to, shall we say, in the sense that people don't think, oh, yes, there is something else out there, we don't offer it here, but actually, why don't you go and try and find out if you can get this treatment elsewhere? Yes, I think that there is a wider acceptance that the internet may give you better information. And those of us in the focal therapy clinic are well established prostate cancer experts, primarily, and secondarily, as focal therapy experts, therefore we can give them an opinion on whether what they're being offered is absolutely the right treatment for them or whether, yes, there are other options available to them. Clare Delmar I mean, it's interesting that you sort of compare the lack of information that some men receive from their actual clinicians, but then there's an overabundance of information on the internet and we see this reflected in a lot of the comments that men who come to us make. And it makes me wonder about how many men are actually misinformed about prostate cancer and about the range of treatments. At the clinical level, you obviously can't do anything about the internet, but certainly at the clinical level. And basically I think that those patients that do come to us, we've actually created, if you like, clinical champions in some of our patients. As you know, a lot of our patients are drivers for this treatment and for men to get the appropriate treatment with the minimal side effects and they are willing to act as patient advocates, if you like, that they're very happy to discuss their experiences and so on. But we often do find that peer to peer talking and discussion and communication is vitally important, not just for the patient themselves, but also for their partners, that they find that helpful to discuss, if you like, a commonality in their suffering, if you like, and going through the pathway and the process. And they love to talk to people who have come the other side of it, they survived several years and come through the treatment and so on and so forth. We find that, yes, we give them all the scientific data, which some patients find very useful and reassuring. But I think it's also the fact that they are reassured by the fact that some of us have been doing it for a long time and it's that experience in the doctor that they would see rather than some newfangled treatment that they've just found on the internet. And I always say to my patients that, look, this treatment has actually been around for 25-30 years. Particularly high intensity ultrasound and cryotherapy has been around for many years as well. But that if there was a new focal treatment and we are looking at one at the moment, then we would make sure that we researched it properly and so on. I want to pick up on the point about being an experienced clinician and how that reassures and brings confidence to patients and that leads me to think about training and focal therapy. And I just want to point out to our listeners that you're one of the focal therapy specialists that will be contributing to the Imperial College, London's Masterclass in September on focal therapy, which is aimed at other clinicians. I was involved in teaching and training on the first one, which was now three years ago, and then the last one got put back because of the pandemic. So we're very much looking forward to welcoming clinicians that have been there before and also newer clinicians. The training starts right from initial learning about selection and correct patient selection. All the tools that we have in medicine for all the treatments and all the conditions, it's very much choosing the right treatment for the right patient and also ideally getting it right first time. So the masterclass is right based upon selection and selection criteria as well as appropriate and good imaging. We now have multi-parametric MRI scanning and it has to be done correctly in a unit that does lots of them. And then the next process is obviously the biopsies and the types of biopsies that we do and we're involved with every stage of that process in terms of diagnosis as well as leading onto precision treatments. And given the pace of development in both the diagnostics, as you've just explained, the different modalities and the acceptance of focal therapy over the last 5-10 years, how do you predict patients' knowledge of this and their access to focal therapy will change in the next five years? Raj Nigam Well, I would hope that it would improve significantly and there are a number of studies that are focused upon that. Firstly, of course, patients need to have a wider understanding of what the side effects of treatments are, at least those are

standard and those that are offered. And there has been a published study from the True North Foundation, which is a global organisation funded by Movember. And they've produced a paper already on what they call the true results of a radical prostatectomy, for example. Whereby they did not ask the clinicians involved, they just went directly to the patients and did questionnaires on the true burden of the side effects from such a procedure and a similar one is taking place in radiation. So firstly, patients need to know truly what are the side effects with the existing treatments. But also, I think that even at the right beginning of the pathway where a lot of patients know about perhaps getting their PSA tested, but they don't necessarily know what the next stage should be. And there is a study called the Prostagram study where a few local hospitals are selecting men just to have, if you like, the male equivalent of a mammogram. Breast cancer screening is well established in the United Kingdom and in parts of Europe, but prostate cancer screening certainly does not have the direct evidence base, if you like, nor even the will from politicians to have a prostate cancer screening programme. And there have always been problems with the PSA tests, which we all know in terms of cut offs and also overdiagnosing men and also overbiopsing men with elevated PSA levels. So we've always been looking for a better test and we had the most parametric MRI, but that was deemed to be too long and too cumbersome and too expensive for broad based screening. So a Biparametric scan, or a fast scan, if you like, has been developed whereby no contrast is given, takes about ten minutes to do, and it's actually being marketed for primary care. Should GPs have direct access to a good quality biparametric MRI scan and will that pick up men with significant prostate cancers early enough? Clare Delmar So it actually helps in the selection that you referred to earlier, which is really integral to any kind of physical therapy offer? I mean, there isn't a woman around, I guess, who hasn't heard of a mammogram Clare Delmar Of course Raj Nigam But how many men have heard of a prostagram? In fact, I did a blog about this two weeks ago, exactly about increases in imaging and how that will actually help screening. But I just want to pick up on this True North Foundation study, because I'm not personally familiar with that. Raj Nigam Yeah, it's a fairly recent report, but the True North, like I said, funded by Movember, picked out eight projects in the UK and different aspects of what they called survivorship in prostate cancer. So some of them were related to the side effects that patients experienced and how those could be overcome. Some of them were for more advanced disease and one of them, which was led by Caroline Moore at University College, was based upon post radical prostatectomy follow up and what sort of side effects were experienced by those men. And like I said, it was an unbiased study, insofar as it went directly to the men that had had the surgery, rather than to the departments or to the surgeons that have done it. Clare Delmar I'm going to make sure I find that and I'll make sure that goes into the programme notes for our listeners. Well, Raj, as usual, you give so much food for thought and your experience and knowledge is just incredibly helpful for just sort of clarifying the ultimate complexities of this whole world of diagnostics and treatment. So I want to thank you very much for joining me today, as I know you're going off on holiday, so this is a real nice opportunity to grab you. Clare Delmar A transcript of this interview and links to Raj's practise are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk, and follow us on Twitter and Facebook at The Focal Therapy Clinic. GPs have been under continual criticism in the last year and a recent NHS survey on General Practice revealed a significant decrease in patient satisfaction, mainly in getting appointments but in a number of other areas too. Ageism and confusion over test results have particularly impacted men with prostate cancer risk, symptoms, diagnoses or post-treatment conditions. But, equally, these same men have also had a tough few years, as thousands of men have been "put on hold" due to the pandemic. It is a cruel irony that diagnostic methods such as imaging and biopsying have advanced considerably, giving men choice in treatment with better outcomes – but they have to go through primary care first to access these pathways. Focusing on alternatives to the GP for delivering primary care may be the way forward, and three approaches are beginning to emerge. One-stop diagnostic centres, sometimes called polyclinics, have been advocated in the NHS for some time and may be building momentum as the NHS reorganises around Integrated Care Systems. These centres are designed to be community hubs, situated away from hospitals, where local patients can receive imaging and other diagnostic services. Since the official rollout of these centres in 2020, 90 have been set up across England and over 1 million diagnostic checks have been carried out, according to the NHS. Mobile health clinics dedicated to men's health, as in the "ManVan" set up by the Royal Marsden Hospital in London. This initiative has a potentially large role to play in reaching high-risk communities and reducing the number of men diagnosed with prostate cancer at A&E centres: "Diagnosing prostate cancer early and

maintaining a healthy lifestyle result in better outcomes. Around 20% of prostate cancer is first diagnosed via A&E - the aim of the Man Van is to target groups at high risk of delayed diagnosis. We will also be carrying out a broader health check for other potentially serious conditions such as high blood pressure and diabetes" according to the Marsden. Digital apps are another approach to primary care, and as more people use smartphones and digital devices they become a realistic option for monitoring personal health indicators and using this information effectively in communicating with primary care providers. In terms of apps specific to prostate health, several are available for men who have been diagnosed and are undergoing treatment. A 2020 review by the Urotechnology group of the EAU asked the question, "Do prostate cancer-related mobile phone apps have a role in contemporary prostate cancer management?" and after reviewing 44 prostate cancer-specific mobile apps, concluded "The use of (prostate cancer mobile apps) is currently in its infancy and do require further development before widespread integration into existing clinical practise. There are concerns with data protection, high readability standards and lack of information update in current PCAs. If developed appropriately with responsible governance, they do have the potential to play important roles in modern-day prostate cancer management" Do you have a view on how GPs or other approaches to primary care can better support prostate health? Reasons to be Cheerful A conversation with TFTC consultant, Alan Doherty

Joining the podcast today is Alan Doherty, Clinical Director at the Birmingham Prostate Clinic, and recently voted one of the UK's top ten prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail. Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer, and joined the Focal Therapy Clinic last year to develop his expertise in delivering focal therapy. Having now treated a large cohort of patients with focal therapy following the Clinic's rigorous MDT review, he's even more positive now about the approach than he's ever been, and joins Clare today to discuss how this experience makes him optimistic about the future of focal therapy and, most importantly, the future for men diagnosed with localised prostate cancer.

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Alan Doherty, Clinical Director at the Birmingham Prostate Clinic and recently voted one of the UK's top ten prostate cancer specialists in the national poll of consultant urologists published in the Daily Mail. Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer and he joined The Focal Therapy Clinic last year to develop his expertise in delivering focal therapy. Having now treated a large cohort of patients with focal therapy following the clinic's rigorous MDT review, he's even more positive now about the approach than he's ever been and he joins me today to discuss how this experience makes him optimistic about the future of focal therapy and most importantly, the future for men diagnosed with localised prostate cancer.

Clare Delmar And I'm always impressed whenever we chat how positive you are, which is why I thought this would be a great theme to sort of set the stage. It'd be really good way to get you talking about what you've observed from treating your patients. And I guess the first thing I want to ask you is what kind of cases have you seen, well, certainly in the last year since you've joined the clinic and even more recently, that gives you cause for optimism? Alan Doherty I suppose I'd answer that by saying I've been surprised by the enthusiasm of so many patients to have focal therapy and some, of course, are more suitable for it than others. And in a way, how often patients, even if you don't think they're particularly suited for focal HIFU, they often still want it. So it's a difficult balancing act from our end to offer treatments which we think are perfect for them versus patients who have a strong view as to what they want and not necessarily listening to us as clinicians. I think the second thing I'd say is that I've been so impressed by the way The Focal Therapy Clinic are able to assess a patient so that when we are recommending a focal therapy, you can really have confidence that this is the right thing to do. And the reason I say that is because a lot of focal therapy... and management of prostate cancer in general... early prostate cancer... is very much dominated by good quality MRI scanning. Within our group we're able to do that so well and that gives me confidence that when I recommend focal therapy that this is the right thing for me to be doing for a patient.

Clare Delmar It's interesting you say about the clinic bringing you patients that are so enthusiastic and I think that has to do with our approach to what we call patient advocacy, the first port of call for many patients is our wonderful patient advocacy team, so they actually begin to understand each prospective patient's kind of hopes and dreams, as it were, and what their lifestyles are like. But of course, the other thing, when you reference MRI is, we do an extremely rigorous MDT. One is I share ideas with my clinical colleagues who are treating prostate cancer day in, day out and it's always good to share an idea, to have it critically assessed. And then the second thing is the way that we can look at an MRI scan in a live setting and everyone sort of picks up

slightly different things about the MRI scan and what it all means. And I think out of all the MDTs that I do, and you can imagine we do a lot of MDTs, this particular one is the most influential. It's the one where I learn the most and it's the one that I really don't want to miss because it's the one which I give feedback to patients with better information than I can from just myself thinking about the case. Clare Delmar And do you think that the quality is continually improving as well so that you can really deliver optimal care for your patients? Is that it virtually transforms the reasons why for screening for prostate cancer is a good idea. In other words, if you're going to find a cancer early, you have to have a treatment that is effective but also doesn't cause many side effects. And it's this concept of overtreatment which is inherent in the screening of any condition, because if you pick something up early, you don't know whether it's going to be a problem in the future. But if the treatments you're offering for early treatments are associated with a lot of side effects, then the arguments for a screening programme don't really stack up. But if you have a treatment with very low side effect profile, which can be delivered accurately like we can in our focal therapy clinic, it really does give a strong rationale for screening. And that's the first time I think I've ever been able to stand up in front of a lot of doctors and say, well, I think it makes sense to find this early because we can treat it even if it doesn't turn into a problem in the future without many side effects. The more you understand about how we're treating these cases, the more you can see why there's benefit and very little harm. Clare Delmar And of course, a lot of that is driven by the evidence base that's continually being generated. I mean, even this year there have been a couple of studies that have been published about men undergoing focal therapy that have been really positive. Do you think those, given what you just said, will drive its adoption and availability more widely? I think one of the troubles with any treatment is you've got to, I suppose, compare apples with apples and oranges with oranges. Because when you do something properly, as I think we are in the focal therapy clinic, because we're doing it in this multidisciplinary meeting and we're doing it with very high quality MRI scans. Our results are going to be a lot better than if you just do it in a sort of happy go lucky type of approach. So I think if a study is showing benefit when it's not just done by one dedicated group, but it's done by a whole heterogeneous group of people, you've got to say that the likely outcomes are even better than the studies are showing. And I think the other thing to realise, again, something else I've noticed in my last year is that often patients will be prepared to have the main lesion treated with focal therapy and just monitor a smaller lesion on the other side. Now, that's an interesting situation to be in because if you define an outcome by the need for another treatment, well, that particular group are a high risk group because we know that we're leaving a tiny amount of cancer there that's possibly going to get worse in the future. But being prepared to do that because they're confident that we're going to monitor them closely and if necessary, treat them again with a minimal morbidity. I think when you're doing studies, it's really hard to compare apples to apples because you generally have groups of patients who are very diverse and clinicians that are diverse and you're getting sort of quite a few varies. But the point I'm making is if you are showing benefit with that diverse group, then you can imagine how much better it's going to be for the very select group when the treatment is done properly. Again, very interesting way of looking at it, because we're always wondering how and when focal therapy will kind of go mainstream, so to speak. And I was going to ask you, do you see focal therapy playing a more significant role in educating men about their treatment options for prostate cancer? Do you think the urology community is developing more of a literacy around it and adding it to active surveillance, hormone therapy, radical prostate, radiotherapy in the treatment portfolio? Alan Doherty I think what focal therapy does is make you realise how important a good MRI scan is. Because a good MRI scan and good interpretation of that MRI scan by a very experienced radiologist. But if you go one step back, it means that you're not going to biopsy patients who have a normal MRI scan. In other words, if you're confident in your MRI scan, you can really reduce the number of biopsies you ask for. So it will stop people being scared of having a PSA, because traditionally, if you had a PSA blood test and it was a little bit abnormal, you'd end up having a biopsy. So what I'm saying is, I suppose when you are offering focal therapy, you're the type of clinician that's not going to be biopsying people just because the PSA is slightly elevated. Focal therapy is all about seeing the lesion, hoping that it's only in a focal area and then treating it accordingly, and you have to pick it up early so that you can get good outcomes from it. But with time, it's relatively new that MRI scans become a dominant feature in prostate cancer management. And you can imagine, therefore, that if something is new, it's going to take time to really develop. You're going to have certain pockets of excellence and you're going to have people catching up with that and then you're going to have certain pockets where they need to pull their socks up a bit. Clare Delmar But I mean, picking up on your point about doing no harm and the benefit of early screening, I've heard you say in the past that now that you do have this

highly precise MRI, which is only getting better and better. If you can see these cancers and you can define their severity, their location, their size, is it better to treat it than, for example, to do nothing? Because maybe you are over treating people, but that goes for all screening programmes and the trick is to over treat someone... sorry the trick is to try to avoid overtreating. That often doesn't translate down to the patient level because they often sort of undergo an MRI scan, for example, without fully understanding the significance. They might know that it's obviously going to aid in their... well, as you say, whether or not they did a biopsy or not. But I guess connecting that to they might be able to have less radical treatment because this new method allows that is probably something that needs to be educated. Alan Doherty And I think one of the last things to just mention is that people who do focal therapy probably are best as clinicians who don't just do focal therapy do a number of different treatments because every treatment has its limitation. Alan Doherty The more you do it, the more you understand those limitations and the better able you are to advise the patient as to what's best for them because it's not necessarily just the short term outcomes that matter, it's also the long term outcome. And every patient is different and has a different personality and has a different value system. So it's quite fun being a clinician in this day and age because we've got so many different ways to treat people increasingly without making them miserable when just giving them benefit. Clare Delmar Yeah, and so much more information on which to make those decisions and have those conversations. Clare Delmar So I guess as a final question, what are the reasons to be cheerful if you're a man over 50 and you're faced with the fact that, oh, I've got to go get a PSA test, for some men, this actually makes them quite hesitant, even reticent about getting one. But from what you're saying there's, early screening can lead to, well, you tell me, what are the reasons to be cheerful if you're a man over 50? Alan Doherty Well, I think that if somebody was to encourage a patient to have a PSA blood test, they should be confident that we're only going to pick up a significant cancer that's going to be seen. In other words, that the MRI scans normal, we don't biopsy, and then if we do see something, we're going to pick it up early enough that we can affect the natural history. In other words, that we can make a difference and stop you having to have treatment in the future that have a lot of side effects and even better than that, possibly even stop you dying from it. I think the reason to be confident and positive about the future is that high quality MRI scan and a focal therapy just allows you to pick up and treat early tumours before they are really dangerous. Clare Delmar Well, on that note, I'm going to say thank you so much for sharing your optimism and giving us some really useful pieces of information about how some of this diagnostic information is really transforming what you can offer patients and how they're going to recover. I'm so glad you do these to share information with people because there is so much out there now and it's confusing to patients. Clare Delmar Well, it's great that you can actually help make it a lot more not simplistic, but a lot more easy to digest and, as you say, a reason to be cheerful. Clare Delmar Further information on Alan and his clinical practise is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Prostate MRI: from experimental to essential A timeline of the emergence of the mpMRI in prostate cancer diagnosis One of the key underlying messages coming out of this month's long-awaited post-pandemic Congress of the European Association of Urology was the almost universal acceptance of the role of specialist MRI scans in prostate cancer diagnosis and its continued growth in adoption and implementation worldwide. Debate on its value and role has now shifted to how to improve its efficacy and accuracy, with a particular focus on PET/MRI. We've come a long way since the design of the PROMIS trial, launched in 2012 and published in 2017. It set the stage for a significant paradigm shift in prostate cancer diagnostics using specialist MRI scans, testing the value of Multi Parametric Magnetic Resonance Imaging (MRI) for men with a suspicion of prostate cancer who had been recommended to have a prostate biopsy. It investigated whether MRI could be used (i) to advise whether or not men might safely avoid biopsy and (ii) to improve biopsies for men who have them. PROMIS demonstrated the following: TRUS post PSA blood test results is a poor test for the diagnosis of clinically significant prostate cancer. The sensitivity was only 48% and thus missed over half the cases. Specialist MRI scans performed after the PSA blood test provide a highly sensitive test (93%) for the detection of clinically significant cancer and if performed prior to the biopsy, can identify about 25% of men who might safely avoid a biopsy. Performing an MRI scan prior to biopsy was highly cost effective. Approval from NICE came in 2018, with guidance recommending that "all men with suspected prostate cancer should be offered a specialist MRI scan when they're referred to the hospital in England, before a biopsy." While this was welcomed overall, it also prompted some concern about the scale of the task to implement MRI for prostate cancer across the country, and the readiness of the

NHS to achieve this. In 2019 Dr Philip Haslam, mpMRI lead at the Royal College of Radiologists, suggested that the introduction of MRI would increase radiologists' workloads quite a bit over the next few years. "We've only got a finite number of trained radiologists in the UK and a finite number of scanners that everyone is fighting to use, who says prostate cancer gets priority?" he asked. In spite of these concerns – which are still present – access to MRI for prostate cancer diagnosis has been building across the NHS. While Prostate Cancer UK expressed concern that in 2018 only 57% of hospitals provided the specialist scans for prostate cancer patients, by 2022 this had increased to 82% of hospitals. What we're most concerned about now is on the standards of imaging and radiology reporting that informs the diagnosing clinician in his/her diagnosis. It goes without saying that a high-quality MRI scan and report is absolutely essential to focal therapy. Whatever the perspective, confidence in the presence, location, size and severity of lesions on the prostate is essential to assessing a patient's suitability for focal therapy and to the success of his subsequent treatment. We often see patients whose MRI scan and, more often, its reporting is inadequate to make an accurate and safe assessment for focal therapy. It appears for some men the success of scaling up access to specialist MRI scans for the prostate has come at a cost in quality and variability. We see variability in scanners, radiographic expertise in imaging and, crucially, radiological expertise in reporting on individual patient scans. Dr Clare Allen, consultant radiologist at UCLH and the Focal Therapy Clinic, has led a study investigating an approach to standardise prostate MRI practice across a group of London hospitals. It explored prostate specialist MRI protocols across 14 London hospitals, seeking to determine whether standardisation improves diagnostic quality. Its conclusions were clear: "targeted intervention at a regional level can improve the diagnostic quality of specialist prostate MRI protocols, with implications for improving prostate cancer detection rates and targeted biopsies". We strongly believe that bringing imaging and reporting standards in line across hospitals would benefit so many men, improving their diagnoses and giving them options for treatment. Two additional developments may eventually impact the variability in quality and access that we see with prostate imaging. Rapid MRI screening is being developed at Imperial College London, which would give large numbers of men access to imaging at a standard sufficient to make decisions on further diagnostics. "Prostagram" is being developed as a mass screening protocol, similar to how mammograms are used to screen for breast cancer. Artificial Intelligence (AI) tools for reading and interpreting specialist MRI scans of the prostate are also in development. Most of these are designed to enhance the role of the radiologist rather than replace it, and show promise in lesion detection, volume estimation and characterisation. Do you have questions about the role of mpMRI in prostate cancer diagnostics? We'd love to hear from you. The latest trends in prostate cancer treatment and diagnosis. TFTC consultant Tim Dudderidge discusses prostate cancer innovations. Consultant Urologist Tim Dudderidge joins OnFocus to discuss recent trends in technology and research. He's an innovator in focal therapy and has co-investigated most of the clinical trials and studies that have built the evidence base for focal therapy and advanced its adoption and practice. Last year he was appointed as Clinical Champion for Prostate Cancer UK, which will give him even more impact on innovative clinical practice across the NHS. In this episode, Tim shares his views on some of the key issues driving practice in diagnosing and treating prostate cancer, and how this is impacting both patients and clinicians. Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is consultant urologist Tim Dudderidge, who works with the Focal Therapy Clinic and is based at University Hospital, Southampton. Tim is an innovator in focal therapy and has co-investigated most of the clinical trials and studies that have built the evidence space for focal therapy and advanced its adoption and practise. Last year, he was appointed as clinical champion for Prostate Cancer UK, which will give him even more impact on innovative clinical practise across the NHS. He's here today to talk with me about some of the key issues driving practise in diagnosing and treating prostate cancer and how this is impacting both patients and clinicians. That's why I thought mid summer and sort of halfway through the year, so it's a really good opportunity to kind of round things up. There has been a lot going on since the start of the year at the Focal Therapy Clinic, but also in the wider prostate cancer community. Can you tell us about some of the trends you've seen with the patients that are coming to the Focal Therapy Clinic? I think one of the things that happened a little while ago is there's a lot of attention about another form of focal therapy, the Nanoknife. And this is mainly because they were launching a new NHS clinical service at UCL and it has been used by colleagues in London for some time and we haven't really seen, I guess, any sort of UK data that

makes us think about changing practise. But I think around the world they have been accumulating data and it looks like a very strong contender to be kind of regular tool for focal therapy. It works a bit like cryotherapy in a sense, it's a needle based technology and that's perhaps the most useful for targeting the front of the prostate and maybe glands which have contraindications to HIFU. So I'm really interested to see whether NanoKnife might offer, in certain circumstances, an advantage. We have this warming catheter with cryotherapy which can sometimes inhibit the action of the ice, and that's interesting and it might also be more sort of targeted, maybe that the extent of the ice when we're using cryotherapy is a bit uncontrolled and maybe that's why some people don't preserve erections in that treatment, maybe Nanoknife will offer some advantage there. So I think this is an interesting trend and I know we're looking at starting a Nanoknife programme as well, so I'm really excited about that. Clare Delmar What's interesting is that we're seeing, if I can even generalise a little bit more, just some new modalities for delivering focal therapy. So I guess on that specific point about the new modalities, what do you think of how these will be adopted and accepted or I should reverse that? I think as a practitioner you need to have enough tools that you can tackle nearly all of the cases, but not necessarily all of them. And for me, I think HIFU and a needle based technology together probably covers most things. It may be that we learn a little bit more about some of the technical advantages of some of the other ablative technologies, so that maybe we have three in the clinic, but I think that there is a danger of having too many because you then start to sort of dilute the evidence base a bit and you're not sure whether your different ablation modalities may actually be delivering the same result that you're quoting from the evidence. Like, there was a study using photodynamic therapy drugs and I know there are companies developing that, even though the two CAD drugs seems to have stalled. And the key principles of developing a new one will be to have something that's very easy to control, very easy to plan, where the sort of cut off between where you intend to treat and where the treatment action finishes is very tight, so that you define your treatment volume and the margin of tissue around that, that you want. But anything else beyond that is left alone, any technology that can improve on our current ways of doing that will get some attention. At the moment, my preference is to stick with HIFU and cryotherapy because technically I'm very experienced with those now and I think that if you go and see a focal therapy practitioner, what you really want to know is are they really experienced with the tools that they're using? I'm not sure it particularly matters which tool, as long as that tool delivers a good focal treatment. It's very much the same with, you know, it doesn't matter how you do certain operations, as long as the person who you're seeing doing them is doing them with a high frequency and is very experienced at them. The advances in imaging... Tim Dudderidge That's a good segue actually into the other thing, which is coming up a lot in the the focal therapy clinic is men coming along with MRI scans and biopsies, you might say, but MRI scans, particularly, where the quality of image puts them at a bad starting point to be considered a candidate for focal therapy. And we saw this lovely publication from Dr Claire Allen from University College London, and her team looking at something that's been coined, PI-QUAL, and this is a sort of quality assessment scoring system for MRI scans. And I think it could be a good way of individual centres self assessing their work and saying, oh, it's just up to standard, what do you change? And in fact, in our own centre, we noticed that one of the centres that we're using regularly for imaging is probably not as good as we'd like it, and we're going to try and actually tweak the protocol so that it's similar to the one that we're using in the main centre. And I think we need to be sensitive to the quality of imaging, because if we're not using good imaging at the very beginning of the pathway, then it tends to undermine all of the other steps that follow. We do see it again, a mixture of different approaches and I'm not sure if we really know which is the right one. On the one hand, with MRI that's done well and bearing in mind some of the people who are adopting a less intensive biopsy programme with their patients are not basing that on good imaging. But if you've got a really good MRI, you can argue that if you target the area of interest, maybe you don't need to target all of the normal looking bits of prostate. Some people are adopting that and my slight worry is that sometimes they're doing that when the imaging is not of great quality. Our approach is that we are accepting, yes, the scan is mostly right, but sometimes it's not right, and therefore having some limited systematic biopsies, which means biopsies taken throughout the prostate, but not sort of every five millimetres, maybe three per sector, which might mean nine on each side, as a bare minimum, this gives you a kind of map of the prostate which you can really rely on because the histology doesn't really lie. Obviously, you can have some degree of sampling and more biopsies you get, perhaps the more confident you are. But if you combine that systematic sampling with the targeted biopsies that we know we need, looking at directly at the lesions that we've seen on imaging, we feel that gives the best preparation for considering focal therapy. But at the same time, if somebody comes along and they've

got good imaging and they've only had targeted biopsies, we might say, look, this is not exactly as we do it, but it's a very reasonable way of doing it and we will sometimes just explain the uncertainty. Most of the patients I say will accept that if the imaging is good but if we say look your imaging was not up to standard most of those men who are keen on focal therapy will accept a re-biopsy just sort of verify it helps us to verify that the focal therapy we're about to do is a sensible decision because the last thing we want is to do a focal therapy and then a year later discover that the other side of the prostate had just as bad cancer which was probably there but we didn't find it properly. That's a regular theme I think in our patients at the moment Clare Delmar Yeah, I can see that. I want to turn a little bit to some of the trials you've been involved with because as I mentioned in my introduction on a wider basis you've been closely involved with a number of these trials that have generated a powerful evidence base for the efficacy of focal therapy. Tim Dudderidge Yeah so the CHRONOS study was interesting because it had two branches to it and the branch that I think probably the urology community is most interested in is the CHRONOS A study and this is a randomised control trial between partial ablation or another way of saying focal therapy against whole gland radical treatment and this is within a group of men who we would consider suitable for focal therapy so typically it would be intermediate risk disease situated in one half of the gland and on the other half of the gland preferably no disease but we would accept a small amount of low risk disease that could subsequently be monitored. And so we recruited a reasonable number it was quite difficult to recruit to this trial because essentially we are asking men to suspend their preference if they have one and to try and convince them that actually it was very illogical in many ways to have a preference when we have these two good treatment approaches both of which have strengths but of course they have weaknesses too and we don't know which package offers the best balance of strengths and weaknesses and so every time they said well I like the sound of low side effects we would say well, do we know it lasts? Or they might say well, radical prostatectomy is well established I like the sound of something that's tried and tested and we say yes but what about the side effects? And so constantly trying to bring people from the polar extremes of their decision making and have them hovering in the middle where they genuinely like us felt we don't know what's best. And if you can get the doctor and the patient on the same page with that we call that clinical equipoise where we just don't know what's the right thing to do. And this is the time when we can do a randomised control trial and expect men to reasonably accept and randomise allocation. And you can imagine that many men, especially when they've heard their friends or they might have heard in the media about some treatment that has had a good outcome, they very quickly latch on to something that they think, oh, this sounds good. And all of our clinical pathways are designed to encourage men to do that, to identify, to self identify with the treatment that they like the sound of. And what we found was it was really quite challenging to get men to accept randomization, but some men did. But we're sort of coming around to the conclusion that it seems difficult, maybe impossible, to recruit 700 or 800 men to be randomly allocated to treatment like that. That's how many men we would need to answer the question, which is the main question everyone wants, is which is the best approach? Have you seen this happen in other, even non-prostate oriented and other kinds of trials before? Tim Dudderidge Well, a good example in the prostate world is when robotic prostatectomy came along, it's was very difficult to randomise people between open surgery and robotic prostatectomy. There was a three way study, I think Locro was called, and that famously didn't recruit because the cat was out the bag. Once robotic prostatectomy was available and all the centres that were doing it, people came there and they wanted the robot because they just had this feeling it was better. And as is always the case with new technologies, sometimes the benefits that are presented are much more of an incremental gain rather than a sea change. So randomised control trials are really important because they tend to neutralise a lot of the perceived gains from observational studies. So I don't discount for a minute this is an important thing to do, but in reality, the choice with focal therapy and radical therapy is a different choice to two drugs you might be comparing, or two variations of a different approach. And so I guess, having tried really hard to recruit to this randomised trial, and it was too much of a struggle, I think, to try again, my feeling is that we can say that that has failed and we have to therefore rely on the next best thing, which is observational data, but with statistical methodology to try and make the comparison most fair. And maybe if we're going to do that, rather than doing it using retrospective data that we've collected, we could set up a prospective, a proper trial where it's supported by nurses, not the sort of more ad hoc data collection we have for the registries and actually maybe this is the only way we're going to get a meaningful comparison I think the other thing to accept is that men are making these choices more of a philosophical thing. So people, if you say, look, what if this treatment is 10% less good after ten years rather than it being equally good? When I explain focal therapy to men like that I'm saying it might be

equally good or it might be less good, we just don't know. But if you get less side effects for the first period of time and then maybe you have to have an extra treatment with a greater risk because even surgery patients might need extra treatment, comparative risk anyway. When you put that to men, they're quite happy often to sort of kick the can down the road and say, I would just like to be left unaffected by side effects for as long as possible because I recognise this disease is not always a kind of lethal entity. So I think putting it to men like that sometimes is a way of helping them to understand the lack of evidence and the uncertainty and helping them to make a choice which is more important to them.

Clare Delmar Yeah, it's really interesting even just hearing you talk now the language is evolving in itself. I mean, even we talk about focal therapy and then we talk about the modalities to deliver it. But increasingly there's this new term around ablation, which I know is a technical term, but often patients don't understand that in order to get the information you're describing about risks and uncertainties I think this is something that you and your colleagues at the focal therapy clinic really excel at is really helping men to understand their choices. And even use of the word managing as opposed to curing is an interesting choice of language. And of course, even if you apply a curative therapy in inverted comments, lots of those men don't get cured. I think perhaps it's more realistic to talk about managing the disease when we know that we're leaving low grade disease for surveillance. That's a very clear example where we're not curing the patient, we're just helping to prevent progression. There's this predict prostate website which is.. And men see that the incremental gain of radical treatment is maybe a few percentage points at 15 years on survival. They're like, why do I need to put myself through radical treatment for a 3% gain at 15 years?

Clare Delmar Yeah, that's interesting and I just wanted to touch on as we just sort of move to the end here. I mean, the things you've talked about imaging, biopsies, histology, you talked about as they continue to advance, focal therapy becomes more viable for a larger number of men, even though you're building up the database and the evidence base to support that. So how do you see this trajectory playing out in terms of focal therapy along the spectrum of active surveillance on one end and more radical procedures on the other end? But the side effect of doing that is that we're likely to identify cases that we don't want to know about and don't want to treat and we're also probably going to have to do more activity. And so there's a sort of a funding question really as to whether this is important enough for the country that we invest in this. So my approach, if I was in charge of designing the whole thing, I would really start to encourage research on MR guided screening. They've done a bit already with Imperial, great thing with prostogram and obviously that's paired up with PSA, of course. And then we need probably more artificial intelligence to interpret those scans because we just don't have enough radiologists otherwise. The exciting thing as well about AI is that we're bringing that into image screening of histology cases as well. We need to try and iron out this issue about whether we can rely on targeted biopsies alone or whether we do, as I'm doing, a lot of systematic biases that would obviously reduce a lot of costs if we could safely cut those out and give treatment based on the images alone. And I think that the way that we get to that point is by having a really rigid quality control of MRI for prostate. If we're going to see this massive expansion in MRI for prostate, we've got to have some sort of standardisation and rules. You find that with cervical smearing and everything, you don't have 20 different ways of doing that. It's a very standardised process and that also links into the question of contrast or no contrast in the initials sort of test. And we've got trials ongoing through colleagues in London, they're going to answer that question and eventually we'll get to the point where we're finding more cancers as a consequence of the stage shift that we'll have in that process. We will need to do more surveillance and more focal therapy, but I'm hoping that we will be able to deploy more and more appropriate radical treatments to those people who need them. And if we could do all of that, I'm pretty convinced that we could substantially reduce the deaths from prostate cancer in this country.

Hash Ahmed, Mark Emberton, Caroline all of these people are doing amazing things to push the trials forwards. And in Southampton, we've really focused on supporting those trials and recruiting for them. And my other big wish is that I sort of join them and start designing my own trials, so that's the sort of next the five year plan for me is to perhaps take a sidestep and become more of an academic. And on that note, I want to thank you very much for joining us and sharing what's happening both in the trial world and on the actual clinical coalface, so to speak.

Clare Delmar A transcript of this interview and links to more information about Tim and his work are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

NanoKnife, A new Option for Prostate Focal Therapy Joining OnFocus today is Stuart McIntyre, Director of Marketing & Business Development at AngioDynamics, developer of a new approach to

focal therapy called NanoKnife. It is currently running a clinical trial called PRESERVE, described as a Pivotal Study of the NanoKnife System for Ablation of Prostate Tissue in an Intermediate-Risk Patient Population and which will evaluate the use of AngioDynamics' NanoKnife System for ablation of prostate tissue as a focal therapy option for prostate cancer patients. Stuart's here to talk about how his company developed the NanoKnife system and what his expectations are for its adoption. PRESERVE trial:

<https://www.angiodynamics.com/announcements/first-patients-treated-in-preserve-clinical-study/> Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Joining me today is Stuart McIntyre, director of marketing and business development at Angio Dynamics, where they're developing a new approach to focal therapy called the NanoKnife. It's currently running a clinical trial called Preserve, which is described as a pivotal study of the NanoKnife system for the ablation of prostate tissue in an intermediate risk of patient population. And this will evaluate the use of Angio Dynamics' NanoKnife system for the ablation of prostate tissue as a focal therapy option for prostate cancer patients. Stuart's here to talk to me about how his company developed the NanoKnife system and what his expectations are for its adoption. Stuart, thank you so much for joining me today. Stuart McIntyre Clare, thank you for allowing me to be a part of your programme. I'm keen to hear from you how it's going, but as a lead in, I'm interested in you personally and individually because I know you trained as an engineer. So I'm just interested to know how you got involved and how your training as an engineer informs your work with ablation technologies for prostate cancer. Stuart McIntyre Yes, Clare, I've been privileged in my career to train as an aeronautical engineer, but then also to move into the medical device space and apply some of that engineering training to the challenges that we have as a company in providing treatment options for, in this case, for prostate cancer. And you can imagine any medical device is a function of some pretty intricate engineering and using some scientific principles that create a very particular biological effect and give clinicians a tool that has some very special capabilities needed to treat in tissue. Clare Delmar Yeah. So on that note, let me ask you how the NanoKnife fits into the range of ablation modalities for prostate cancer. So maybe you can open by telling us what IEH means and how this is actually going to drive the NanoKnife's progress. Stuart McIntyre We call it irreversible electroporation in terms of the NanoKnife technology. And that phrase irreversible electroporation relates to a scientific phenomenon that when you pass a high voltage alternating electrical field, not an electrical current, but an electrical field, it agitates the electrons in that field. And those electrons create... they orient with the polarity of the field that's alternating at very high frequency. And those electrons effectively puncture the cell walls of the soft tissue inside of that field. And by puncturing the cell walls, the cell walls can't then repair themselves and they die a natural apoptotic cell death. And that's the effect of NanoKnife, this high frequency alternating electric field that causes the soft tissue cells between the electrodes to become punctured and non viable and therefore die. So it kills the soft tissue cells without disturbing and disrupting the underlying structure of the tissue. Clare Delmar Okay. Stuart McIntyre Vessels and nerve pathways are preserved, whereas the soft tissue cells are killed. And that's the nice unique feature of irreversible electroporation. Clare Delmar So just applying that to cancer cells or cancerous tissue, because you'd use the phrase soft tissue. So these trials, this is actually a way to investigate and explore how cancer cells and cancerous tissue in particular, when it's highly targeted, is ablated, as you say, and the non cancerous tissue is saved, which is, of course, the whole idea of focal therapy. But how does this technology and this electric field that you're describing, how does that actually address only the cancerous tissue? Stuart McIntyre Yeah. So the challenge in the prostate, and it's the same with other cancerous masses in the lungs, liver or other places. The challenge in the prostate is to destroy the cancerous cells whilst preserving the structures that are critical for the rest of the patient's health. Clare Delmar Indeed Stuart McIntyre i.e. in the prostate we're talking about the potency of the urethra, we're talking about the nerve bundles and nerve pathways that flow through the prostate to control swing to function, erectile function, and all of these matters. And so the NanoKnife technology allows those structures to be preserved patent, but while still killing the cancerous cells in the space. Of course, there are other clinical concerns that all technologies have to be careful to avoid. So puncturing the outer wall of the prostate and creating injury to adjacent organs and so on. And of course, each technology offers a particular utility in terms of these features so Nano Knife joins a group of different interventions, all having merits and to some extent demerits in this regard. Clare Delmar Yes, that's exactly my question. How would you in an ideal world where we have this kind of array or portfolio of various modalities to undertake focal therapy, how would yours be

preferable or more appropriate for one patient's condition than another? Stuart McIntyre Yeah. The clinical data, diligently collected and independently collected to understand the nuances of how one technology operates in comparison to another, and therefore, how they may impact in terms of the patient choice, this is the really important thing. The Preserve study is a good example of a proper randomised study to clinically assess these technologies. In this case, the concerns and the endpoints of those studies are what is the impact on the patient's continence? And there are secondary questions around how does the technology then impact other opportunities for care that may become necessary down the line? How does it impact the ability of the clinical team to go on to do a radical resection, for example, in the future? These are the types of questions that these clinical studies are trying to answer.

Clare Delmar Okay, I want to come back to that actually. That's exactly what I want to talk about in a minute, but I want to just kind of zoom out a little bit not to discuss not so much the technology itself, but to sort of explore with you how NanoKnife kind of fits into the whole growing array of focal therapies and what this means from a bigger picture. So, for example, do you think that by enhancing the range of focal therapy approaches, that this will impact how other treatments and other options are going to be taken up? And, for example, do you think active surveillance will be challenged more in future simply because you have more opportunity to do focal therapy? Stuart McIntyre Yeah. But I recognise that if one is diagnosed with an intermediate stage cancer in the prostate and your options are simply leave it there and preserve your sexual function and continence for a while and hope that it doesn't get to a point where it's really life threatening, that may not be an attractive option if there is a therapy that can allow the cancer to be addressed decisively and whilst retaining those important life features without removing the possibility of treatment in the future. And I think our hope for NanoKnife, based on the data that's coming from centres that have been using it and their reports, is that it potentially gives that prospect. And therefore, I envisage NanoKnife and other technologies that will come forward, I'm sure, to offer similar features, will start to provide patients an alternative to the sort of active surveillance watch and wait, i.e. Let's not radically resect today because prostate cancer does tend to be slow growing and therefore, if we don't do anything today, it may take a long time before it becomes life threatening. And why subject yourself to the unpleasant side effects of some intervention now when you may not need to? And I think it's in the context of that sort of patient thought process that these technologies play, I think will play an increasingly relevant role in creating perhaps an early option to address the disease without removing the option of more aggressive treatment in the future. I know that I, as a man, certainly in such a situation, would want to have something done if I was diagnosed with an early stage disease that could have something done with it that didn't have catastrophic life consequences in doing it.

Clare Delmar What's interesting about having more options just within focal therapy itself is I often think of focal therapy as the ultimate personalised treatment because it's so focused on, based on all the targeted imaging and the targeted biopsying and targeted histology, that we know exactly what we're going for. So I guess one of my questions is, as we learn more about these different focal therapy approaches, whether it's HIFU or cryotherapy or water vapour therapy or your approach, do you think this will have an impact on patients, seeing that this can become more personalised and that some modalities might even be preferable for individual patient circumstances? Stuart McIntyre I think personal care and personalised care is an aspiration in many fields of medicine. And I think I'm sure clinicians will agree that the most important thing with any diagnosis, is to understand the unique features of the particular biology that your particular disease presents. Some cancers present as highly aggressive and requiring very urgent and very radical interventions straight away, and knowing that and being able to choose that care pathway that is personal to that particular biology of that particular tumour is really important. And so as we get into more analysis of genomics and detailed disease characterization, the more we're going to be able to get into treatment pathways that are personalised to the patient. And coming back to that reality then the range of tools and options and treatment options available to apply the very best treatment to that very personal situation becomes important. And I come back to NanoKnife and say, well, look, here is a technology with some very specific features that for certain patients with certain conditions in their life and status of their disease, may therefore be a very welcome option in comparison to other treatments that are available.

Clare Delmar So on that point, let's go back to the Preserve trial, and maybe you can tell us a little bit about how this trial is progressing. What are the early indications and what do you foresee? Stuart McIntyre We've just recruited the first patients into the Preserve study in the US, and that study will recruit over the coming months. It's important to note that Preserve comes on the back of quite a long series of single centre experience and data, both in the UK, in Germany, in France and in the US, and also in Australia, where those single centres have reported very interesting outcomes. You

don't go into these more structural studies without first having some good early indication that there is genuine potential in the technology. Clare Delmar Yes. Stuart McIntyre So we're hopeful that these more sophisticated trials will produce the definitive data that will position this technology within the scheme of care options for prostate cancer patients and hopefully give active men with intermediate stage cancer a real opportunity to address their disease without some of the implications of today's technologies on key factors in their lives. Clare Delmar And what sort of time frame are you looking at for this more definitive data to be produced? Stuart McIntyre I think Preserve will report in the course of the next 18 months in terms of the recruitment analysis and the initial report. And there are a number of other trials beginning to be structured and schemed in the UK both in terms of treatment registries and in terms of again, more prospective randomised studies that centres in the UK are also now working on and planning to proceed with. Clare Delmar Okay Stuart McIntyre So I think the picture of data of quality evidence over the next two to three years for this therapy will become increasingly populated and I imagine that treatment will become more widely available. Clare Delmar Very good. Well, we will look forward to hearing how that progresses and I'd like to thank you very much, Stuart, for joining me today. It's been really interesting to hear about what you've been up to. Stuart McIntyre No my pleasure, Clare. My pleasure. Clare Delmar A transcript of this interview and links to more information about NanoKnife and the Preserve trial are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Not surprisingly, the vast majority of our patients are at, what some term, "an advanced age" meaning ... well, what exactly? The question of how to accurately measure age comes up all the time as we engage with so many men who "don't act their age", e.g. Yet, so often healthcare providers base treatment decisions on a set of assumptions about age that effectively discriminates against men like these. So we've been watching the many conversations, research and debates around geroscience – the science of ageing – with interest, hoping to learn how advances in understanding, measuring and eventually slowing ageing will impact the management of diseases of ageing such as prostate cancer. An announcement last week that a new fund in Saudi Arabia plans to spend \$1 billion a year to study treatments to slow aging therefore caught our attention. If there had been any doubt before, it now appears that geroscience is now well and truly on the map, and the new fund sees it as the next frontier in medicine and healthcare. As the fund's CEO remarked, "Our primary goal is to extend the period of healthy lifespan... There is not a bigger medical problem on the planet than this one." So what can we expect from this research and development? And the question stands, that if ageing – the greatest risk factor for developing prostate cancer – can be either slowed or reversed, will diseases of ageing like prostate cancer reduce or even disappear? At the core of geroscience is the belief that if you can slow the body's aging process, you can delay the onset of multiple diseases and extend the healthy years people are able to enjoy as they grow older. This is exactly the question asked by a team of researchers in the Journal of the American Geriatrics Society: "Given all the above considerations, why has geroscience not yet involved more clinicians? Historically, scientists studying fundamental aging processes and investigators exploring mechanisms underlying individual chronic diseases rarely interacted. Furthermore, investigations within individual chronic diseases typically either ignored or controlled for chronological age – ironically removing from all consideration the one major risk factor shared by all adult chronic diseases." The authors describe how geroscience can both help to explain variability in diseases of ageing and underpin more targeted and personalised treatments. "Beyond limitations of disease-specific paradigms, there is accumulating evidence of growing inter-individual differences (heterogeneity) in all facets of aging, from biological and physiologic to social and behavioural domains. Increasing heterogeneity with aging leads to the critical observation that the existence of varying disease clusters in different older adults likely has implications for matching individuals with explicit interventions (targeting), a core principle of precision medicine and ultimately treatment effectiveness." And finally, the authors call for a geroscience-guided approach to treatment: "Geroscience-guided approaches ... cannot ignore personal preferences and care goals which also become more heterogeneous with aging, requiring scientists to identify and better understand such preferences, and compelling clinicians to better implement these individual choices into individualized clinical care plans" What does all this mean for men, with or without a prostate cancer diagnosis? But with geroscience increasing its presence in the media, it could well have a cumulative impact through public awareness. Maybe the impact will be felt attitudinally and behaviourally as people increasingly believe that they can control their ageing – even through basics like diet and exercise – which could have an impact on both

prevention of disease and recovery from treatment. Increased recognition and acceptance of geroscience could also drive more personalised treatment, as patients engage with their clinicians with more understanding of their health and the confidence to present their knowledge and aspirations, and clinicians have more information on which to base an individual's recommendation for treatment. What do you think about the possibilities of geroscience in preventing, slowing and managing prostate cancer?

Shaping Prostate Cancer Literacy A conversation with Martin Wells Martin Wells, a campaigner, fundraiser and support group leader from Lancashire, joins OnFocus to discuss what it's like going through prostate cancer diagnosis and treatment as a gay man. He set up two support groups to help men and their partners address these challenges - Out with Prostate Cancer and Shaping Prostate Cancer Literacy. Out with Prostate Cancer <https://outwithprostatecancer.org.uk/> Shaping Prostate Cancer Literacy <https://www.youtube.com/channel/UCjNP3x0ebbh7hzbHcEwudbg>

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Joining me today is Martin Wells, who, following treatment for prostate cancer at the age of 53, has been a force of nature in supporting other men in their experiences with prostate cancer. He says, 14 years ago, when I was diagnosed with prostate cancer, I quickly learned that being a man gets in the way of being a man with prostate cancer. There were no support groups in East Lancashire for men and their partners with prostate cancer so together with my urology nurse, we started a support group in East Lancashire, and even now, it's still going really, really well. And then I started two years after that with another guy, another support group called Out with Prostate Cancer. And leading on from that, I started a third group because I found we often don't have the language to talk about prostate cancer. So I started a group called Shaping Prostate Cancer Literacy to allow men to explore the language and literacy we need not only to talk to ourselves about prostate cancer, but to talk to other people and to help other people talk to us about our prostate cancer journey.

Clare Delmar Well, I just got it from a wonderful newspaper article that was telling the world all about what you're doing. So, again, maybe we can talk a little bit about what's motivated you to do all that, but it's really wonderful to have you here today.

Clare Delmar One of the things I really would like to start off with is to ask you very directly that as a man who happens to be gay, do you think that the language and the education and the behaviours around prostate cancer are focused on men who are heterosexual and that potentially it effectively excludes men who are gay?

Martin Wells It's a really interesting question, and I've thought about that a lot over the 14 years since I was diagnosed. I've come to see a phrase which I find very powerful, and that is being a man gets in the way of being a man with prostate cancer. And I think I can slip in other words, being a gay man gets in the way of being a gay man with prostate cancer or being a man who's got some psychosexual problems, whether I'm straight or not, get in the way, etc, etc, et cetera. So what I've seen is I don't think as a human being, I know how to be seen out there, and it's easy for me to slip into the labels bit. I'm a gay man, therefore, I'm kind of, like, been in a minority, and you need to look at me.

Clare Delmar So do you think that there's a lack of understanding about what it is to be gay and the psychosexual damage of having prostate cancer?

Martin Wells For me, I feel as though I'm a man and I happen to be gay, whatever that means. Okay I might have slipped that in because it's easier in the conversation, but I'm a man and I happen to be gay. And what I've seen is on these Mardi Gras episodes in the summertime where there are certain men, gay men, bisexual men, whatever out there parading themselves in a particular probably a very sexualised way. My impression is people out there think what being a gay man is all about is sex and being outrageous. But I think in a previous conversation, we spoke a bit about how even some of the psychosexual aspects to having prostate cancer, being treated for prostate cancer and certainly recovering from it, you think perhaps may exclude non heterosexual men. I know 14 years ago the reason why I kind of got on a bit of a soapbox for starting the support groups, particularly the second one out with prostate cancer. That was because almost all the literature then and things have moved on because of what we did. Would your wife like to come along, a) assuming someone was married, whether they're straight or whatever? I mean, there are single people who are straight, whatever that means, who've got prostate cancer. How does a logo which represents a man who's got prostate cancer, gay or straight, represent a trans woman who might have prostate cancer. Your focus on the literature and literacy, I think, is in the name of your title of your other group. Can you talk a little bit more about that and even more generally about the disease itself?

And one of the things I'm particularly interested in is the sort of carrots or sticks approaches to prevention and to getting yourself checked, because often we see that many promotion campaigns around prostate cancer are around sort of the "or else" message, as opposed to do this because your quality of life could be preserved,

which, of course, leads itself to the conversations around new treatments. What do you think about that and about the messaging and the literacy that you saw 14 years ago and what you see now? And I go back to that phrase, being a man gets in the way of being a man with prostate cancer. Intellectually, I know, and I think most people know they ought to talk holistically better with a better quality, whatever that means, with their health professional. But there's something in a man's DNA which prevents them from doing that, and that hasn't been tackled. That's assuming a health professional knows perfectly how to handle somebody who doesn't know how to talk about this thing, which I think is a sexual cancer, like penile cancer, testicular cancer. That kind of cancer is one of those taboo subjects, vulva cancer in women and better not mention the word vulva or penis or testicles. And because of that, nobody has got a literacy, a language, a lexicon on how to talk about it.

Clare Delmar Do you think that it's a combination of the messaging itself or also the medium? So, for example, the fact that we have so many more media to get these messages out, whether it's the traditional Facebook groups or YouTube videos, but now we have things like TikTok. Do you think that that's something that we all ought to be focusing on a little bit more and to improve this literacy so that men can engage with their partners and they can also engage in relationships with their own health care providers?

Martin Wells You see my biggest competitor, or if I'm running a support group, the biggest competitor is McDonald's, is Amazon, is Currys. They have departments and whole teams of people working on marketing strategies, cartooning, copywriting on how to get a message across within five to 10 seconds max. And there's poor old me with a computer and some imagination, but I haven't got the crafting skills to put something across, what looks effortless but has taken many man person hours to actually hone. So if somebody says, oh, why don't you read this pamphlet of 70 pages that will help you get to grips with it? What I'm saying is it's like, well, how does somebody obviously we're in an audio podcast here. But when I was having chemotherapy before I had it, the health professional was saying, you'll probably get quite fatigued, actually, Martin, at some point. Now I've got in front of me a little toy I remember from being a kid, and it's a little giraffe, and it's got lots of little beads in it. And when I press the button underneath it relaxes the little cotton threads in it, and this little giraffe collapses instantly. So when I say now to people, this is what fatigue looks like, this little giraffe collapses immediately and they go, oh, yeah, right, I get it. Where are the people who are doing this kind of communication, using little assets like that to get the message across?

Clare Delmar Have you seen any examples of where it's being done well or where it's showing travel in the right direction? I've got in front of me a plastic Coke bottle and I've taken the label off and I've printed three replacement labels. And it took me a long time to think of this because at the moment, the treatment I'm on, I've got no libido. Now I know what it's like now when I'm describing things to people, I'm saying, which Coke bottle are you picking up? Are you picking up the Libido Classic where you are fully sexualised, or have you still got some libido, or are you totally lacking libido? That kind of thing to me is really easy to pick up, but it takes a lot of effort to get to that point.

Clare Delmar And also, I guess you've spoken to so many men over the years with your groups that you sort of know how they might respond. And I see in their eyes, I see in their facial expressions that frustration of I kind of know there's something I want to communicate with you, but I just can't put it into words. I think now there's enough resources out there, enough charities with prostate cancer to support men on their initial journey. When they get past that stage, I think there's now a big opportunity for the graphic designers, the cartoonists, the copywriters, to invent ways of communicating what the medical profession communicate in very boring good medical ways. And I think you mentioned charities or the research organisations who are constantly fundraising, as you know, because you've done fundraising on their behalf. It would be interesting to sort of see an initiative around better communication and better messaging so that men overall have a better experience while they have to endure prostate cancer. I mean, you raise a really important point about how men go through this experience and how messaging and different media to do that can really improve their situation and possibly their outcomes eventually.

Martin Wells And there is an interesting fact there also, Clare, because my older brother has got prostate cancer and his approach to his what I call his journey and my journey. For instance there should be in front of me a whole raft, a smorgasbord of help and assistance, and I can look at it and go, Can I have a little bit of that, please? Interesting people are very different than how they seek information, process it, which actually leads me to something else we've talked about, which is getting a little bit more sort of, I don't know, clinical here. But it would seem that the goal of all men would be to have early diagnosis, which would then allow non invasive procedures that would maintain the quality of life and some of the things we've just been discussing. With COVID, this is so important over the last two years, being a man gets in the way of being a man with prostate cancer and with COVID that has assisted that phrase no end, because, Look, I don't need to go to the doctor. What I mean is getting

some form of check, if you call it that, digital rectal examination. Just because my PSA is high from a blood test, that doesn't necessarily mean I got prostate cancer. But what I've seen is a lot of men get to the doctor because their partner has got a bit pissed off with them saying, blimey, you're up in the night three times again, get to the GP, get to the doctors. So if that's not so obvious and how difficult that is to change behaviour, I think men have this built in DNA not to be seen to be weak. And going to the doctor is a confession of something wrong with me and I kind of don't want to know. Clare Delmar And so what would be your message then to our listeners about that, about overcoming that or recognising it or doing something about it? Martin Wells I would say to someone, be courageous to witness that going on inside yourself and push that to one side, pick up your phone and book your appointment. It's not an exercise where you have to strip off naked and run through the street and burn £100 and it's a very difficult, painful procedure. Clare Delmar Well, I think on that note, I think we'll draw this to a close, but you've given some very powerful insights and I want to thank you very much for joining me today. I think that there's a lot more to talk about, but I think you've been extremely helpful and certainly the message about everybody's different and you really just have to go out there and take some control. A transcript of this interview and links to more information on Martin and his support groups are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Patient Engagement The rich dataset that comes from patient engagement Earlier this year we talked about the importance of patient advocacy in our work at the Focal Therapy Clinic, describing how the vast majority of patients who approach us do so for a second opinion, following experience with or advice to proceed with treatments that lead to fear, uncertainty and doubt in their lives. Our patient advocate team have spoken with hundreds of men over the last two years, and have developed a comprehensive picture of what is happening to men who are diagnosed with early-stage prostate cancer across the country and how to reduce, and sometimes eliminate, the FUD underlying their treatment decisions. Patient voices, heard through the personalised patient engagement practiced here at the Clinic, give us the richest dataset to inform our own practice as well as the knowledge of patients, practitioners and policymakers in the general public. They help us to understand some of the themes we see playing out in the prostate cancer "community" – ageism, health inequalities across geography and race, mental health, and the challenges of accessing honest & unfiltered information about diagnostic procedures and treatment options. In a world driven by information, this qualitative data is invaluable and enables us to continually evolve our approach to patient care. For our patients, the level of knowledge and empathy shown by our patient advocates gives them the confidence to make crucial decisions about their treatment and, most importantly, share this knowledge and experience with others. Many have found that friends, family members, and coworkers had little understanding of the many ways prostate cancer changes lives. Their experience with us has given them a vocabulary and a confidence to engage people around them without fear or judgement, and in many cases, to actively build a community of knowledge and practice. Many of our patients have taken part in our podcast series, motivated by an opportunity to share their experience and encourage others. Over the last few months some patient experiences stand out in their detail and the insights they gave us. Mr D, aged 88, is severely sight-impaired, partially deaf, and has had a pacemaker for about 6 years. He received an unexpected prostate cancer diagnosis which has yet to be confirmed by an MRI scan, or a biopsy. Neither he nor his partner received any information or counseling on prostate cancer, and their understanding is very limited. He has also received conflicting information from his consultant and his GP concerning his PSA history, which is concerning. His partner was told on the same day as the diagnosis that no treatment will be offered to Mr D. She was very happy to receive the information we sent her about prostate cancer, and she told us she now feels more informed. She has subsequently been able to use vocabulary and information related to prostate cancer to consult further with Mr D's GP, on his behalf. Mr P has been waiting anxiously for a referral for a biopsy, having survived a 5-year struggle against leukaemia. The treatment he received has impacted his lungs, eyes and kidneys, and he feels neglected, having waited 8 weeks for an NHS referral appointment, thus far. Being able to access basic services like an MRI and a biopsy through TFC will be life-changing for him. Mr M suffers from arterial fibrillation and has had hip surgery under local anaesthetic due to potential complications with general anaesthetic. He feels limited in terms of his treatment options, but he now feels comfortable discussing his situation with one of our consultants who has the expertise to deal with more complicated cases. Mrs O called the Clinic, serendipitously, on the day that her husband was undergoing his biopsy at a London hospital. She expressed sincere gratitude for the conversation,

saying that we were a 'port of call' during one of her darkest hours, whilst she waited anxiously to see her husband after the procedure. She felt comforted to be able to ask questions, to express her emotions, and to address her uncertainty about the future. Since then, she has phoned the Clinic several times to ask for clarity on issues that have been unclear, prompting her husband to request a referral to one of our consultants for a second opinion on his diagnosis. Each of these patient experiences, along with hundreds of others we've engaged with, demonstrate the complexity and emotional toll prostate cancer imposes on men and their families. Fortunately, as we build our knowledge based on these conversations, we're increasingly able to offer support and connect patients with other health care providers who can help in areas where we can't. Do you have an experience to share, or are you interested in learning more about other patients' experiences with prostate cancer? All Men Deserve Access to Non-Invasive Prostate Cancer Treatment

A conversation with Grant Evatt about prostate cancer and HIFU treatment

Joining OnFocus today is Grant Evatt, a veteran army commando who now practices law in a firm he founded to specialise in personal injury cases. He has coordinated the Military Special Interest group for the Association of Personal Injury Lawyers (APIL), and is a recognised authority in military claims. He has won millions of pounds for his injured clients and their grieving families and is much liked and respected by them, and his peers, for his exceptional client care and dedication to their cause. Grant's here to speak with me about his experience with prostate cancer and HIFU prostate cancer treatment. Grant Evatt, Alma Law practice <https://www.almalaw.co.uk/our-people/grant-evatt>

Clare Delmar Hello and welcome to On Focus, brought to you by The Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK. And with this sombre fact comes a multitude of challenges and opportunities. I'm Clare Delmar. Joining me today is Grant Evatt, a veteran army commando who now practises law in a firm he founded to specialise in personal injury cases. He's coordinated the military special interest group for the association of Personal Injury Lawyers and is a recognised authority in military claims. He's won millions of pounds for his injured clients and their grieving families and is much liked and respected by them and his peers for his exceptional client care and dedication to their cause. He's here today to speak with me about his experience with prostate cancer and specifically the treatment he sought with HIFU. Grant, thank you so much for joining me today. I'm really looking forward to our chat. Grant Evatt Clare, it's a real pleasure. Clare Delmar Good. Why don't we just jump right in and talk about HIFU before we get into some of the contextual issues about your own personal experience, how did you actually learn about what HIFU prostate cancer treatment was, its availability, and how did you find a practising urologist that offered it to you? Grant Evatt It's a good question. And my father, he just WhatsApped me one evening and said, have you seen this clinic in Southampton? That was my first and only introduction to The Focal Therapy Clinic and HIFU and what I did was after my diagnosis and the recommendations from the treating consultants, I contacted Tim Dudderidge, one of the consultants, who is one of the HIFU practitioners here in the UK. I paid for a private consultation. I mean, if you try to preserve your life and everything else down below, then I think the small amount that I paid was money well spent. And I went to see him and he explained to me what HIFU was, and I went ahead with it. Clare Delmar And you mentioned your dad. So how did your family history with prostate cancer impact your actions? Grant Evatt That had a huge influence on the decisions that I made, because my grandfather, who fought in the Second World War, in fact, he was one of those soldiers evacuated from Dunkirk, and he went into North Africa afterwards, also into Mediterranean countries. He died aged only 66 in the 1980s of prostate cancer. Clare Delmar Okay. Grant Evatt Subsequent to that, my biological father also developed prostate cancer about the same time as his father. I mean, I'm sure you'll probably ask me the question, how did you feel when you were diagnosed? In late 2020, Covid year of course, none of us can forget that, encouraged by my father, I went for a second routine PSA test. So I had a PSA test, very simple blood test, and it came back raised, but not raised by a significant amount. But because of my family history and my understanding of what had happened in the past to the men in my family, the recommendation from the consultants was, Grant, we've got to do something about this now, because if you leave it, it is certainly going to get worse and it's going to escape the prostate and go into the other organs in that part of your body and the bones and everything, and then the chances of improving my life expectancy were just going to be slowly diminished a lot longer I left it. Clare Delmar So because of the history you actually actively sought the PSA test and you obviously had a GP that was quite willing to cooperate with your request. Grant Evatt My GP was absolutely fantastic. Clare Delmar That's good to hear that's very good to hear. So then when you said you had this raised level in 2020, then you were referred to a

urologist initially? Grant EvattI was referred to urologists, who then sent me for a 3T kind of MRI scan. They're not called that, but they put some die with that MRI scan, they were able to actually see the lesions, the small tumours in the prostate. I can happily tell you and anyone listening to this, I had more pain parking the car than I did actually going through the procedure. I mean, they really did look after me. Subsequent to that was the consultation with the consultant urologist, and I was unaccompanied because of it and masked up and everything. And it's such a shock because we all think, particularly people from my background, we all think we're indestructible. That's what I discovered. Clare DelmarSo when you were given the diagnosis and after the initial shock, the information that you had to process did that also include recommended treatment? And how did that set off your journey to find HIFU treatment for prostate cancer? Grant EvattI was given two recommendations. It was a case of where we'll do some active surveillance for the next few years and then we'll get in there. But I was discouraged from taking that option, the only other option, and there are only two options, and that was what's called radical prostatectomy, which is the removal of the prostate gland. Now, before I even looked up and learned about HIFU and went to The Focal Therapy Clinic, I'd decided on that route. So Christmas 2020, I decided that in the new year I'd have radical prospects. There was something about sort of experimental treatment which I had to read, but nothing specific. If my father hadn't put me onto HIFU, then I think I'd have ended up having medical prostatectomy in February last year, instead of which I had HIFU. And talking to you now, I am very well indeed. Clare DelmarYeah, that is an incredible story, especially that your family history. Not only was it what caused you to go seek the initial PSA test, but actually he pointed you in the direction that's giving you back your health today. I just like to turn a little bit because you mentioned about your grandfather and specifically his role in wartime, and you're an army veteran, obviously, and quite a specialised commando, no less. Can you tell us a bit more more about in that community what your experience is with the information and awareness that veterans receive about prostate cancer and how things might be better or worse or different in the military community? Grant EvattIt's a very good question, and it's one that I anticipated you would ask, actually. First, I can respond by saying most, excuse me, I'll only talk about men here because it's a cancer that only affects men. Most men who join the army join, maybe Air Force, Royal Marines, join very early, very young. Myself, I was sixteen and a half, twelve months after the end of the Falklands conflict, and that influenced me to join the military in the first place. Clare DelmarOkay. Grant EvattI served twelve years. You tend to serve 22 years or 24 years or some go on to have a much longer service, until 55, they're complete lunatics and they just can't get enough of it. But jokes aside, what tends to happen, though, is most men who leave the military leave some years before they become a prostate cancer sort of potential risk. I think it is, but I can only talk about my own community because we all chitchat to each other. We've got one down in Plymouth, not this week, the middle of May, 60th anniversary of the Regiment and the 40th anniversary of the end of the Falklands war. Clare DelmarOkay. Grant EvattWe do chat amongst ourselves and I do know some friends who had prostate cancer or have it now. I was. Clare DelmarYeah, I take your point about and you've given some very good examples and the detail about the age, specifically of when people leave. So I guess the question is, do you think that the armed forces, I mean, it clearly has influence on men's health issues. Do you think that they could play a different kind of role and maybe not so much while men are in active service, obviously, back to some of your points about age, but just in terms of having a male dominated community that they have the opportunity to disseminate and to promote and disseminate information that those men could also even share amongst men outside the community. Certainly what is high on the agenda and has been for three, four, five years, mainly because of the conflicts in the Middle East, is men's mental health, the mental health of veterans. Clare DelmarYes. Grant EvattAnd I suppose really if you've got mental health issues, you get prostate cancer as well that could tip you over the edge. Clare DelmarYes. Grant EvattI believe, there are bound to be others who disagree. But I do believe that within the veterans community, what's important to me, particularly my role as a solicitor and I represent injured service men and women and veterans... Clare DelmarIndeed. Grant Evatt...is that we share our knowledge. Hence me saying, yes, I want to talk about this because just me doing this podcast, if this is heard by one 50-something veteran with no symptoms, which was myself, otherwise fit as a fiddle apart from dodgy knees and hips and elbows and shoulders and all that. If I could persuade just one guy to make a call to his GP and go and have a prostate cancer PSA test, then this 15-20 minutes chat with you, Clare, I think it's worth its weight in gold. And since my getting the all clear - okay, I've got to keep having blood tests every six months or so - but I'm not worried about it at all. Guys, if anyone's listening, I have put it on Facebook, I've even put it on LinkedIn and people have spoken to me about it. I've had people from all around the world who know

me, who have said, what do I need to do? It is so much easier to prevent the worsening of this dreadful disease now than it would be if you leave it too late. I didn't have any. Clare Delmar Yeah. Grant Evatt And I had a cancer growing inside my body. Clare Delmar Yeah. I mean, I completely take your point about the PSA test, and I think your message will certainly amplify that. Given that you kind of had a shift, as it were, from one direction of treatment to something completely different, what would be your advice to somebody who was newly diagnosed with prostate cancer? Grant Evatt Okay, first thing I say is don't panic. Don't panic unless they're wheeling you into the operating theatre five minutes later because it's that urgent, which is unlikely, very unlikely. Look, the NHS costs us billions of pounds each year, and it is the role of the doctors to try and prolong our lives and make us well. And you, as a grown adult, provided you can read and understand this stuff, you take personal responsibility for you, for what happens to you. The reason they said that is because they'll never have to see me again, because once the prostate cancer is gone, I'm not going to get cancer. With the prostate gone, I am no longer potentially a burden to the National Health Service. But for me, the risks were erectile dysfunction and incontinence. I had to accept the very high risk that I would have both those problems from my early 50s for the rest of my life. Clare Delmar And if I could just interrupt really quickly, I know you talk about research. Was that told to you by your consultant urologist, or was that something that - Grant Evatt It was. I would have actually given my consent to the procedure and they would have said there are always risks of surgery... Clare Delmar Of course Grant Evatt... But the largest risks in radical prostatectomy is you're left with those two conditions, incontinence and erectile dysfunction. The internet is a dangerous but a wonderful place. Go to Prostate Cancer UK but go to... Clare, you're not paying me to say this, but guys, go and look up The Focal Therapy Clinic and consider your options and honestly, if you need any more information, ping me a message and I'll be happy to chat to you as well. Clare Delmar Well, that's the best recommendation I guess we can get. I hope we can get this out to a lot of your colleagues both in the military and outside and I really want to thank you so very much for joining me today. Grant Evatt Clare, it's a pleasure and my life is better because of having gone through this. A transcript to this interview and links to more information about Grant and his work with military clients are available on the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Focal Therapy and the "Middle Way" in prostate cancer treatment Focal Therapy is viewed as the preferred "Middle Way" of treatment for prostate cancer patients. In a world of extremes, lots of us struggle to find a viable "middle way" in many aspects of our lives. More recently, the American psychotherapist and author Eric Maisel commented, "The middle way cannot be achieved by dividing two extremes in half" Men diagnosed with localised prostate cancer often see their treatment options as two extremes – Active Surveillance and radical prostatectomy, with nothing in between. It's only when these men actively seek alternatives that they discover focal therapy – the "middle way" in prostate cancer treatment. A trio of researchers considered the role of focal therapy as an alternative to AS and radical treatments in 2018, and concluded that "focal therapies have begun to find their "middle ground" place between definitive therapies and active follow-up". A year later, Dr John Davis from the MD Anderson Cancer Centre in Houston, Texas posed the question: "Is there a middle ground between Active Surveillance and Definitive Treatment?" at the annual International Prostate Cancer Update. Dr Davis recognised the value of establishing a middle ground but urged caution in defining "endpoints" of that "middle", citing the need for improvement in both MRI and ablation techniques. More recently Dr Steven Scionti, of the Scionti Prostate Centre in Florida, asked "If there were a clinically and economically balanced approach to detecting and treating prostate cancer, what would it look like?" He examined criteria that would illuminate a logical middle-ground approach to diagnosing and treating prostate cancer, which are as follows: Less invasive, early & accurate diagnosis Availability of minimally invasive ablation treatments At least five years of data showing balance between effectiveness and quality of life Can be done as a focal treatment for qualified patients Salvage treatment is an option for patients with radiation-recurrent prostate cancer Applying these criteria, Dr Scionti determined HIFU focal therapy to be a "Golden Mean", standing up well as a logical and balanced response to the needs of today's patients. He concludes "HIFU is a logical treatment consideration for the following types of patients. Those who are diagnosed with low-to-moderate risk localized prostate cancer may seek a "Middle Way" or "Golden Mean" between radical whole-gland treatments and observation as a way to buy time before treatment. Those who are drawn to Active Surveillance, including lifestyle changes in diet, exercise, etc. may discuss with their doctors the merits of a focal HIFU treatment as a way to destroy the tumor while preserving their

healthy prostate tissue, urinary and sexual function. Those whose cancer has come back after radiotherapy (external beam or seed implants) may logically consider a HIFU ablation as a potentially curative alternative to hormone therapy.” TFTC Consultant Urologist Tim Dudderidge also regards focal therapy as a middle way for many of his patients. “So we now have a paradox where patients who previously we weren’t treating because the outcomes didn’t seem so good are exactly the patients we need to treat radically, and the patients who get really good outcomes actually maybe they don’t need any treatment at all ...and somewhere in the middle is this group of patients where we’re increasingly uncertain about the benefits of more radical treatments, but we’re also a bit uneasy about doing nothing and just monitoring. These patients are the ones where there’s an opportunity to use something less invasive that still gets the advantages of treatment.” The scope and breadth of the “middle way” will continue to evolve and redefine as diagnostics and focal treatments improve, and most importantly as both patients and clinicians become more conversant about individual perspectives on risk and quality of life. It’s not as simple or black and white as “total cure with side effects” versus “partial or temporary cure with no side effects”. But one thing is for sure: patients’ knowledge about their treatment options is growing, and their confidence in challenging clinicians and seeking alternative opinions about their care is growing too. This, combined with continual development in approaches to focal therapy and evidence on their efficacy, will both widen and strengthen the Middle Way for prostate cancer treatment. Do you have questions about focal therapy and where it sits between Active Surveillance and other definitive treatments such as radical prostatectomy? Insights from the Recovering Man

A conversation with Mish Middelmann, author of the “Recovering Man” blog

Joining me today is Mish Middelmann, aka “Recovering Man”, the title of the popular blog he produces on his experience with prostate cancer. Mish is an organic veggie gardener, prostate cancer survivor and convenor of the global Recovering Men prostate cancer support group. His blog at www.recoveringman.net very candidly chronicles his own prostate cancer journey and those of others affected by prostate cancer. In his professional life he is a systems coach helping leadership teams and organisations worldwide embrace both change and diversity and inclusiveness. Prior to this he was the co-founder and CEO of a software start-up in Johannesburg, South Africa. He’s here to speak with me today about the insights he’s gained through his own experience of prostate cancer and working with hundreds of others through his support community.

Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Joining me today is Mish Middelmann, aka Recovery Man, the title of the popular blog he produces on his experience with prostate cancer. Mish is an organic veggie gardener, prostate cancer survivor and convenor of the global Recovery Men Prostate Cancer Support Group. His blog, Recovering Man, very candidly chronicles his own prostate cancer journey and those of others affected by prostate cancer. In his professional life, he’s a systems coach, helping leadership teams and organisations worldwide to embrace both change and diversity and inclusiveness. Prior to this, he was the co-founder and CEO of a software startup in Johannesburg, South Africa. He’s here to speak with me today about the insights he’s gained through his own experience of prostate cancer and working with hundreds of others through his support community.

So thank you for reaching out to actually discuss the undiscussable.

Clare Delmar Yeah, we like that. So I want to just start off by commenting that in your blog you’ve talked in some detail about support for the non clinical aspects of living with prostate cancer. And I’m really interested in hearing more from you about this and what you’ve learned from the many men you’ve spoken with about not so much per se the treatment which we can get onto, but the so called non clinical aspects.

Mish Middelmann Well, thanks. I mean, I think the deal is that there’s a kind of an alliance between us that are diagnosed with cancer and the people who diagnose us, which is we all want to fix it. And it’s a little bit like you’ve taken this great big journey to New York and you arrive at JFK and it’s very exciting, but you would know and I’ve experienced that, when you arrive at JFK, once you’ve got your baggage, you’re dumped out on the street. I was just going to jump in and say, unless you’re flying first class, but yes...

Mish Middelmann That’s an experience I have yet to have.

Clare Delmar Absolutely. And most of us, too.

Mish Middelmann But the point being that we don’t have much of a roadmap. And in my experience, the clinician who’s done this amazing, magical treatment for me is not actually optimised for dealing with the stuff that I’m dealing with. It’s kind of like we’re out on that curbside at JFK, but there’s no cabs and there’s no buses and there’s no shuttles, and your friend hasn’t come to pick you up. So in your discussions with all these men that you speak with, and I presume their partners, too, on occasion, do you think that there is an ideal model of support for so called non clinical aspects and for men going through prostate cancer diagnosis and treatment?

Mish Middelmann I think there’s so much that we can

do. And really the start of the ideal roadmap for me is it's about adaptation rather than a perfect fix. There's a small proportion of us who do get a perfect fix, and lucky for them, but most of us, we are adapting to new bodies. And a lot of what I think the integrated care map needs to look like is a bunch of resources to help us adapt to our new bodies and to care for our bodies because we all know the cancer cells... there are going to be more mutations in our cells, even if you've taken every single one out of our bodies in the treatment. And so we need to have healthy bodies to keep the cancer from really coming back in any significant way. I want to start there because that's kind of probably where the resources started for me was having a supportive partner. I think it's huge to have a supportive partner, and it takes an enormous amount for both partners to be able to talk about. It's often called the divorce disease or the couple's disease because it's so easy for either partner, male or female, but either the one with the cancer or the one without the cancer to just be freaked out and said, my partner is not what they used to be, I'm out of here. Or for the owner or the ex owner of the prostate, the one who's been diagnosed to kind of go, Well, I'm not the man I used to be, so I'm out of here. And all the men I talk to say that nobody spoke to them about their diet, their physical fitness and exercise, their mental health. And it's even more rare to have anybody kind of engaged with the kind of issues that are needed to develop a sexual inventiveness. And suddenly that thing that used to kind of be in a certain way, it doesn't function that way anymore. And it's about being inventive and recreative and how do you make love rather than how do you just kind of poke around and it's all of that. But a simple roadmap would help. Clare Delmar I mean, you mentioned about the changes in your sexual identity and your sexual function, to put it bluntly, it's a change in your sort of status. You're now dealing with something called vulnerability. Mish Middelmann Yeah, that's the bottom line. Clare Delmar I think in my own conversations, and I'm sure you've had them too, and maybe even experienced it. There are so many of these resources out there which you pointed out, it's how you kind of package them. We agree that there are so many of these resources out there, but it's almost like a cruel irony that we live in this world that there's so much information out there, it's almost information overload to coin the term. And yet so many men feel unable to access and acquire the information they need to make the optimal choices about their care. And I'm interested what you've learned from your conversations about how men do seek the information and the support they need for some of the issues that you're describing. Mish Middelmann Thanks for raising that, because this is really one of my biggest, really ongoing research interests is what enables us to get the information, which, as you say, it's all there somewhere. What enables us to get it and what enables us to act on it? Clare Delmar Exactly. Mish Middelmann Getting it, we can Google, but I'm particularly well resourced, but it took me about a year to find the stuff, and now a lot of it is on my blog and it's all quite familiar. But what I've noticed in working with other men is a lot of people acquire information more through conversation and stories than through sort of download. I'm telling my own story in excerpts, a bit like Charles Dickens, another episode every week or two, like a TV series, and I'm getting other people to do the same. And what I'm noticing is that men and their partners kind of pick up on stuff when they're ready. And that's so contrary to the more clinical sort of model of like, now the treatment, there's a date, there's a hospital visit. I don't want to put all the blame if I'm suggesting that on the clinical establishment, because what I see is we're like hand in glove. Just get the cancer out. Clare Delmar Yeah. Mish Middelmann So we come in with this deep desire for a complete solution, and often our clinical practitioners come with the equivalent desire to give us a perfect solution. There's a lot of examining, understanding, adapting, as I keep saying, and I think the diagnosee and the diagnoser are both not naturally tuned to doing. We're both naturally tuned to just let's get the quick fix and get out of here. Clare Delmar Yeah. But I wonder if you've noticed how much it varies across different types of men, for lack of a better term. And one of the things I'm particularly interested in is do you find variations in the age of men when they first get their diagnosis? Mish Middelmann Not being a clinician, I can't give you data on that. I was diagnosed at 61, and there was a little bit of that voice that sort of like you're an old guy. But I could feel he was on the edge of saying it's a sort of minimal care because you're old now. So even if we are only diagnosed at 70, we still got the chance of living for another 20, 30 years or more. Whether it's all true or not, their belief is, the doctor lied to me and said I would be fixed, and now I'm not and I'm angry. And he's taken away my joy of sex or he's taken away my just joy of simply walking without a nappy. It's anger about what clinically they call quality of life issues, which is really all aspects of health, other than the very specific thing that the treatment addressed. Some of them are treated by physiotherapy or psychotherapy. Clare Delmar Counselling... Mish Middelmann Or visiting my conversation group. Clare Delmar So then I was going to just pick up on that because I hear similar things. People who come to our clinic often are also angry for various reasons, and some of them correlate with what you're saying. Do you think that they

feel like, well, I was considered too old, which is you've touched on that already, or I'm a gay man, for example, or I don't have a partner or some way that they might be categorised, that they feel that they've almost been stereotyped. And I just wonder about that because you've met a lot of men who have undergone this treatment and this experience. And do you think it's been seen to impede any kind of progress in their care? Mish Middelmann Yes, and thank you for mentioning it. When you mention this, the biggest one is black men who are much more at much higher risk of prostate cancer than anyone else than any other men and yet get less treatment. And I think gay men often feel like and I noticed so much of the research is heteronormative, so much of what's written and the International Index of Erectile Function, which was really popularised by Pfizer and Viagra marketing people. And it's highly off putting to anybody who is sexual and makes love in ways that are different to the heteronormal kind of stereotype and that's people of all genders and sexualities and races and so on. And underlying those specific categories is also just a sort of a broader category that I think is lurking behind all of these is kind of the stereotype of the broken man. Clare Delmar What do you mean by that? Mish Middelmann Well, yeah. I don't know how much this comes from the practitioners and how much comes from the diagnosees. But I noticed a lot of us feel like, well, until now, my life was about possibility and my male identity is sort of I'm driving, I'm energetic, I'm an initiator. And my manhood is way more than my erection and my sexuality is way more than that as well. But I do think that there is a sort of underlying stereotype of what it is to be a man that is not serving us. That male stereotypes kind of block us. Clare Delmar Right. Mish Middelmann And I think he's very wise and I think he's accurate. So when I said I'd love to have integrated care, what I don't believe is it's all about someone giving us stuff. I think there's a lot of us about us being empowered and empowering ourselves to kind of claim the way forward. How do we help other men and their partners be empowered to find their way through this, to actually create the roadmap? How do we get enough information and feedback about our health so that we're getting feedback that we can take action on? Clare Delmar Yeah Mish Middelmann Not just saying I must go to a professional and have them diagnose me. Clare Delmar Right. But I would say that it's precisely by having conversations with people like yourself and getting these stories out there that is the beginning of all of this. And you've done a wonderful thing with your blog, and I congratulate you on that and wish you all the best in taking it forward. I'm sure our listeners will have found it very stimulating, very insightful, and hopefully we'll do it again. Mish Middelmann Thank you so much. A transcript of this interview and links to more information about Mish and the Recovering Man blog are available on the programme Notes on our website along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Key Trends Driving Progress in Focal Therapy

Several trends are driving progress in the awareness, effectiveness and availability of Focal Therapy to men with localised prostate cancer, leading to more and better treatment choices.

Key Trends Data on its efficacy and outcomes.

A pivotal study of 1400 men following HIFU prostate cancer treatment over 15 years demonstrated both the efficacy of this form of focal therapy and the quality of life benefits to men who had undergone it. This broke new ground in providing evidence for offering focal therapy to men with localised prostate cancer. Increased awareness of non-clinical aspects of prostate cancer treatment, eg sexual, urinary and mental health conditions – are leading more and more men to question radical treatment. A dedicated group of campaigners and healthcare professionals are actively discussing these issues through social media platforms, on- and off-line support groups, and channel-based initiatives in workplaces, sports and social clubs and annual events. Continuing advances in diagnostics and imaging in particular are driving more precision and accuracy in biopsying, giving clinicians better understanding as to the location, size and severity of cancerous lesions on the prostate. This is key to determining the suitability of a patient for focal therapy and ultimately its likelihood of success. Ablation is a word you will be hearing more of as new forms emerge, clinically tested and adopted. It's a generic or nonspecific term for destroying tissue, and in terms of prostate cancer, ablation means the reliable and precise destruction of cancerous tissue while avoiding structures important for normal sexual and urinary function. Over the years, many types of energy sources have been used to ablate prostate cancer, including heat generated by ultrasound or laser, and cold generated by expansion of gas. This range of energy sources is expanding. Most established with clinical evidence building over 15 years is: HIFU prostate cancer treatment and Cryotherapy. New approaches to focal therapy are building evidence bases:

TULSA - Trans Urethral Ultrasound Ablation

is performed in a MRI scanner using software that provides thermometry or real-time temperatures within the prostate and surrounding structures. The temperatures are sent to the ablation device so the power output from the device is

continuously adjusted to achieve the desired temperature at the boundary between the prostate and the surrounding normal structures. Its key benefit is the real-time monitoring of temperatures within the prostate, although the requirement to achieve this within a MRI scanner limits its availability. Irreversible Electroporation (IRE) provides the technology for a new form of focal therapy known as NanoKnife. While initial studies were limited but promising, a larger clinical trial is currently being undertaken in the USA. Called the PRESERVE trial, it aims to evaluate the effectiveness of NanoKnife on a wider cohort of patients. Water Vapour provides a powerful and effective energy source for treating non-cancerous diseases of the prostate, and is now being developed to treat cancerous tissue as well. Cancer ablation via water vapor is fuelled by the energy that is generated when liquid water converts to vapor, or steam. A key difference between it and other ablative technologies used in clinical practice is the uniformity of its application. Methods using thermal energy stem from a single point that is either hot or cold, and that energy then transfers from cell to cell, progressively getting cooler, or warmer, the further from the source that it gets; this leads to heating or cooling that is uneven and can be challenging to control, according to Mike Hoey, who invented the water vapour technique. He says: "With water vapor technology, the vapor is given under pressure and moves through the space between the cells over the course of a few seconds. The energy produced is evenly distributed throughout the area and ablates uniformly as the vapor changes back to water." Mike joined us recently for our OnFocus podcast – have a listen here. Two additional ablative approaches that are being looked at for prostate cancer are based on Microwave and laser technologies. Both of these show promise but are in need of more evidence – watch this space. Do you have questions about when and which source of focal therapy is suitable for localised prostate cancer? New approaches to delivering Focal Therapy Michael Hoey, founder of Francis Medical Minneapolis joins OnFocus Today's OnFocus features Michael Hoey, founder of Francis Medical in Minneapolis, Minnesota and a veteran healthcare entrepreneur with a deep passion for helping men with prostate cancer. Prior to establishing Francis Medical in 2018 to focus on new treatments for prostate cancer, Michael co-founded NxThera to develop and commercialize urology applications of a vapor platform technology that he invented. This resulted in the highly successful treatment for non-cancerous prostate disease known as Rezum which is benefitting thousands of men across the world. Michael is a former professor, having taught and led research at the School of Medicine at the University of Minnesota. He joins OnFocus to discuss new approaches to focal therapy and their adoption into medical practice. <https://www.francismedical.com/> Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we address issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and too often ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Michael Hoey, founder of Francis Medical in Minneapolis, Minnesota, and a veteran healthcare entrepreneur with a deep passion for helping men with prostate disease. Prior to establishing Francis Medical in 2018 to focus on new treatments for prostate cancer, Michael co-founded NxThera to develop and commercialise urology applications of the vapour technology that he invented. This resulted in the highly successful treatment for non-cancerous prostate disease known as Rezum, which is benefiting thousands of men across the world. Michael is a scientist and former professor, having taught and led research at The School of Medicine at The University of Minnesota. He's here to speak with me today about new approaches to delivering focal therapy and their adoption into medical practise. Clare Delmar It's amusing, I guess, is one way of putting it that you're speaking from Minnesota. Clare Delmar All right, well, let's jump right in, because there's a lot of exciting things that you've been doing and that I know you want to share with our listeners. And why don't we kick off by you telling us about how you got involved in finding new approaches to managing prostate cancer? Ended up leaving that because I knew I couldn't make a living there, went on to my college, graduate schools, professional schools, whatever, and ended up at the University of Minnesota. And one day I got a call from my dad and he said that his local physician said that he had prostate cancer. Well, that was very shocking to me because dad was my rock and I did not expect him to get sick that way and especially with prostate cancer. I had him come up to the university and I went with him, sat on the other side of the table when we went to see my associates as his treating physician. It was an incredible learning experience to be there with somebody that close to you and then listen to people on the other side explaining to him about procedures to treat prostate cancer and about the side effects in the matter of statistics. I, in some capacity, lived them through him and realised what a challenge that really is to men who have conventional procedures, such as removal of the prostate or irradiation of the prostate. And unfortunately for my dad, his cancer had metastasized and he ended up passing from the disease

anyway. And I decided that I was going to make a choice and that was to stay at what I was doing at the University of Minnesota and continue my research and my work and so forth, or I was going to go out into the private world and try to do something about this and find a new way to treat prostate cancer that is more humane, still efficacious but more humane in terms of the side effects and the other implications. And some of the things that people don't realise also, is that even when you take a prostate out, yes, you are in the majority of the cases, not all the cases, but the majority you are treating their cancer and preventing them from dying. But one thing that people don't necessarily realise, the prostate is an organ, it does several things, and there are things that we have not fully elucidated. And when you remove that, it has neurofeedback and hormonal situations that no one discusses because it hasn't been studied well. And the same thing goes with when you irradiate it, let alone all the other things such as the incontinence and the impotence and potential rectal fistulas and protracted pain. And just along with the normal surgery process of removing the prostate, for example, it is a full surgery. I wanted to become an entrepreneur, to build a product to do this, but I didn't have the product design yet. And I happened to have my hand resting on the engine while we were going through the dino polls. One of the things that startled me is I didn't have my gloves on, it was just my hands, how cold the intake runner got. It's like, well, wait a minute, there is vaporised liquid going through the inside of that intake runner. Prostate has a capsule, and then it has the tissue, the glandular and stromal tissue and urethra and so forth inside of that. If you want to kill the tissue inside, but you don't want to harm the tissue outside of the prostate capsule, the energy has to stay within. And I had several other energy sources patented prior to this that I could do that differentiate from the inside to the outside. When I felt that cold temperature on the intake runner, I knew that liquid vapour was running through and I could use that. Unfortunately, even though I also had an MBA, this was my first foray into the private sector world. I spent all the money that I had saved up during my time up to then and ended up with second and third mortgages on properties. And eventually I decided I had to go work for someone else and yet learn or go back to the University. It's been 20 years since I left the University to eventually get to this point to be able to do a company to treat prostate cancer. And I want to come back to this concept of humanity, which is actually a word that you brought in earlier in your discussion. And in previous conversations, I've heard you use the term humane in describing your approach to managing prostate cancer. And I wonder if you could just elaborate bit little a more about how you define this in the context of the diagnosis and treatment of prostate cancer. Michael Hoey Well, you know, it's really interesting because you don't think about these things until you have an experience. And reminds me when I used to teach is that normally you would just take things you learn out of a book and then turn around and regurgitate that to the students. And if I hadn't done something and didn't know it that way, I would go out and experience it. So in my labs, I would do things to recreate what I learned from textbooks, understand it, then I can teach it. Well, it's the same thing here, is that once I learned what it was like to experience this from the human standpoint, the human side, now I could relate to that and do something about it. So I started thinking about what does it take if you are presented with a patient who has prostate cancer, what does it take to figure out how to treat that cancer in a way that will save and spare his life and yet make it more humane? So if you start with the diagnostics, there's been a lot of discussion about PSAs and whether or not they have value or not, because they aren't a one to one indicator of prostate cancer. Michael Hoey There are other things, infections in the prostate, or if you have been riding a bicycle or a horse recently, it sloughs off that prostate component, it's a protein on the membrane that comes off, it gets into the blood and you measure it. However, if you look at it, Clare, and you look at the men who have a very easy methodology to say, Should I even explore whether I've got prostate cancer or not? But now, what happens once you have this higher or accelerating rate of PSA count in your blood? I have been involved in many biopsies, which is different because that's sitting back, looking at it as a medical practitioner, if you are looking at it from the human side, which I did with my father, you realise this is not the most inhumane thing that's ever been done, but it is something that men do not wish to do. And so from that diagnostic standpoint, you think about what's been done recently, especially with MRIs, multi parametric, MRIs. They're designed specifically to look at the tissue in the prostate, and especially for ones that are more the tissue that's more rapidly growing, has more fluid moving in that area, and they can find areas that are suspicious for prostate cancer. And the thing is that it misses the minor things, but it catches the majority of cancers that are intermediate and later stage, the minor ones you would maybe like to know. But at the same time, a lot of times, those patients are just sitting there and being watchful waited anyhow. And it could be in the future that the MRIs can be adapted even better so that you don't need a physical biopsy at all. Now, when you get to the treatment again, this was over 20 years ago that I started this at University of Minnesota. In my mind,

where to go with the treatment that was going to be less invasive, less morbidities, and yet, just as efficacious. In 2008, I believe it was, that the Focal Therapy Society started, and it was a group of people that thought the same way that I did, even back then that's a long time ago. And since then, they have progressed and progressed, and they've gotten to the point now where there are many different technologies available, whether you talk about cryo or laser, RF, even microwaves in there. There are plenty of options out there that are trying to do exactly what I'm doing, but they're all just a little bit different. And in fact, I wanted to ask you about that, because another way of looking at your approach is you're kind of adding a new modality to the arsenal if I can call it that way under the focal therapy umbrella.

Michael Hoey Now Clare, that's a really good question, because it doesn't relate just to prostate cancer.

Michael Hoey But in general, I'm not convinced that most physicians think about, oh, I've got to have this product or that product or that product. It's like when you go into surgery, you've got several different tools there, and you pick out the one for a particular application, and you grab that and you use it. Now there are things that can make one stand out more than the other and choose one more than the other. Example, if a patient presents with cancer up in the top part, the anterior part of the prostate, the physician, the urologist surgeon may look at that and say, okay, I'm probably not going to use a particular one. I won't say which one it is, but there's two of them, actually, that do not do a good job up on the anterior part. That's one way to look at it, then another way to look at it is even physicians are still business people. And so if something at least in the States, and I know it's different in different countries, but at least in the States, there is reimbursement. And the greater the reimbursement sometimes the greater incentive for some people, if everything else is the same.

Michael Hoey The only thing that could happen that could really change that is if what comes in has the ability to treat all parts of the prostate, not just certain parts, but all parts of the prostate. And if it can treat on the inside and not cause the side effects on the outside because the incontinence, the impotence, the rectal fistulas, all those things are outside the prostate. If you can treat inside and not treat outside, then at some point they may take that particular one more than they would the other ones.

Michael Hoey It's probably like it is in every other field, certainly amplified in the medical field, because in the medical field you have human lives at stake. I mean, as you know, as I mentioned, I've been at this now for a couple of decades, and I've only had this company started for three years, but I have been driving towards making this happen for almost 20 years, a long time. Generally speaking, it's about five to seven years to get a product from concept to commercial use. I know things have changed in England that occurred a few years ago, which slows down the process somewhat. Reimbursement changes, economies can change, which can have an impact on things as well as whether you move to new things or not. And so I think the biggest thing about this is, for example, Peter Carroll, who is one of the leading urologic oncologists in the US and in the country. I don't believe he's a focal therapist, but on a call with Francis Medical that we had with them a few months ago, we asked him that. And one of the things that he said was the train has left the station and therefore there's no turning back. And even though it's taking a longer time than you would like it to, the thing is that it's driven for the patient. And if you produce and develop something that's driven for the beneficence of people that are on the receiving end, that the efficacy stays up, but the morbidities go way down. As one of my best friends, who has done more robotic prostatectomies than anyone in the world by a long shot, said, you know, Michael, that this is going to replace an awful lot of the robotic assisted prostatectomies.

Clare Delmar Well, on that note, I think that's good news for prospective patients and for anyone who has a loved one who's been diagnosed with prostate cancer so I think we'll end there.

Michael, that's quite an optimistic way to end so I want to thank you so much for speaking with me. I think we may want to have another conversation in a few months because, well, on the one hand, it's slow to be adopted. I think we might be in a place now where, as you say, the train has left the station and we might find that to push the metaphor the track and the drivers are getting a lot more expert at this not to mention that the patients out there and prospective ones are becoming more aware. When I set out to do this a long, long time ago, the whole vision was again to treat the patient efficaciously but minimally invasive and when we did our very first patient right now the patients could be done without anaesthesia but they won't that will be at a future date but that's just to say how low the pain scores are with us but when we did our very first patient and we woke him up, we sat there and looked at him to see his response, what did it feel like? And this patient looked at us and smiled, he got up, we helped him to his wheelchair, he went, changed his clothes, went through a couple of tests, put on his clothes and he walked out the door, this was in a South American country and he got up, walked out the door, he came back the next morning with his wife.

Clare Delmar A transcript of this interview and links to more information about Michael and Francis Medical are available in the programme notes on our website, along with further information on

diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Managing prostate cancer in an era of delayed diagnoses Two reports were released this week which present the challenging healthcare landscape facing those with suspected cancer. The House of Commons Health Committee report on cancer services revealed that progress in the early diagnosis of cancer in the NHS has been stalled. Based on data up to 2019, the report showed that only 54% of cases are diagnosed at stages one and two, considered vital for increasing the chances of survival. It pointed out that the NHS aim is to diagnose 75% of cases in the early stages, but there has been no improvement in six years. This situation is based on pre-pandemic data, and many believe the situation to be far worse than reported by the Commons. According to Gordon Wishart, professor of cancer surgery at Anglia Ruskin University and Chief Medical Officer at Check4Cancer, "Analysis of 2019-2020 data from the South East London Cancer Alliance, has confirmed an overall 3.9% increase in advanced cancer stage presentation (Stages 3 and 4) and, for prostate cancer there was a 3.8% increase in patients presenting with Stage 4 disease. This stage shift for prostate cancer is likely to increase when further data from 2020-2021 is analysed". The report's findings have implications for patients and providers alike. As prostate cancer campaigner and patient advocate Andrew Gabriel commented, "in addition to the lives unnecessarily cut short, families broken by early loss of a member, and reduced quality of life, failing to cure a prostate cancer patient costs 10-20 times more than curing them by catching it earlier. That's a financial time bomb for the NHS". Cancer campaigner Chris Lewis offers this advice to those concerned by the report's findings: "Prostate cancer is particularly difficult to navigate at the best of times. Push for everything you require!" Professor Wishart adds "there has never been a better time to consider prostate screening using a PSA blood test. If your PSA is high for your age, a prostate MRI scan will help decide whether a prostate biopsy is required or not. If you are unable to get a PSA test from a GP then, you can get a finger-prick PSA blood test sent to your home so there is no need to attend a clinic. You can get further details about PSA home testing by clicking [here](#)" The second report giving cause for concern was published in the Lancet and showed that over a third of cancer patients in England were diagnosed not through GP referral but in A&E departments. Comparing the UK with other countries, it further revealed that countries with higher levels of emergency cancer presentations have lower survival rates. The study found that those aged 75 and over were more likely to be diagnosed in an emergency, as were those whose cancer was advanced. Emergency diagnoses also resulted in a twofold higher risk of dying in the next 12 months compared with people who were diagnosed at other times. We urge all men over 50 to request a PSA test from their GP, and if that is unsuccessful, to seek out a hospital-based self-referral unit like the one at Southampton or mobile prostate screening service like the one recently launched by the Royal Marsden. We will continue to campaign to make PSA tests available and accessible to all men over 50. Do you have a story to share about screening for prostate cancer or encountering obstacles to obtaining a diagnosis? Focal Therapy – a view from across the Pond An interview with Dr Art Rastinehad, Director for Prostate Cancer at the Northwell Health Cancer Institute in New York State, Vice Chair of Urology at Lenox Hill Hospital in New York City and Head of the Focal Therapy Society Dr Art Rastinehad joins OnFocus to discuss how focal therapy is being implemented in the US, and how US and UK clinicians and researchers are collaborating to advance its development. Dr Art Rastinehad is Director for Prostate Cancer at the Northwell Health Cancer Institute in New York State and the Vice Chair of Urology at Lenox Hill Hospital in New York City. He trained at the National Cancer Institute as an Interventional Urologic Oncologist and is the first urologist to be dual fellowship trained in Urologic Oncology and Interventional Radiology. He has expertise in a wide array of interventional radiological and surgical techniques, including image-guided procedures, prostate artery embolization, laparoscopic and robotic surgery, and he has authored and implemented clinical trials of new techniques in the diagnosis and treatment of localized prostate cancer, including focal therapy. Recent publication - consensus on moving to Focal therapy Active Surveillance <https://pubmed.ncbi.nlm.nih.gov/33676851/> Dr Art Rastinehad's website <https://drrastinehad.com/> Clare Delmar Hello and welcome to On Focus, brought to you by The Focal Therapy Clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. As we move into 2022, I'm going to be diving deeper into some of the more challenging issues faced by both patients and clinicians, including advances in technology, clinical adoption of innovations, inequalities and non clinical aspects of prostate cancer. Joining me today is Dr. Art

Rastenehad, director for prostate cancer at the Northwell Health Cancer Institute in New York State and the vice chair of urology at Lenox Hill Hospital in New York City. He trained at the National Cancer Institute as an interventional urologic oncologist and is the first urologist to be dual fellowship trained in urologic oncology and interventional radiology. He has expertise in a wide array of interventional radiological and surgical techniques, including image guided procedures, prostate artery embolisation, laparoscopy, and robotic surgery. And he's authored and implemented clinical trials of new techniques in the diagnosis and treatment of localised prostate cancer, including focal therapy. He's here today to discuss how focal therapy is being implemented in the US and how US and UK clinicians and researchers are collaborating to advance its development. Thank you for that kind introduction, and I look forward to discussing the topics that we have laid out this morning. Maybe you could start by telling me and telling our listeners about what drove you to introduce focal therapy in your practice and how has it been received? I first started focal therapy and researching this in 2009 at the NIH with doctors Pinto, Wood and Choyke. We really felt that targeted biopsy was going to lead to a possible scenario that we could actually treat the areas that we biopsied with some type of energy or modality. So since I finished my fellowship in 2011, focal therapy has always been a part of what we're doing. I initially first started with cryo in our practice, but we've expanded that to include nanomedicine, IRE, HIFU and modalities that hopefully are advancing. So let's talk a little bit about your practice - what and who is a typical patient that comes to you for focal therapy? We were collaborated with Hashim Ahmed from Imperial College develop a high throughput biopsy program so patients don't have to wait from the time that their PSA is elevated to the diagnosis, if they even have prostate cancer. From that, those patients, some of them have one or two two lesions, are focal, their PSA is less than 15 or 20, and they have well visualised disease that we feel those patients would be optimal candidates for focal therapy. These patients can be enrolled in several of our trials that we typically do, or we are part of The Focal Therapy Society registry, where we track the outcomes of these patients with respect to cancer control as well as quality of life metrics. Because what's shocking, Clare, in the United States, prostate cancer was the last solid organ malignancy that wasn't diagnosed with imaging until recently, 2019, when the AUA endorsed image first for all patients at risk of prostate cancer. That leads me into something I was going to ask you next, which is about what the actual pathway is from initial presentation to ultimate treatment. Art Rastinehad When it began, most insurance companies in the United States did not cover MRIs for prostate imaging, but I would say mid 2015, 16, it really started to take off. A lot of private payers were paying, of course, Medicare in the United States, our national health care for older adults covered it all the time. Everything must be transperineal, which decreases that infection rate, so the risk of a screen test is low. As well as every patient must have an MRI before a biopsy is done or attempted to obtain one. We have a collaboration with our radiology colleagues here to have a high throughput mechanism for that. And then within that next week, we have the patients see their primary care physician if they need to have a biopsy sedation or they're booked to see the clinician to review the MRI, and then a biopsy is done. So we're able to shrink that down to about two weeks, which is what we feel really exciting because typically this in the United States takes six to eight weeks, sometimes for patients to get through the whole situation just to get a biopsy to find out if they even have prostate cancer. That's interesting because I completely recognise that sort of paradigm shift, if you will, from the imaging and then how that leads to these much more accurate biopsies. What's interesting, what you're telling me is that a lot of these men going through your pathway will then have that very natural discussion of, well, yeah, focal therapy may be an option for you, is that correct? Because just to contrast it to often the patients that come to the The Focal Therapy Clinic in the UK is they've often already had a treatment recommendation, which is often what they don't want to hear, i.e a radical procedure or a hormone treatment or sometimes even AS, which I want to talk to you about in a few minutes as well. But I think what you're telling me is your patients tend to go right down a pathway, whereas if they're candidates, you present them with that option right away. We have about 15 physicians doing targeted biopsy, and we have a pathway for them, and they move through that. We haven't standardised it that everyone's forced to go into certain buckets for what they have. The challenge with focal therapy is that if a patient hears about it, then hears that you still can maintain your continence, you're not going to leak after the procedure, you're going to maintain your erections, and you're a possible candidate. They don't want to hear anything else about, you could have a radical prostatectomy or radiation therapy with hormones because they're like, why would I do this? I believe it's a misnomer to claim that a prostatectomy is cancer cure because the biochemical recurrence rate is pretty much the same across the board. So regardless of the therapy they pick, they're going to have to deal with a biochemical recurrence in some fashion in 30% to 40% of our patients. And what we're trying

to say is maybe we can decrease the incidence of metastatic disease and impact on your quality of life by this theory and process of focal therapy. But once someone hears that this is an opportunity, it's really hard to change that direction because they don't see a downside. They're like, I understand there could be a recurrence, but I'm young and I do not want to go through the challenges of wearing diapers or having oral pills I need to get an erection or injections or even a prosthesis. So this is really that challenge and I think the team from Imperial did a study that showed there's a treatment regret is around 40% of what decision people pick they're unhappy with what they've chosen and wish they could have chosen differently the first time around. Do you think this message is cutting through and not only the future of it, but also people's access to it? As you mentioned in the bio that I'm one of the founding members of The Focal Therapy Society. We have sponsorship from our parent organisation, Endo Society, and we're pushing this forward. It's exciting and I think it's going to make up a large proportion of the market share in the future. As we get better imaging, better staging, we better identify patients for focal therapy, it's only going to improve our outcomes. Clare Delmar And it's interesting because when you spoke earlier in the US context, which of course is quite different here. But one of the things I'm fascinated by, what these various different insurers or payers as you describe them, you've got two that are dedicated to older people. Do you think they've had an impact on some of these innovations in prostate cancer treatments like focal therapy? Art Rastinehad One of my colleagues, Dr. George, works at a VA and provides focal therapy to those patients. The NIH was dedicated to training physicians with these image based surgical skills, and that has really helped see the US with high quality individuals that can understand imaging and treatment. The other part of the question, when we look at this, the landscape in the US, I wanted to comment, a lot of times when we start, people are like, well, we need more data, then you get more data. And some of the staunchest critics today currently are like, well, it should be the standard of care. Which is mind blowing to me because these are the same people that put up roadblocks initially with fusion biopsy. But other people are like, well, this should be just completely integrated into the options for patients in the United States. I don't disagree, but I still think that we should make an effort to track and follow people's outcomes long term to make sure we're making the right decision. As we mentioned, we have the Focal Therapy Society has that sponsored registry, which we chatted earlier about those collaborations across the pond. Dedicate your career towards focal therapy and imaging, because this is going to be the future. And I was the guy that already decided to do two fellowships, one in oncology one in interventional radiology so I've kind of run with it. And thanks to him, on the dark days when we're challenged by either our colleagues and the negativity early on, I just kept forging forward and it's really worked out for me and my career and a lot of other people have come along and joined the group. I noticed you very recently, that you co-authored a paper which aims to build a consensus, I mean, it happened to be sort of international, but a consensus on treating patients who are on active surveillance and moving them towards focal therapy. I'm just wondering if you can comment on what this means and how you actually see this impacting clinical practice and the growth of focal therapy. Art Rastinehad So every year or so, The Focal Therapy Society wants to address a few clinical questions and then use the key opinion leaders and the scientists from around the world to develop a consensus. And by doing this, we wanted to look at the question of if you're on active surveillance and you fail, what could be your next step? Because if you look at it, we're going to have people progress from active surveillance depending on different clinical variables. It's not an alternative to active surveillance, but if a patient has low risk disease that's non-imageable, not been seen, it really puts them in a very low risk category. But if they have a new visible tumour and they have progression of their Gleason score, why not offer these patients focal therapy? And I think we have developed a strong consensus that it should be offered, and that was the exciting thing about that and identifying which are the best patients for that. I actually interviewed last year two men who were both started on active surveillance at exactly the same time, and one went on to have focal therapy, and the other one waited a bit longer and wasn't able to do that. I guess my final question - this has been amazing discussion - would be let's focus to our listeners and to men who have recently been diagnosed with prostate cancer. What would be your advice to people who have been diagnosed with early to intermediate localised prostate cancer? Art Rastinehad I think first and foremost, remember that this is a slow growing, mostly non lethal disease when patients are diagnosed with low risk prostate cancer, pure Gleason six prostate cancer, we do not believe should really be called cancer. So I don't want to first say, I understand how you feel, you're scared, but in the end, you won't die of this disease. We're trying to make this into a chronic condition that we live with that does not impact your quality of life because it is a disease of aging. And I think focal therapies play a major role in keeping men from suffering the side effects and unneeded radical therapies when they're

diagnosed. Number two is if it wasn't done with imaging, like using an MRI or some type of high quality imaging for the diagnosis, you need to get restaged and reassessed. We do not use ultrasound based only diagnostic techniques for patients with prostate cancer anymore. What's exciting is PSMA may augment how we stage a patient after they're diagnosed, which is great in the United States because anyone with an initial diagnosis of prostate cancer, we can get a PSMA, PET CT. So we're able to really stage patients better today and it's only going to improve tomorrow. Since I'm an interventional radiologist, I do prostate embolisation for BPH, I have patients that have low risk prostate cancer. With 150 gram prostate, we don't want to really disrupt the anatomy sometimes so we can do an embolisation, the prostate shrinks, patient symptoms improve, and we continue to monitor that. And if imaging is not a part of their diagnostic strategy, I would look for a second opinion. And I think we're all on the same page, and I think you've definitely communicated how exciting this whole area is, and I hope we talk again in a few months time as things develop. We've been doing this for so long, but as you see mainstream people become aware of this, physicians now have been trained in these techniques and imaging in the United States, MRI quality has improved a lot, and as that improves, it only makes more patients available to be candidates for focal therapy. A transcript of this interview and links to Art Rastinehad's clinical practice and his research are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk. Follow us on Twitter and Facebook at the The Focal Therapy Clinic for listening and from me, Clare Delmar. An account of the experience of a patient with Active Surveillance

We received an unsolicited email last week that told a story we've heard far too many times. In Jan 2019, I was diagnosed with Gleason 6 localised PCa, so the NHS recommended me for active surveillance. Just 12 months later, I was Gleason 8 and with locally advanced PCa: T2c, N1, MO based on a PMSA PET, with suspicion of bone involvement. Active surveillance is a dangerous option, especially now the 5-yr trial is out showing that HIFU is a very good curative option with minimal side effects and no downstream treatment, plus it can be done 2 or 3 times and doesn't close off the radiotherapy or surgery options. So please can we get rid of active surveillance and move to HIFU for localised PCa - to me it should be the standard of care for newly diagnosed men. Regards, (name withheld)

We spoke with the sender last week, who described the conflicting opinions over both his diagnosis and his treatment options and lapses of communication he experienced after he received his initial diagnosis in 2019. Deciding to use his private health insurance, he found the advice and support he received privately a mixed bag – while he was able to access higher-level diagnostic tests (PSMA) he also had limited access to information and expertise on treatment options. He feels strongly that many men run a high risk of being undercared for and undertreated when they agree to AS, and can only benefit when they are fully informed of all options available to them. A recent posting to Prostatecancer.net addressed the experience of Active Surveillance from a patient perspective, and offers some insightful comments on what it takes to benefit from it. In addition to providing tips and advice, it demonstrates candidly and at a practical level what to consider when faced with the choice of AS in the era of evidence-driven non-invasive curative treatments like focal therapy. Alan Doherty, Head of the Birmingham Prostate Clinic and Consulting Urologist for the Focal Therapy Clinic, believes Focal Therapy offers a significant advantage over Active Surveillance for most men who are suitable for both approaches to prostate cancer management, and this advantage has increased steadily over the period that he's been practicing focal therapy. In his view, we now have 2 things that have transformed treatment for prostate cancer and have underpinned the advantage of focal therapy: highly accurate imaging of lesion size, location and severity which supports targeted treatment 15 year evidence on outcomes - quality of life and oncological – for men undergoing Focal Therapy “It's a no brainer,” says Alan. There's minimal harm in treating localised prostate cancer focally, but there could be harm in not treating it.” Do you have experience with Active Surveillance? Prostate Cancer Recovery and Music Therapy

Alphonso Archer shares his experience with prostate cancer and his research project on music therapy and prostate cancer patients. Alphonso Archer joins OnFocus in this episode to discuss how his prostate cancer diagnosis changed his life in a very positive way and inspired him to reclaim his passion for music. Alphonso, a former IT sales professional decided, after a prostate cancer diagnosis in 2016, to pursue his lifelong love and passion for music and trained to be a music therapist. He is currently completing a master's degree in music therapy and researching how men with prostate cancer benefit from music therapy for his dissertation. He is also an active member of a support group for black men diagnosed with and recovering from prostate cancer. Alphonso Archer's music: <https://open.spotify.com/artist/0p6CGWh3GSj8amuiU7Atsk> Alphonso's research

https://uwe.eu.qualtrics.com/jfe/form/SV_4ZufpFVGmJOgBZY Clare Delmar Hello and welcome to On Focus, brought to you by the the the Focal Therapy Clinic engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. As we move into 2022, I'm going to be diving deeper into some of the more challenging issues faced by both patients and clinicians, including technology, clinical adoption of innovations, inequalities and nonclinical aspects of prostate cancer. Joining me today is Alphonso Archer, a former IT sales professional who, after a prostate cancer diagnosis in 2016, decided to pursue his lifelong love and passion for music and trained to be a music therapist. He's currently completing a master's degree in music therapy and researching how men with prostate cancer benefit from music therapy for his dissertation. He's also an active member of a support group for black men diagnosed with and recovering from prostate cancer.

Clare Delmar Why don't we just start by you telling us what your personal experience with prostate cancer has been like?

Alphonso Archer Well, first of all, I knew nothing about prostate cancer as a young person in his 20s or even 30s. And my sister told me that my father had some treatment and she mentioned it was prostate cancer, but my father never told me about that. I was away at university and so on, and he had some treatment and apparently it was successful. I say apparently because he's now passed away, so I've never had a chance to even ask him about it. And as a black person, I discovered I was totally shocked, actually, when I found out that in the UK, one in eight men will get prostate cancer, but then learned that it was one in four black men.

Alphonso Archer And that kind of made me really set up as a black person because it was just such a glaring disparity in that statistic.

Alphonso Archer So I started to do a lot of reading, and I found some really interesting stuff in the UK and in the US about I was trying to understand why, et cetera, et cetera, et cetera. And my doctor, I'm very friendly with my doctor, but he kind of said, Look, Alphonso, you're young, you're fit. And then I pushed back on him and said, well, actually, from my reading, this is actually scary because my father had it. And again, my doctor said, look, don't worry, you're still within the range of normality here.

Clare Delmar Again, Alphonso, when you said they started to go up, you are getting them every year.

Alphonso Archer And then it started to rise, and then kind of said, well, let's check it every six months. And then one day the test came through and it was slightly above the range for my age, but it was showing abnormal. I said, look, no, I said, I'm really getting concerned here and again, I kept pointing back to what I read about black men. I'd already had a DRE with my doctor, the digital rectal examination, which most men dread. And so I had the same checks with my urologist, and they found nothing untoward and the same results. And then he started telling me about the biopsy, which I'd already known about, read about it. And I felt kind of just putting me off to delay it a little bit because of the unpleasantness of the biopsy. The biopsy showed that I had prostate cancer, and fortunately, because I caught it early, it was Gleason six, which is the early stages. So we had the discussion around active surveillance, and I started to understand what that meant. And then suddenly, I guess the whole world of confusion opened up with all the plethora of options and treatment. And you kind of get that whole feeling of your world kind of caving in, my gosh, what am I going to do about this? And the consultant, who was a surgeon was kind of saying, well, Alphonso, you're young, you're 50, you're mid 50s. I knew that was the ultimate radical option would be to do that, but psychologically, I just was not ready for that. I thought, well, I can actually plan and let's do this in the summer when I've got six, seven weeks holiday. And that's the hormones, that reduction in your testosterone...

Clare Delmar Exactly

Alphonso Archer ...causing all kinds of psychological effects, which is quite depressing, really, in terms of having a body that has been very fit, very active, and brain that thinks a million miles an hour suddenly it just felt really lethargic and constant hot flushes and things like that. And then the actual radiotherapy having to the way you have to prepare with drinking a pint of water because you need, et cetera, et cetera, going through that whole preparation. And then when the treatment starts, suddenly you're kind of losing control of your pelvic area and you literally rushing to get to the loo, get off the table, you're just bursting to go. All those challenges, it was kind of dehumanising, really, and quite a difficult thing to go through. After the treatment, I was on a three month PSA cycle of testing every three months and reporting back. But then they talked about this bounce after the radiation, then after the next three months, check, the levels drop right back down again. And I've been having three monthly checks, but I'm now on six monthly cycle because my PSA stayed constantly low. And I had a last check last week and it's still 0.1, but it's great, so it's really stable.

Clare Delmar Well, you sound it and that's great, but you've also been extremely honest and very hopefully so about the emotional and mental and psychological ride you've had to go through to get to this spot. I don't even want to use the word comfort because that almost demeans it, how it's been such an integral part of this process.

Alphonso Archer Yeah, music has been huge because I've been a musician since a very

young child and learned to play piano and guitar. I was in Church when I learned music and then becoming a musician myself, I just continued to use music for me. So for me, even back as a young child, music was a safe haven for me, a way to close out the noise in my life, in a family home, et cetera. And so when I went through my prostate cancer treatment, I found that in that summer when I was having treatment, I kind of made some radical decisions around where I thought, well, I'm not going to die immediately, but I thought, you know what? I started working on an album that I've always wanted to work on but never felt compelled or motivated to start it. But going through that whole treatment, I was suddenly writing songs and using music a lot more to access my emotions around what I was going through. Alphonso Archer And music kind of helping me just to, I guess, get to that unconscious place really that words just couldn't do. Clare Delmar So then how did you make the transition to sharing that with other I know you work with children and now you're working with men with prostate cancer. Alphonso Archer When I got my diagnosis, I was a salesman selling software, corporate software, and doing pretty well in that world. But when I got my first degree, that was in '85 when I graduated, it was a degree in sociology, psychology. And I worked for a few years as a welfare officer, using, I guess, that degree a little bit and working with people, working with young men and women that have been put on demand. And if they were actually not sent down, then I helped them to find services, access to housing, and things like that. And I think that when I was diagnosed with prostate cancer, I decided I looked at my whole life and thought, you know what? And just through my reconnection with music on, I guess a deeper, more spiritual level, it was like a light bulb turning on. At the end of the three months, I decided it wasn't for me and set up a music business originally to teach. And that's what I started doing, teaching music, set my studio up at home, and then just through contacts, I managed to end up, I ended up working in a school with children with autism. I knew nothing about music therapy at the time, but I was working with children that were selectively mute, for example. Alphonso Archer And then there were so many stories starting to evolve with all these different children, these wonderful children. And then that's how one day someone came in who was a music therapist, and they said to me, Alphonso, what you're doing is music therapy. If I'm kind of being called a music therapist, which is a clinical licensed term, I thought I might as well go and study. Tell us a little bit about the dissertation you're doing, and this is your opportunity to shout out to people about participating in it, I think. What are you expecting to do and how are you expecting to help them through your musicianship? Alphonso Archer As a student music therapist, having worked with children with autism, and I've worked in hospitals with clients with bipolar or schizophrenia or emotional trauma related to abuse, whether it's sexual abuse or physical, verbal abuse and all the traumas that arise from that. I've learned in a clinical way how music can help people access these psychosocial challenges, emotional dysregulation and psychological distress. I wanted to look at how do black men in particular, I thought I'd focus on black men because of the disparities around prostate cancer for black men. And I think, let's look at how do black men use recorded music and song choices to process the impact of their prostate cancer. And what the research shows is that African Caribbean men, they struggle with the side effects of prostate cancer linked to these socially constructed ideas of masculinity and in addition, link to things around erectile dysfunction and all these stereotypes around black male sexuality and then link that with prostate cancer. I thought, well, let's look at how music is potentially help these men and help black men to process some of these challenges, even if it wasn't through formal music therapy. But it could just be someone just putting on a song or whether it's the motivation to go through their treatment or just to help with psychological distress. So literally I've got a link that I'm sending out now to support groups and to people that can share that link for people to participate. So I'll put that in the program notes for this interview, and I guess one other question is, is there a link to your own music that our listeners can access on any of the music platforms? I just wrote a whole bunch of songs and I'm a musician so everything on there I play and I just use voices of people that can sing. I wrote this album actually I called it Formula for Life because at the time of being diagnosed with prostatectomy cancer, literally within a month of that as well I discovered that I had a condition called an AVM, an arteriovenous malformation on my brain that I again discovered purely by just being a bit persistent with my doctor. I called Formula for Life because they gave me a formula for the chances of me having a brain haemorrhage which made me decide to have this treatment for this AVM. Well, we'll have the links for your own music, for the Formula for Life album and for the call out to participants in your dissertation research. Clare Delmar And we'll follow up hopefully in six months we might have a lot more sort of interesting feedback from the participants from your study. Clare Delmar A transcript of this interview and the links we discussed to Alphonso's music and his research study will be available in the programme notes on our website along with further information on diagnostics and treatment for

prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at the The Focal Therapy Clinic. An interview with Mr Raj Nigam: Consultant Urologist A conversation with Consultant Urologist, Mr Raj Nigam. Joining me today is Raj Nigam, Consultant Urologist at the Royal Surrey County Hospital and the Focal Therapy Clinic. He manages men with all andrological conditions including erectile dysfunction, male infertility, Peyronie's disease and male hormonal problems. He also has a major interest in prostate cancer and in particular, precision diagnostics and focal therapies Raj is widely published in national and international journals, and has lectured extensively over the last 20 years. His current research interests are in advanced diagnostics in prostate cancer and the evolution of new treatments to treat prostate conditions. He's here today to address perceptions and misperceptions on personalised medicine – a term that we hear a lot about and which means many things to many people. I've asked him to join me and give his views on what personalised medicine means for diagnosing and treating prostate cancer.

Clare Delmar Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. As we move into 2022, I'm going to be diving deeper into some of the more challenging issues faced by both patients and clinicians, including technology, clinical adoption of innovations, inequalities and non-clinical aspects of prostate cancer. Joining me today is Raj Nigam, consultant urologist at the Royal Surrey County Hospital and The Focal Therapy Clinic, Raj's clinical specialty centres around urological oncology and andrology. He manages men with all andrological conditions, including erectile dysfunction, male infertility, Peyronie's disease and male hormonal problems. He also has a major interest in prostate cancer and in particular, precision diagnostics and focal therapies. Raj's widely published in national and international journals and has lectured intensively over the last 20 years. His current research interests are in advanced diagnostics, in prostate cancer and the evolution of new treatments to treat prostate conditions. He's here today to address perceptions and misperceptions on something called personalised medicine. It's a term that we hear a lot about in the media, in various clinical studies, at the GP surgery. We'd like to learn a little bit more about what this means, and I've asked him to come to talk a little bit about what that term means to him. How would you define it and what do you think it means for men diagnosed with prostate cancer? I mean, doctors have been trying to personalise medicine for throughout the history of medicine really. It's just a term that has gained much more traction over the last 15 to 20 years or so, particularly with the launch of the Human Genome Project and so on, people started musing about what that could hold for an individual once their whole genetic code had been mapped, people could figure out what sort of conditions they might be more prone to and therefore target detection and diagnosis of those conditions in those people. And really, the NHS itself has embraced this, and they actually quote and say that we want to move away from what they call a one size fits all theory to a more personalised approach, particularly in terms of prevention, detection and even diagnosis and treatment options. And those particular categories people have gone along part of the way, shall we say, but there's a lot more to come. That's interesting because it's so it's not something that's kind of like a consumerist term, you know, like we're going to treat you differently than somebody else. And then that itself is manifested in a wealth of personal data that can be used to both prevent diseases and treat conditions. We understand more about each individual through the things we just talked about, but also we address them differently or we deal with them differently. And one of the things I'm interested in getting at is that the majority of our patients come to us for a second opinion, so they've already had some engagement with the medical profession for lack of a better term. Do you think that the experience of having gone through something before and the information they bring helps you and helps us to provide a more personalised service? I mean, I think that we can personalise the service more once we have that knowledge and also the patients have that knowledge. So once the patients have been through the standard NHS approach, they would have had certain aspects of their condition discussed to a greater or lesser extent, and they would have been offered certain treatments. The truth of the matter is that in prostate cancer, it isn't as much a personalised approach as we would like. And the very fact that patients are coming to us for a second opinion almost implies that they are a self-selecting group who would like to know more about their condition and what other treatment options they are in order to have a more personalised approach. And it's important to note that those men at different ages may have very individual goals of their therapy. The older patient, for example, who is over 80 years old, may be quite happy to have control of their prostate cancer with minimal side effects for another five to ten years. I've had some patients who still want to have further children, so the approach to their treatment should really be targeted and personalised, taking into account the needs of that particular patient. And that's how I see personalised medicine and focal

therapy offers them an option along that approach. I mean, based on some of the qualitative or sort of non-clinical aspects you've just discussed, but also on very comprehensive diagnostic criteria, do you think that that's a very highly personal form of medicine, even more than many other treatments, just because it has this combination of very individually specific data that's come out of all the diagnostics plus these discussions that you have in order to select a patient? The process that we go through in selecting whether a patient is suitable for focal therapy is very precise and detailed. And that sort of approach is not necessarily required for a whole gland approach, such as radiotherapy or radical prostatectomy. Because that degree of concordance defining exactly how much cancer there is exactly where it is in terms of locality, is absolutely vital for focal therapy surgeons. Whereas in a whole gland approach, it is not so personalised because the approach is very much to remove the whole gland or treat the whole gland with radiation. So the diagnosis of cancer in itself is not sufficient for us, and we go much deeper than that to select those patients that are suitable for focal and indeed taking into individual desires of that particular patient, in terms of acceptance of certain side effects and so on. So like I said, we like to think we're offering a much more personalised approach than that offered through the NHS. Clare Delmar So when you talk about this review and the actual discussions that you have with other professionals to actually select a patient and actually define their suitability, that's actually what you're referring to there is the MDT, correct? I'd like to get a little bit more sense of how this is very distinctive and how it actually drives this personalised treatment. I mean, when you discuss both the technical or medical or clinical aspects of each patient, as well as his family life, his mental outlook, everything else. The MDT meeting is a concept that has arisen through the NHS and has been present for many years, at least ten years. Its initial goal was very much to individualise the patient and discuss their particular situation. Unfortunately, certainly on the NHS, the meetings have got so big that they become a tick box exercise. What I think it is important to your listeners to recognise is that the MDT is there to make recommendations. One of the biggest criticisms of MDTs in various articles and scientific papers is very much that the patient is not present. The surgeon that has seen them and spoken to them is present, which again, is not always the case within the NHS. So our MDT, we like to think, are far more personalised because, for example, I will be able to say that, look, this particular chap has got recently married, you know, erectile function is extremely important for him or indeed, our eighty year old gentleman who normally, you know, if nobody knew that patient was being discussed, would be thought of as, Oh, let's just watch and wait and not treat his prostate cancer. He looks after his wife and so on, and he really would like to have treatment and has got a good life expectancy ahead of him. So I would like to think that, you know, our particular MDTs are a bit more personalised for that particular patient, and therefore we hopefully come to the right conclusion for that particular patient. Clare Delmar And do you see any additional drivers of personalised diagnostics or treatments coming in the near future? I mean, you spoke in earlier part of this conversation about the genome project and various biomarkers that might be associated with that. Do you think you know, whether it's biomarkers, genomics, advanced imaging that some of this will contribute even further to better personalisation? Raj Nigam Yes, I think all of the above, I think that there already have been certain strides, particularly in terms of targeted therapy for other cancers. And also targeted diagnosis, and we're probably about 15 - 20 years behind in terms of research compared to breast cancer. So a woman's breast cancer is very individually characterised right at the outset in terms of the the genes and the receptors for those genes that are present within that cancer. And in other cancers, immunotherapy for melanoma, for example, you know, the characteristics of that individual's tumour are present and therefore targeted therapies towards that are being developed. We already know that the genomics and so on are there to discuss risks that the patient may or may not have cancer. There are tests that are already available whereby we'll be able to judge on that individual's readings, whether they should have a biopsy, for example. Similarly, post biopsy, once you diagnose the cancer, there are tests that one can do, genetic markers, to see that their individual cancer, how likely it is that they are going to have an aggressive cancer, for example, that needs more urgent treatment. Artificial intelligence, in terms of imaging, we know that imaging techniques are improving all the time. And I suspect in 10 - 15 years time, I may be saying to you that we don't need to biopsy men anymore and that, you know, the imaging is so good that we can avoid biopsies. We're not there yet, unfortunately, but I think we're moving in that direction and there will be algorithms that you can feed in the patient risk factors, you know, their family history, their ethnicity and so on into the algorithm for AI and you know, they will come up with the relevant readings on the MRI scan. Clare Delmar So the MRI will actually be highly personalised because it will have taken into account some of these emerging biomarkers or other genetic information that goes into the algorithm. It then tells you through the image whether or not this person has cancer, how how bad it

is, how severe it is, how fast it's moving, where it's located, etcetera? I mean, basic programs have been developed, but I think that we still have got some way to go to actually maximise the potential of imaging. And like I said, I think we're already there in some cancers where we don't need to biopsy. The imaging is strong enough for us to make that diagnosis, and I suspect that prostates will be a few years away from that. Clare Delmar But it's almost like the more information you have, not only is it more personalised, so to speak, but it also means you can be far less invasive in how you do further diagnostics and potentially treatment ultimately. I mean, like I said at the moment, we just have a relatively crude marker, which has been around for many years, which is a Gleason grade to assess whether a patient's prostate cancer is aggressive or not. But within that, there are lots of other measurements that can be made, you know, on the biopsies and so on, which will help guide us as to how truly aggressive it is and therefore, what sort of treatments would suit that patient better. And links to Raj's clinical practice and research are available in the program notes on our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Personalised healthcare is at the core of the approach to prostate cancer here at The Focal Therapy Clinic. The charity Prostate Cancer UK gave evidence last month to Parliament's Health and Social Care Committee, for the latter's inquiry entitled "How can the Government improve cancer outcomes in England?" In its evidence, PCUK provided eleven key recommendations to the Government, which included: A shift away from symptoms awareness, which is reflective of later stage diagnosis to instead focusing on raising the awareness of a man's risk to prostate cancer, within primary care as well as with the public. A focus on reducing the number of late stage incurable diagnoses, to the more curable stages of diagnosis. A standardisation of national data collection that includes equipment and health inequalities. Its final recommendation was a call to increase the level of personalised care: "More needs to be done on personalised care to achieve the commitment made by the Government. There are likely to be very good examples of personalised care happening across England that can be utilised as a learning exercise. The Government should look to these models, understand the challenges and solutions and use that information to inform future commitments and investment in this area of cancer care to support NHS Trusts that are struggling. A handbook was published by the NHS in 2020 which outlined what personalised care pathways would look like for cancer patients. It set out requirements for Cancer Alliances to work with local systems to ensure that every patient has access to personalised care interventions from diagnosis by 2021. Interventions include: "Personalised Care and Support Planning based on Holistic Needs Assessments, Health and Wellbeing Information and Support, and End of Treatment Summaries (collectively formerly known as a 'recovery package'). In its evidence to the Health and Social Care Committee, Prostate Cancer UK referenced the National Cancer Patient Experience Survey, stating "In summary, the NCPES shows variation and poor levels of access to care plans. Health and wellbeing information and support for men diagnosed with prostate cancer rates highly but, again, there is huge variation in what men experience. More could be done to ensure all men have a high quality experience beyond their diagnosis." At the same time as personalised care is accepted as a healthcare strategy and providers are attempting to implement it (with varying outcomes), medical technology is enabling personalised treatment for prostate cancer, based on increasing understanding of individual patients' genetic makeup combined with precise diagnostic information and targeted interventions. The challenge with all of this information is to translate it into truly personalised care and treatment. This is something clinical and non-clinical practitioners must address all the time, and – captured in a recent review on prostate imaging which posed the question "do we Treat the patient or the scan?" Combining personalised care with personalised treatment underpins all patient engagement at the Focal Therapy Clinic. Our practice is based on five elements: Providing a second opinion The majority of our patients have had a diagnosis of prostate cancer and a recommendation for treatment when they approach us, and are actively seeking a second opinion on their treatment options. These men are well informed and well motivated to share information and express concerns and aspirations – giving us an ideal starting point for establishing a personalised care plan for managing their prostate cancer. Patient advocacy All patients work with one of our patient advocates, who listens, learns and supports each patient throughout their experience with our clinic. Our patient advocate team have spoken with hundreds of men over the last two years, and have developed a comprehensive picture of what is happening to men who are diagnosed with early-stage prostate cancer across the country and how to reduce, and sometimes eliminate, the fear, uncertainty and doubt underlying their treatment decisions. The patient advocate is the first port of call at our clinic, providing prospective patients with balanced information on

diagnosis and treatment options empathy and support for the journey they are undertaking a pathway to a second opinion with a world-class clinical team Patient advocacy is a core element of our entire approach, from initial enquiry through to MDT and treatment. A Whole Man approach Understanding who each patient is – his lifestyle, what he cares about, his relationships, how he spends his time, and his aspirations for the future - is critical to us in supporting the management of his prostate cancer. TFTC Consultant Urologist Marc Laniado emphasises the importance of discussing mental health issues with his patients, and giving men “permission” to talk about how they feel and their ability to cope with having prostate cancer. When it comes to treatment decisions, many men are not counselled about long-term side effects of individual treatments, which can impact mental health. “While they want to get rid of their cancer, they don’t want to lose sexual or urinary function. It’s a balancing act, and men are best able to cope with this when they have the information they need at the right time and in the right place”. Consultant Urologist Alan Doherty adds, “understanding what a man is capable of behaviourally and what support he has to sustain successful behaviours is crucial to a positive treatment outcome”. Advanced diagnostic technology & clinical practice Imaging – our practice relies on state-of-the-art prostate imaging to plan for biopsy, confirm diagnosis and guide treatment. The quality of reporting we undertake is unrivalled and provides the clinical team a basis for determining a personalised treatment plan. Biopsying - our clinical team rely on state-of-the-art trans-perineal MR/US fusion biopsies to give them the highest level of accuracy in sampling tissue and confirming the location, size and severity of each patient’s prostate cancer. The MDT All FTC patients are presented to a fortnightly MDT meeting where their diagnostic information, overall health and wellbeing and lifestyle aspirations are discussed and reviewed in detail by a consulting team including patient advocate, technologist, radiologist, consulting urologist. Treatment recommendations are reached by consensus and actively communicated with each patient. Over the last two years these meetings have taken place online which, according to FTC Consultant Urologist Tum Dudderidge, delivers enhanced benefits for patients who, while not in attendance and unable to advocate for themselves, can access images and recorded content from the meeting. Tim adds: “if you’re in an MDT and all of those (patient specific) issues are clearly recorded, then the MDT has a chance to be aware of that. Otherwise, there’s a danger that people make assumptions about a patient’s longevity, about activity, about what the patient’s interests are. And then the MDT might come out with a recommendation, which is too focused, and doesn’t allow the breadth of discussion that should happen for every patient, regardless of their age or what assumptions we might make about their lifestyle.” What is your expectation of personalised care and treatment? The importance of Patient Advocacy An interview with one of the Focal Therapy Clinic’s Patient Advocates, Eva Tomopoulou Joining me today is Eva Tomopoulou, a patient advocate with the Focal Therapy Clinic. Eva is the first port of call for patients who approach the clinic, and she has engaged, guided and supported hundreds of men in their journeys to understand their prostate cancer diagnosis and ultimately to choose the optimal treatment for it. She’s here to talk about the role of patient advocacy and the benefits it brings to patients and their families. If this is of interest to you or someone you know, please get in touch: <https://www.thefocaltherapyclinic.co.uk/patient-advocacy-a-critical-asset-for-men-on-the-prostate-cancer-journey/> Clare Delmar Hello and welcome to on focus brought to you by the physical therapy clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer among men in the UK, and with this somber fact comes a multitude of challenges and opportunities. As we move into 2022, I’m going to be diving deeper into some of the more challenging issues faced by both patients and clinicians, including technology, clinical adoption of innovations, inequalities and non-clinical aspects of prostate cancer. Eva is the first port of call for patients who approach the clinic, and she has engaged, guided and supported hundreds of men in their journeys to understand their prostate cancer diagnosis and ultimately to choose the optimal treatment for it. She’s here to talk with me about the role of patient advocacy and the benefits it brings to patients and their families. It’s been a really interesting few months setting up the Patient Advocate program, and I think one of the things we’ll mention at the end is we are continually looking for more patient advocates and there’s been a very interesting recruitment drive and a lot of this you have led. But I’m interested in talking with you right now about what you actually see as the role of a patient advocate. Eva Tomopoulou So the way I think about my role, the way I think about patient advocacy is that it’s all about active listening. And what I mean by that is that we’re there to listen to people’s experiences, particularly at The Focal Therapy Clinic the patients we usually get it will probably be the first time for them that they which have had a chance to have a lengthy conversation about their diagnosis. So for a lot of them, they would be the first time someone would ask them

questions about the diagnosis and try to help them make sense of it, which I think is really important. And another really crucial point of the patient advocate role is to really give this this people will come to us the sense that they're not alone in this so that there's other people that are going through this experience. There is support for them available and there is information for them available that can help them better understand either their options or their diagnosis. But you know what's interesting about the patients at The Focal Therapy Clinic is they're often coming for second opinions, so they already have a diagnosis. And so I guess I'm interested in observing that many of the men who come are pretty well informed. And and so I'm curious about how that level of information helps them or maybe even hinders them and how that plays into the fact that, as you say, not many people have actually listened to them before. I would say that's quite a big topic, so they will have known what options are available to them. But it is very, very often that we see that patients have a very vague understanding of what their diagnosis means, and most of the time is not a very detailed understanding of what their diagnosis means. And we're just talking here about the very, very basic information, like what does their biopsy, what what is their Gleason score, things that I did not do doing this job every day, I would expect people to be more aware of it or to have such, I guess a lot about. But it is very often that I find that patients are not really sure they have a vague idea of the staging. They definitely most of the times they would have heard about the treatment options that would be available to them. And what I see is that most of the times they come out from this conversation is the understanding that their life will never really be the same after having treatment. So I guess when I ask about how much information they have, they have enough to know that they would like to inquire more about focal therapy and learn about other ways to approach their treatment. The patients we usually speak to, all the people who listen to their options given to them by their consultants, and they just don't feel certain that this is the right choice and they start looking for what else is out there. And I hope that there must be something out there that this can't be just what is available to them. At this point, they start finding out about focal therapy, HIFU, and this is at that stage they would get in touch with us and we would start informing them, starting from the question that is usually what I hear most of the time is why? And yeah, that that's usually the starting point, and it's a very fair question, one that I find quite more complicated to answer the more I do this job, to be honest with you, because I also don't understand why they haven't heard about this. I mean, it's not so much that the onus is on them for not not having heard about it, but if you are and other people offering them this information. It leads me to ask you something else aside from information and maybe some asymmetry of information. What are the other, you know, more typical challenges that you hear from the patients that come to you? What other challenges do you think that men who are faced with a recent prostate cancer diagnosis are experiencing? Eva Tomopoulou A lot of the patients that we speak to at that stage, they're quite overwhelmed with the diagnosis. So that is a big part of the role of the patient advocate is to try to navigate that and to just kind of take it back to trying to be as informative as possible and reassuring that there are treatments out there; that this is a journey that a lot of people go through. We spoke recently about decision regret in one of the latest blogs that you did for The Focus Therapy Clinic, and this is something that I find quite crucial that a patient who's informed and who is very well aware of their options and what would they mean for the quality of life as a patient who can make decisions that then they would feel much more comfortable with? And I think this is a really, again a really big part of the relationship we have with the patients. You know, tell me some interesting stories about men who you feel have particularly benefited from, you know, advocating for them. Eva Tomopoulou Going back to what we discussed in the beginning about our efforts to recruit a new patient advocates. It's been really amazing to see that patients who have gone through The Focal Therapy Clinic we've spoken to are now active advocates in the field in different capacities, and they've been really inspired by their journey and their experience. And I think it's just, like, invaluable that the role of the patient advocate seems to be such a crucial part of the journey that prostate cancer patients go through. And it's really helpful and it's really meaningful, and it's always going to be an integral part of this of this process. Clare Delmar And it's lovely to hear that people who benefited from advocacy from people like you or some of your other colleagues now want to become advocates themselves. And that's kind of the ultimate sort of validation that they've experienced something good and they now want to share it with others. Eva Tomopoulou I've really been amazed by this, and it's really I mean, it's a great validation for all the work we do to see that, to be honest with you. Clare Delmar So can you tell us a little bit about what you're looking for in terms of other people coming on board to join the patient advocacy team? I mean, we were looking for people who may have had experience with prostate cancer themselves or in their immediate or, you know, some kind of other first hand experience. And who can really speak for that journey, starting from the diagnosis and not

knowing what to do and how to move forth to go through treatment. You would be excellent to hear from as many people as possible who have things to contribute in other people's journeys, who feel they would like to support other people and other patients going through this. Will Eva, thank you so much for joining me today, and good luck with the recruitment program and doing wonderful work. Clare Delmar

A transcript of this interview and links to our patient advocacy program are available in the program notes at our website, along with further information on diagnostics and treatment for prostate cancer, as well as additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Black Men and Prostate Cancer, 1 in 4 vs 1 in 8

What has changed in the past 7 years since the 2015 report showing black men are twice as likely as white men to develop prostate cancer? In 2015 Public Health England and Prostate Cancer UK published a report showing that black men were twice as likely as white men of developing prostate cancer and twice as likely of dying from it. The authors called for better targeting of prostate health information to the black community, and funding for research to better understand these disparities. Most recent data from Cancer Research UK shows prostate cancer rising for the population as a whole, predicting a rise of 12% between now and 2030, and acknowledges that it is most common in black men. The 2015 callout for research funding and targeted communication campaigns have been mixed. Research on ethnic disparities in prostate cancer has improved and the Institute for Cancer Research last year published results from a groundbreaking study on genetic variations in black and white men that account for varying risk in developing prostate cancer. The authors stated: "Most genetic studies of prostate cancer have focused on White men of European ancestry. However, Black men are known to be at an increased risk of being diagnosed with or dying from prostate cancer, and there is an urgent need to understand their risk profile to implement early detection strategies. The new analysis compared men with and without prostate cancer in order to identify 86 new genetic changes that influence the risk of developing the disease – bringing the total number of genetic changes associated with it to 269. These inherited genetic changes each individually has just a small effect on the risk of developing prostate cancer, but when many are combined they can substantially increase risk. Researchers believe that the changes they have identified are part of the reason for the racial disparities seen in prostate cancer incidence". Exemplary approaches have come when several organisations partner to deliver a coherent message through multiple channels, as the Wessex Cancer Alliance has done by joining forces with several local partners to produce a series of multimedia offerings including podcasts and online support groups. Last year we interviewed two black men who were diagnosed with prostate cancer at the start of the pandemic and put on Active Surveillance, with very different outcomes. Delroy Wright and Marcus Grant described their respective journeys with honesty and insight. Black men continue to bear twice the burden of developing prostate cancer as white men, and with overall cases on the rise, the situation merits renewed attention. What has changed is the public perception of health inequalities, thanks to Covid 19, and a level of activism bringing together men in the black community. Thanks to Covid19 there is a wider and deeper appreciation amongst the public of the concept of health inequality, and more organisations are seeking ways to address it. Originally reported in great detail in 2010 by Sir Michael Marmot, significant variations in life expectancy, poor health and health outcomes across the nation were shown to constrain overall fairness and health amongst the UK population. Revisiting his findings ten years on in 2020, Sir Michael found that little had changed and health inequalities had in fact widened across several population groups. The CORE20PLUS5 programme has been established by the NHS to reduce health inequalities at a national and system level. Bola Owolabi, Director of Health Inequalities at NHS England, describes how clinical leadership is a key aim of this initiative: "The challenge isn't new. Health inequalities have been around for decades, and they certainly won't disappear overnight. As clinicians, the impact of health inequalities on the communities we serve is something we will see throughout our careers. We need health and care leaders to be mindful of the challenge – and the opportunity they have to make a difference" The NHS Race and Health Observatory has just this week published its report on racially-based health inequalities, showing that "Ethnic inequalities in health outcomes are evident at every stage throughout the life course, from birth to death," says the review, the largest of its kind. Yet despite "clear", "convincing" and "persistent" evidence that ethnic minorities are being failed, and repeated pledges of action, no "significant change" has yet been made in the NHS". More specific to prostate cancer, the National Prostate Cancer Audit is looking more closely at variation in access to prostate cancer treatment with a focus on the experience of black and ethnic minority groups. Its approach is to prioritise clinical research around higher risk populations and to target these groups in recruitment for trials, and to work more closely with local support groups to gain

deeper insights into the experience of black men with the NHS. Black men who have experienced prostate cancer are also stepping up to the plate with new approaches to engaging men in the black community around their health. One notable example is Errol McKellar, who is building a community of activists by pulling together men who have or have had prostate cancer with health practitioners, community activists and public health specialists. Errol, a former football player/coach/scout from east London, was diagnosed with prostate cancer and his experience led him to establish the Errol McKellar Foundation. Errol and his foundation aim to make prostate cancer screening more available and accessible to all men across the UK, and he is working to develop a system of mobile PSA testing services that can reach men in their workplace, community, sports and leisure facility and neighbourhood. He talks candidly about his experience in our recent podcast and in a recent Men's Health interview. You can learn more by visiting the foundation website and following its activities on twitter and facebook.

Blank 2 Blank Page (2) blank HIFU Prostate Cancer, New Evidence: cancer control without side effects A new study shows HIFU has good cancer control 15 years after treatment A study of nearly 1400 men receiving HIFU prostate treatment over 15 years was published last week in the journal European Urology. The study, led by Professor Hashim Ahmed of Imperial College London, aimed to report oncological outcomes and adverse events following focal high-intensity focused ultrasound (HIFU) for treating nonmetastatic prostate cancer. It demonstrated that "Focal HIFU in carefully selected patients with clinically significant prostate cancer, with six and three of ten patients having, respectively, intermediate- and high-risk cancer, has a good cancer control in the medium term, 8 years" The importance of this research cannot be understated, as building a strong evidence base is crucial to adoption of HIFU to treat prostate cancer as an alternative to more invasive and radical treatments. Dr Mark Porter, practicing GP and medical commentator for the Times and the BBC, opened his weekly Times column today with the comment: "If I needed prostate cancer treatment, I would want HIFU" He comments further: "If I were diagnosed with prostate cancer and were one of the 8,000 to 10,000 men a year that Ahmed believes may be suitable for HIFU, I would certainly ask for the treatment. It is becoming more available on the NHS, with at least three more UK centres thought to be considering adopting it this year, but most men who are eligible still won't be offered HIFU prostate cancer treatment anytime soon (unless they opt to go privately)" And goes on to say: "This new study can only help to improve adoption — and access — but there are other hurdles too. If your department runs a specialist radiotherapy service (the most common treatment), or has just invested in new, very expensive equipment to perform robotic prostatectomies, it has a vested interest in carrying on and developing present services." Tim Dudderidge, Consultant Urologist with University Hospital NHS Trust and the Focal Therapy Clinic, is a Clinical Champion for Prostate Cancer UK and a contributor to the study. We have known through our patients that men having HIFU have a very good experience generally. It's very reassuring to see that the cancer cure rates for the types of men we treat are good. Those who develop recurrence can nearly all be treated with other curative procedures such as re-ablation, surgery or radiotherapy. What is totally clear is that all men with newly diagnosed prostate cancer should be told whether or not they are potential focal therapy candidates. If they are they need appropriate counselling and access to a range of treatments including HIFU And cryotherapy. This will require a nationwide approach to training and up-skilling of prostate surgeons across the UK". Another modality which is extending the possibilities for Focal Therapy is the NanoKnife as a compliment to the HIFU Therapy. Prostate Cancer Diagnosis the Precision Imaging revolution continues Prostate imaging: the diagnostic revolution continues A conversation with Oliver Hulson Oliver Hulson, Consultant Radiologist at Leeds NHS Trust and Clinical Champion for Prostate Cancer UK joins OnFocus today to discuss the critical importance of radiology in the diagnosis and treatment of prostate cancer, and what he's doing to both advance imaging effectiveness and instill these advances in clinical practice. Clare Delmar Hello and welcome to on focus brought to you by the focal therapy clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer among men in the UK, and with this somber fact comes a multitude of challenges and opportunities. As we move into 2022, I'm going to be diving deeper into some of the more challenging issues faced by both patients and clinicians, including technology, clinical adoption of innovation, inequalities and nonclinical aspects of prostate cancer. Today, I'm joined by Olly Hulson, consultant radiologist at Leeds NHS Trust and clinical champion for Prostate Cancer UK. He's here to discuss the critical importance of radiology in the diagnosis and treatment of prostate cancer and what he's doing to both advance imaging effectiveness and instill these advances in clinical practice. Well, I have such an interest in imaging, and I see this as an area that's probably had some of the greatest advance in the last ten, five, even the last couple of

years. But before we do that, and or maybe a nice segue into that is maybe you could just share with us a little bit about you and you I know you trained as a radiologist. Well, I think I've always had an interest in men's health as a man who likes to stay healthy. And I was training in radiology at a time when multi parametric prostate MRI was gaining traction in the diagnosis and treatment of men with prostate cancer. I've been a consultant for just over five years, and even in this relatively short space of time, there've been further significant developments in the area. As you know, pre biopsy MRI is now become firmly embedded in the patient pathway for suspected prostate cancer within NICE guidance and as a significant role in the management of patients on active surveillance. So I'm excited to see what developments the next five years have in store of my career. Clare Delmar OK, well, indeed. So maybe you could talk a little bit more about how you see the development and perhaps even more importantly, the acceptance of multiple parametric MRI impacting the diagnosis and treatment of prostate cancer in this country. Olly Hulson I think that's a really good question. We've already seen the effects pre biopsy, multiple parametric prostate MRI has on patients with suspected prostate cancer. We know from good quality research that it's highly accurate in detecting clinically significant prostate cancer, and around 90% of these cancers can be picked up on MRI and perhaps almost as important, we know that in the case of men with a reassuring PSA level with a reassuring DRE that a physical examination of the prostate and a reassuring MRI scan, we can safely exclude clinically significant prostate cancer in these men, such that these men can safely avoid a biopsy and be followed up with a PSA test or a further MRI if needed. As I said previously, multi parametric prostate MRI is well-established in the management of men on active surveillance and again from good quality research we know that there's no contraindication to continued surveillance for these men if their PSA is reassuring and the MRI is reassuring also, so we can safely follow these men with serial MRI scans and avoiding either repeat biopsies and also disadvantages of progressing to treatments as well. I think in the future, there'll be further advances relating to artificial intelligence in the interpretation of prostate MRI. And I know there's a number of companies making exciting developments in this arena, so it will be fantastic to see these developments come to the market. I think these artificial intelligence software solutions are being utilised in the detection of cancer on MRI, but also to assist us with treatment planning, tumour surveillance in the active surveillance program and also decision making as well. Clare Delmar Mm-Hmm. OK. Well, I mean, that kind of introduces a something I wanted to talk about, which might be a little bit controversial, and that's this sort of so-called shortage of radiologists generally in this country. And then I expect even more so within the specialism that you're practicing in, uro-radiology. And obviously, that would be one driver of some of the artificial intelligence solutions you were just describing. But before we do, I'd like to just hit on this point about sort of not just the productivity of a radiologist, but I guess the variability of how radiologists read prostate MRI scans. So why don't I just throw out a hypothesis that a limiting factor in realising the full impact of multi parametric MRI in diagnosing prostate cancer is that there is this variation in the quality of reporting across hospitals. And if so, how do you see this challenge could be addressed? Olly Hulson I think it's a really good point, but I'm not sure that I agree. In professional forums the last few years about whether we should be certifying radiologists as being accredited in the interpretation of prostate MRI. And I agree that whilst we need to maintain standards in reporting and this is the best thing for the patient. One, as you've alluded to, we don't have enough radiologists currently to report the imaging that we undertake. And I think taking an approach of accreditation may deter others from taking on this work, and it may also deter trainees from embarking on a career in prostate MRI and uro-radiology thinking, actually, if I need to become accredited, this is another hurdle I need to get through an already packed training program. I think probably a better approach would be to develop kind of regional imaging networks and regional imaging collaboratives where colleagues can discuss cases, share cases, look at difficult cases together and learn from one another. So that's the protocols that we set up on the MRI scanners to get the best imaging as possible out of the machines. And I think arguably this would have a significant improvement on the quality of reporting by osmosis, really, if we're kind of learning from one another and learning from the best rather than looking at accreditation. Clare Delmar And sharing those interpretations? Olly Hulson Exactly. Clare Delmar Is that what you're doing with Prostate Cancer UK? So I mentioned in my introduction that you were recently appointed a prostate cancer UK clinical champion. Is this the kind of work you're doing in that regard? Olly Hulson I have been in the past actually, and I've been working with them looking at the adoption of MRI across the country. I think in my role as a radiologist in Leeds, I perform a lot of prostate biopsies, and when I'm talking to these men, when they come in for the biopsy as part of my initial patter with them, I ask them how they've come to this point. I was hearing with kind of relatively alarming frequency, the same thing over and over again

from these men that they'd been to their GP or they'd been to the, you know, the nurse at their GP practice to ask for a PSA test, either because they had symptoms or not uncommonly, because, you know, a friend at the golf club had been diagnosed with prostate cancer or someone down the pub had been diagnosed with prostate cancer and they thought, Well, maybe I should get my PSA checked. And then when they go to their GP, the GP says, Oh, well, maybe if you've got no symptoms, we shouldn't be doing this or the risks of a biopsy and the risk of you getting significant infection after a TRUSS biopsy, or there's a risk of over-diagnosis which... and I hate that term because you can't over diagnose cancer, you can over treat cancer. So as part of my program with Prostate Cancer UK for their clinical champions, I'm trying to educate and empower GPs and nurses in primary care about the significant advances and developments we've made relating to prostate MRI and also trans perineal biopsy and kind of getting across to them the message that maybe the scales have tipped in favour of PSA testing now, and we're not where we were ten or 15 years ago, where we were picking up more insignificant cancers and we were causing infections from TRUSS biopsy. Now we've got pre biopsy MRI so we can safely avoid biopsy in some men and so in Leeds, around 30% of men won't have a biopsy on their initial kind of journey down the pathway. And also with trans perineal biopsy, as you know, the risk of infection is significantly reduced. So my work with Prostate Cancer UK is more about kind of getting that message across to GPs. Clare Delmar And so what are you finding? And although she's on board with what I'm doing and she's very supportive, she's coming at it from a general practice point of view, and they have so much work on their plate, as you'll see in the press. General practice is getting hammered as is the whole of the health service currently, but those guys are right at the front and the message often comes back from general practice is well - Why does prostate cancer matter? Maybe that's a good thing to do, rather than saying, you know, this isn't for you, because that could be that man's only visit to the GP in ten years. That's your one chance to pick up the cancer, I guess. Clare Delmar So how is that being received? Olly Hulson Pretty good, actually. I've been doing some kind of online education stuff and just trying to keep it really open, so an open forum for discussion. And I've been wanting to hear back from GPs as well about their thoughts rather than me kind of pointing the finger and saying, You're doing this all wrong. So far, they've been really supportive, actually, and I'm hoping this will pan out to more men being referred and we pick up more significant cancers. Clare Delmar I mean, just the radiology element actually help in your argument and that what you're saying is that, look, if I can get you to undertake more PSA tests for men now that we have this, this new intervention, we could actually catch more cancers. And I think the message that not all men embark on the pathway are going to end up with the biopsy, they're going to end up with a prostatectomy. The fact that if we do find anything on the MRI scan yet you can say you need a biopsy, but we'll give you the best biopsy first of all, that's a transperineal biopsy. And clearly at the moment, maybe there's an argument that we do over-treat, but we're asking that question more often. So I think that's just the message I'm trying to get across, really. Clare Delmar And, you know, back to the radiology element. I mean, for most of these practices, if they concede to your request and say, Yeah, yeah, you're doing a great job, yeah, we're going to try to do more PSA tests. Can they also guarantee that their patients will be able to get an MRI should that be required? Olly Hulson Yeah, I think we're very lucky in Leeds that we've got fantastic access to MRI and also, as you said, the radiologists to report it. But again, I think Prostate Cancer UK and NHS England are making headway with that, such that pre biopsy MRI, for the most part, is the standard of care now. Clare Delmar And you think back to what you said earlier that some of these some may be diagnostic centres, I don't think used that term, but would actually help in reducing any kind of variation and give more men access to the pathway? Olly Hulson Yeah, yeah, these kind of imaging collaboratives and working together. I mean, are you also finding I mean, I'm presuming that your work isn't concentrated in any one particular area. And I guess my question is in terms of observing other things, what are you observing in terms of different populations? I mean, one of the things we keep hearing about coming out of the pandemic is how these health inequalities across the country, you know, across all kinds of disease areas and all kinds of populations have become even more pronounced. And I think before I embarked upon this project, I don't think that had appreciated the health inequality within prostate cancer, really. So if we consider, you know, the average man walking down the street, his risk of prostate cancer in his lifetime is one in eight, whereas for a black man, that's one in four. Interestingly, they're at reduced risk of prostate cancer compared to the general population. But that doesn't really reflect the true picture because we know that men that move from Asia or the Indian subcontinent, for example, once they move to the UK and adopt the more Western lifestyle, their risk of prostate cancer increases as well. So there's clearly environmental factors we're not aware of such that, you know, people saying, well, actually it doesn't apply to us, and that's not the

case. And also, it's a double edged sword, particularly with black and ethnic minority groups, because we know that our current health interventions aren't particularly great at targeting these groups of patients. And I know that in my own practice, I've probably done over 200 biopsies in the last twelve months, but I can probably count on two hands the amount of black and minority ethnic patients I've biopsied. And that's not to say, you know, as you'll be aware, Leeds is a hugely multicultural, diverse city. And so that's something I want to develop further over the next few months really, about how we how we target these groups and how we get the message to the to the men that need it most really.

Clare Delmar Really important, and my first podcast of this year was with a extremely inspirational man called Errol McKellar, who has set up a foundation to bring mobile PSA screening to minority populations. And I think there there are a number of people who are really trying to implement what you've described, so hopefully this can be implemented.

Olly Hulson Yeah, definitely.

Clare Delmar Super important. So what you're doing is absolutely fascinating, and the other thing I'm picking up is, quite impressed with the fact that as a radiologist who isn't diagnosing clinician per se.

Correct? Olly Hulson Yep, yep.

Clare Delmar You know that you have such a level of a) concern and b) engagement with patients. And so far in our conversation, I think we've been talking at a kind of a sort of a higher level, population level. But what I'm really interested in is, you know, since a lot of people listening to this would be prospective patients or current patients, what would you like to say to men who are patients or could be patients or who have friends who are patients that they need to know about the radiology that underpins their diagnosis and ultimately their treatment? How can patients be better informed about the kind of work you're doing and its importance?

Olly Hulson Yeah. So what I would say is the message I want to go out there to to all men over 50 is that you're entitled to a PSA test. So if you go to your GP or the nurse at the practice and you're over 50, you don't need to have symptoms. If you have a family history of prostate cancer, so be that your dad or your brother or even a family history of breast cancer. So if your mother's had breast cancer or sisters have breast cancer, then we advise that you have a PSA test over 45. And if your GP or the nurse says you know this isn't for you, then ask why and have that conversation with them. And if you do have a raised PSA, this doesn't mean you're going to end up with a biopsy at the end of that, it doesn't mean you could end up with a prostatectomy and your prostate is going to end up in a bucket. But as I've said previously, now that we have access to fantastic quality MRI imaging, we have access to the best biopsy and in a trans parietal biopsy at the first visit. We know that we can provide you with the best possible care and we can pick up the cancers that matter, and we can keep an eye on the cancers that we consider to be lower risk of causing any harm.

Clare Delmar Olly, thank you so much for joining me today. This has been really interesting and I think of enormous benefit to to our listeners, so thanks once again.

Olly Hulson Thanks so much, Clare.

Clare Delmar A transcript of this interview and links to all of his work for Prostate Cancer UK are available in the program notes on our website, along with further information on diagnostics and treatments for prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Patient Advocacy – a critical asset for men on the prostate cancer journey

The role of Patient Advocate at the Focal Therapy Clinic

The pandemic has made all of us appreciate the challenges of managing our health amidst the fear, uncertainty and doubt generated by multiple and conflicting sources of information. Making decisions on our healthcare when faced with what at times seemed like either too much or too little information became overwhelming and stressful for many of us, and often led to avoidance of care or inappropriate treatment. For most of us, the challenges facing our everyday healthcare needs are easing or at least becoming more manageable, but for cancer patients this is often not the case. Backlogs have led to waits for diagnosis and treatment, and in many areas services have been severely constrained. Not surprisingly this leads to increased levels of anxiety amongst cancer patients, which impedes decision-making and reduces quality of life. Prostate cancer patients have been no exception, and are likely to have suffered disproportionately as a community given that prostate cancer referrals showed the largest fall in referrals of all cancer types during the lockdowns. Many have been left feeling detached from their healthcare provider and confused over their diagnosis and treatment. The need for patient advocacy in this community is real, as men who would find navigating their prostate cancer diagnosis and treatment decisions challenging at the best of times are struggling to cope. Research has shown the benefits attributed to men who have sought support in their care through patient advocacy groups and other resources. The vast majority of patients who approach us at the Focal Therapy Clinic do so for a second opinion, following experience with or advice to proceed with treatments that lead to fear, uncertainty and doubt in their lives. Our patient advocate team have spoken with hundreds of men over the last two years, and have developed a comprehensive picture of what is happening to men who are diagnosed with early-stage prostate

cancer across the country and how to reduce, and sometimes eliminate, the FUD underlying their treatment decisions. The patient advocate is the first port of call at our clinic, providing prospective patients with balanced information on diagnosis and treatment options, empathy and support for the journey they are undertaking, a pathway to a second opinion with a world-class clinical team. Patient advocacy is a core element of our entire approach, from initial engagement through to MDT and treatment. Brian Lynch, lead patient advocate at the Focal Therapy Clinic says; "It is a privilege to support men after they have received life-changing and often quite frightening news. We provide them, if they choose, a pathway to a second opinion with a world-class urology team, which is entirely focused on their individual needs and situation." Patient Advocate Eva Tomopoulou values the critical learning that her advocacy work supports, which continually improves and refines her work: "the advocacy work we do at The Focal Therapy Clinic is really important as it allows us to learn every day from different patients' experiences navigating their diagnosis and decisions about treatment. We speak to patients who come to us without knowing what their diagnosis means, or simply what questions to ask their doctors next time they see them. In the time we have with them, we try to make them feel that they can make decisions for their treatment from a position of agency. That means not just knowing all their available options but also understanding what avenue of treatment would make more sense for themselves and their lives. I have seen a lot of patients feeling much more certain about how to move on after they have been in touch with us. We're looking for people who have had experience with prostate cancer, either directly or indirectly, and are passionate about helping others in their journey. We're offering several paid and flexible positions, mainly requiring telephone engagement with follow-up emails to current and prospective patients. If you're interested or know someone else who might be, please get in touch. info@thefocaltherapyclinic.co.uk 0207 036 8870

Prostate Cancer Screening for Black Men, 1 in 4 Shifting Gears in Prostate Cancer Screening

A conversation with Errol McKellar

Joining me today is Errol McKellar, founder of the Errol McKellar Foundation which is dedicated to raising awareness of men's health and in particular prostate cancer in the black community. Errol has a legendary status in the London youth football community, having been a coach and scout for over 50 years and supporting the rise of Premiership and England players Beckham, Cole and Campbell. His car repair garage in Hoxton has also become legendary – featuring in a documentary on his community now on Amazon prime and most impactfully as an information channel to black men about their health, and it's this latter point that brings Errol to talk with me today. Errol was diagnosed with prostate cancer in 2010 and since then has dedicated himself to informing & supporting men especially those in the black community about prostate cancer and, in particular, the importance of getting screened. Errol is one of Prostate Cancer UK's main ambassadors and, along with Linford Christie, David Haye, Danny John-Jules, Viv Anderson, Chuka Umunna and Benjamin Zephaniah is fronting their Stronger Knowing More campaign, which encourages black men to get PSA tests. In 2012 Errol was chosen to be one of the Olympic torch bearers in Hackney and in 2016 his volunteer work in the community was recognised by the Prime Minister when he was presented with a Points of Light Award. In 2018 Errol set up and launched The Errol McKellar Foundation and was invited to 10 Downing Street to talk to the Prime Minister, Secretary of State for Health and the Head of NHS England about the prostate cancer awareness work his new charity will undertake. In 2018 Errol was awarded a NHS Heroes Award for his services to volunteering, and in October 2020, he was awarded an MBE for services for prostate cancer. Errol McKellar

Foundation <https://www.theerrolmckellarfoundation.com/#The>

Street <https://www.imdb.com/title/tt10999260/> Clare Delmar

Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. This is our first interview of 2022, and I want to wish all our listeners a very Happy New Year. Joining me today is Errol McKellar, founder of the Errol McKellar Foundation, which is dedicated to raising awareness of men's health and in particular, prostate cancer in the black community. Errol has a legendary status in the London youth football community, having been a coach and scout for over 50 years and supporting the rise of Premiership and England players. Featuring in a documentary on his community, now showing on Amazon Prime and most impactful as an information channel to black men about their health. Ariel was diagnosed with prostate cancer in 2010 and since then has dedicated himself to informing and supporting men, especially those in the black community, about prostate cancer and in particular, the importance of getting screened. Errol is one of Prostate Cancer UK's main ambassadors and along with Linford Christie,

David Haye, Danny John-Jules, Viv Anderson, Chuka Umunna and Benjamin Zephaniah, he's fronting their Stronger Knowing More campaign, which encourages black men to get PSA tests. In 2012, Earl was chosen to be one of the Olympic torch bearers in Hackney, and in 2016 his volunteer work in the community was recognised by the prime minister when he was presented with a Point of Lights award. And in 2018, he set up and launched the Errol McKellar Foundation, being invited, following that to ten Downing Street to talk to the Prime Minister, Secretary of State for Health and the head of NHS England about the prostate cancer awareness work his new charity will undertake. In 2018, Earl was awarded an NHS Heroes Award for his services to volunteering, and in October 2020 he was awarded an MBE Services to raising the awareness of prostate cancer. Well, that is quite a CV and we have a lot to live up to, but I'm delighted to introduce our role. Errol McKellar Thank you very much for inviting me to come and share my journey with prostate cancer and thank you for your listeners, you know, for hopefully listening to what I have to say and helping us to do something about the issues with prostate cancer. You've got a few questions that we've talked about and now we can share those with our listeners. And I think I mean, I've said a lot, but there's obviously a lot more about your background, and I think it would be really great to start by having you tell us a little bit about your experience with prostate cancer and how this is motivated you to set up the foundation. I mean, as you've said, you know my name is Errol McKellar, I'm a prostate cancer survivor and I'm the founder of the Errol McKellar Foundation. And my journey with prostate cancer started at the end of 2010, when my wife, Sharon, bless her, was complaining about my snoring. And, you know, before we go any further, snoring has nothing to do with prostate cancer, but the reason why I mention it is because a lot of times people find out about their illnesses with prostate cancer purely by accident. I said, Look, if this snoring bothers you that much, if you make an appointment with the doctor, I'll go and a warning to all men. You know, if you ever ask a woman to do something, expect her to do it because that's what will happen. I read a leaflet and decided right that I was going to go to the reception and make an appointment to come back and do this test. Well, I've got to tell you little did I ever imagine at the time that that ten minutes was going to change the rest of my life. I even remember going home that night, and the wife was cooking dinner at the time, and I turned to her and I said, Oh, by the way, while I was waiting to see the doctor about the snoring, I did a blood test for prostate cancer. Because this is fascinating about the fact that you were actually offered the test on the spot, because this is this is actually a first hurdle that a lot of men face that they can't even get the test. So I'm intrigued that a) the reason why you went to your GP, which we're going to come back to, I know about the story, but I'm also interested in the fact that, you know, you were able to get that test on the spot. Errol McKellar Well, I have learnt since that, you know, something that it's not always readily available. So I'm assuming that the time that I walked into the doctor's surgery, they were offering this test anyway, you know, so that's why when I went to make the appointment thinking that I was going to make an appointment like you always have to do in when you go to the doctors. But I'd have to go and make the appointment to come back and do the test, but what's happening was, I think that was a week when they were offering the test and they gave it to me there and then and, you know, so I had no choice of avoiding it because I said, you know, my thoughts was never to go and immediately do the test. And this is why this is why I'm saying to people, you know, if you go back to the beginning of the story where the only reason why I was at the doctors is because I was snoring. One week after that second blood test, I get a phone call and the doctor, says "Mr. McKellar. So we, you know, have given you a phone call to see if you're available to come in this morning and do the biopsy." Errol McKellar Yeah, well, you know, I said, OK and then I put the phone down and I phoned my wife and I said, You know, I've just had a phone call from the doctor. This is an interesting question that you've asked, because just before I put the phone down, I said, by the way, "what is a biopsy?" And I have to be honest, I'm very glad that that's how she explained it to me because, you know, when I had to have the biopsy, it was very difficult. But the importance of it is something that you have to have if you want to have a diagnosis of this issue. And you know, then I started to understand that something is wrong because when I had the biopsy, a week after that biopsy, that's when they called me and my wife and they sat us both down. Well, I got up and I walked out the room, I, you know, I think the conversation went right over my head at that time. I went and I sat in my car and, you know what, to this day, I don't know whether I was scared or frightened or both. I didn't know what to do next because all through my life, I've always been able to understand what I need to do next. What's you know, what I have to do moving on and things that are important and how I deal with them? I think the word cancer hit me in such a way that it left me speechless and think-less, if that makes sense. And you know, it's interesting because and this is why it's very, very important for men to talk to their nearest and dearest right and particularly the women in your life because they end up

becoming your carers and your supporters."Look," she said, "in all the years I've been with you, I've never seen you quit on anything you've ever done."So I had to wipe the tears from my eyes and I had to man up and I looked at her and I thought, You know, is this her way of having a go at me or is this her way of motivating me to get up and do something about this problem?And you know, we came out of the vehicle, went into the building and we sat down with the doctor and I said, Doctor, what do I need to do to deal with this problem?And the doctor looked at me and he said, Mr. McKellar, if we don't remove your prostate, you could be dead in six months.And I looked at him and I said, Doctor If that's what I need to do to keep myself alive, then let's do it.But by then, the cancer had already started to move, so it had already travelled outside of the the cancer wall, as we call it.Burn away the rest of that cancer, which was very difficult, but I had no choice because of the issues of the cancer starting to travel.You know, I was out of work for nearly six months, and I remember sitting down with the wife and saying, Look, you know, I think that I have to thank God for for all of this right, for me still being alive and still being lucky.And I feel that I am lucky because, you know, if my cancer was as bad as what they're telling me, the fact that I'm still here, I have to thank God for that.And you know, my wife turned to me and she said a very, very inspirational statement, which I take with me every day.But I think what you're going to try and do if I know you, you'll take everybody in the ring with you and give yourself a chance of winning on points."And every day I look at that statement and every day when I wake up, that's the statement I wake up with, right?And after being out of work for six months, I went back to work in a garage I used to own in the east end of London in Hackney.And I remember having this conversation with the customer that came in, you know, the first day I was back and you know, he was telling me how pleased he was.You know, he heard what I was going for and pleased that, you know, I'm back at work and you know how I'm feeling generally and during the conversation, a pleasant conversation.But I looked and I said to him, When was the last time you had your prostate checked and the present conversation stopped and he looked at me.So I turned to him again without thinking about it, and I said, I'll tell you what I said, I'm going to give you a 20% discount on the work I'm going to do on your car if by the time you come back to pick up your car, you get your prostate checked.Errol McKellar And you know, I clearly didn't think this one through when I said it to him because two weeks later, when he came back to pick up his car, you know, he turned to me and he said, I took your advice and he was waving a paper in his hand, and I looked at him and I looked up to the sky and I said, Jesus Christ, this is just cost me 200 quid.And I think he saw the look on my face and he turned to me and he said to me, Listen, he said, You know, I'm not worried about the money, he said.And even to this day, I remember the shock when I opened that letter and I read the letter when I read the letter.The ones that came in and told me so you know, this became for me something that I felt I needed to do.And you know, and what was frightening about it is there is over 47,000 men a year that are diagnosed with this particular problem.Errol McKellar There is over 11,000 men that die of prostate cancer in this country every year.Errol McKellar It's currently one in twelve Asian men who die of prostate cancer is currently one in eight white men who die of prostate cancer.More frighteningly, it's currently one in four African Caribbean men who die of prostate cancer.Can I ask you about the key messages you want to get out to to these men and their families, and particularly these men, particularly black men, where the burden is one in four, as you've just cited.And so how do you shape that message to them about being a) aware b) concerned and c) willing to do something about it?Errol McKellar Well, you know, you know, what I've tried to do is is you have to put this message over with some some seriousness, but with an element of of ease so that you can people can digest it, you know, because if you give them too much fear, right, The two biggest problems that I find in getting this message across is the fear and the ignorance.The fear, because once they are told about prostate cancer, the fear is to to eliminate it and hope that it doesn't happen to you.And the ignorance is if it does unfortunately happen to you, you choose to do nothing about it and hope it's going to go away and those two elements.Each race has to understand that the seriousness of this is if it's caught early, we have almost 100% success rate in coming out the other side.So in terms of the what they can do about it, I believe and you've just mentioned about the PSA test, I believe that one of your main implementation driven missions is to make the PSA test more available and accessible to men in your community.And you know, the reason why is because the demographics of everything now is almost mobile as we speak.I would like to have a PSA test done every single year because you know what I'm saying to somebody is early detection is very, very important.Now, would you drive your car with no brakes and wait until you've knocked somebody over before you do something about it?If you have a PSA now and something flags up, it's easier to deal with it than leave it for a year for it to fester longer and the problems become more serious than it was a year ago.Clare Delmar I wanted to ask you about that because as you well know,

the test itself is not without its detractors. And so, so how are you addressing this in both the design and the implementation of this testing service you want to do.

Errol McKellar What we're saying is that currently what we are offering has a 98% success rate. But in the meantime, we can't have people dying through fear and ignorance because they choose to do nothing about it. How do you make something 100%, as you say, is it a question of you're not going to redesign the blood test? It's important that people are involved in the research because it's the research and the testing that's going to improve the end result, right? You know, twelve years ago when I had my test done and I had my operation, you know, I've spent the last five years involved in the research work, and the research work is far, far more than it was when it was done before. But people, you know, as brilliant as all that work is, if people are not aware of it, they will still have this attitude that, you know, I don't want anything put up my rear end, you know, I don't want, you know, the word biopsy puts people off. But what I say to men when I have this conversation, I said, If you think that that's difficult, ask a woman what she has to go through when she has to have her bits and pieces done right. You know, on a regular basis, you know, they have to deal with things that we as men become very squeamish about. But in its more important content that, you know, prostate is something that needs a lot more research and a lot more education. You know, the education is key because, you know, at this moment, I'm dealing with 14, 15, 16 year olds who don't even know where their prostates are. We have to go into schools to educate because if we got boys of 14, 15, 16, I don't know where their prostate is. There will only be at the beginning of that journey, you know, where it is at the moment will have ladies who are learning about periods and understanding more. Young men still don't know the issues with prostate cancer, and one of the things that I'm worried about is, you know, you know, there's a community that, you know, if there's an excuse for not doing the tests, then they're not doing the test, right? And when they go to their doctors, what we want the doctor to do is to do the test on them, encourage them to do so because we don't have an alternative. There is nothing, you know, the only blood test that we have available for test in prostate cancer is the PSA test. Well, and again, as you say, I mean, it gets better if that's even a reasonable term, when you add on the other diagnostic bits. But I want to come back to something you just said, which I'm particularly interested in and you've mentioned quite a lot of things and I just want to link up, you mentioned about COVID and some of the things we've learnt, you mentioned about sort of, you know, boys not knowing about their own anatomy and managing that. But I guess, you know, COVID has revealed so many health inequalities, even that term is something that I think more and more people are familiar with. And you know, one of the things about prostate cancer is there's always been health inequalities in diagnosis and treatment because, you know, as you say, one in four people in the black community are diagnosed, where one in eight people in the non-black community are diagnosed. And I guess one of the questions I have for you is why do you think this persists and what are your observations? The reason why I personally feel that this is in existence is because men in general and particularly African Caribbean men are diagnosed late. If this test is made available, then there shouldn't be a reason for you to be diagnosed late for this. You know, the one thing that everybody's agreed on, whether they agree or disagree, the one thing they agree on is early detection is key. So early detection has to be presented almost like a plate of food that you look at anything, you know what, I need to have some of that food. And, you know, listen, what men have got, we can learn a lot from the women in our lives, right? Because you ladies were proactive in getting your bits and pieces done and getting it sanctioned and authorised right by protesting, lobbying, marching, creating information to say, Look, we need to have some kind of literature to say we are supposed to have this test done at this particular point. That's a simple piece of education, you know, because look, the women have already lobbied to get periods in school. We want to create an annual yearly tests for the PSA and the reason...

Clare Delmar At what age are you? And you know, if anything else, for boys to understand what their fathers and their grandfathers might be dealing with. I mean, at the moment, it's 50 that, so you don't get a letter, you just get a recommend that when you get to 50, you should have a PSA test right now. Well, I you know, I've had two people in those 48 people that have died of prostate cancer. If you're African Caribbean descent or you have a history of it in your family, it should be 45. So at this moment, we're saying 40 should be the point of where it should be done, but equally because of the seriousness of this, particularly in the African Caribbean community. Let's not dismiss it as because what we're saying is, is that if they're not aware of at 14, 15 and 16, you push on ten years right to it at 25 years of age, right? If there's a history of it in your family, you know, we have got evidence that, you know, we've got somebody of 36 that's died of it. We have had other people of information that have had people of 27, 28 that have died of it. So what we're saying is, look, it's clearly an issue in the African Caribbean community that goes without saying, so let's not let's not go down this ritual of, oh, well, if it

was one in four white men, it would be a different conversation. All men because, you know, as I said in this conversation, prostate, don't care about your colour. Clare Delmar OK, so I want to move on to how you're proposing, you know, specifically, I want to get into the real nitty gritty because we don't have too much time left and just have you tell us quickly. And maybe I think as I'm hearing myself say this and thinking, probably want to do a follow up because you've got so much to say, but you are proposing, as I understand it, to introduce a mobile PSA service. What we're saying is our research tells us that there's a lot of men who are still having an excuse not to go to their doctors. They're definitely not happy to go to the hospital because they are worried about what's going on at the moment, so they would rather not go to the hospital. So, you know, for me, those are the two elements that affected those 15 people through fear and ignorance. They chose to do something or chose not to do something or did something when it was too late. So I guess it's kind of like, if you know, if the mountain doesn't come to Mohammed, Mohammed will go to the mountain? And we believe that the mobile PSA testing vehicle with the equipment that we want to put on this vehicle that, as we say, will give up to a 98% success rate in the results. We are confident that we can take the pressure off NHS and the doctors by doing up to 20,000 tests or more per year with this equipment and a mobile system that we're talking about by taking it around. Particularly in the communities, and we're capable of going into the places where the so-called masses don't go. Clare Delmar OK. Errol McKellar We will go into these estates, we will go into the community places and you know, we have the resources and we have the people who can help to make this work. You know, we have a majority of the football grounds around the country that want us to bring the mobile testing vehicle to the football grounds on a match day where the audience base there is at least 75% men. We have the system right where, you know, we are going to treat the whole thing like a traffic light system. It's amber for surveillance and monitoring and red for immediate attention, right where we will bring, you know, a consultant to the table, we will do a care of duty. And what is important is that we are also going to create a data with all of this information so that we can help with a better understanding as to why men, right, are at higher risk, right with prostate cancer, because we'll be able to ask the direct questions, we'll be able to look at it and say, Look, this is what's happening to a black man. And no disrespect to the the authorities like the NHS, but we feel that, you know, they've got a document that is not going to be not going to be reviewed again until 2024. And that's not even including this year's total before we address the situation again, that can't be acceptable in any shape or form. I mean, you know, not only are you trying to do something that's immediately implementable and you've sourced technology, you've sourced expertise. You've got the channels, you know, you've got a vision about building up a data set that can be used for, you know, future benefit. And I look forward to picking up with you maybe, maybe later in the year to see, see, you know where you're going. There's so many ways of looking at this, but I think what you're doing is just an incredible service, and I want to thank you so much for coming and telling us about it today. Errol McKellar Listen, if you have anyone out there that wants to come on board and help because what we're doing and what we're trying to do, we need help. And and you know, they can get in touch with TheErrolMcKellarFoundation.com to tell us if they one want to sponsor or support or, you know, but this is going to happen. Clare Delmar Well, I commend you and I wish you all the best, and I want to thank you once again for joining us today. Clare Delmar OK. A transcript of this interview and links to the Errol McKellar Foundation are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Prostate Cancer Recovery, Tougher than expected Many of our patients tell us about family members, friends and colleagues who have undergone prostate cancer treatment have experienced regret in their treatment choice. This is often a key driver in seeking a second opinion on their own prostate cancer management, and in their enquiries about focal therapy. When we discuss "decision regret" it has often been on a very personal and often anecdotal level. But some recent studies on the specifics of decision regret following treatment for prostate cancer shed new light on the discussion by providing evidence on patient experience in the medium and longer term post-treatment. A study conducted at Harvard Medical School on treatment regret amongst prostate cancer patients was published at the end of last year. Its approach was led by evidence of an association between treatment-associated regret and poorer mental health and health-related quality of life in men with prostate cancer. Highly relevant to our patients was its focus on men with localised prostate cancer, and it investigated levels of treatment regret amongst a population-based cohort of 2072 patients with prostate cancer. It found that treatment-related regret is common among patients with localized prostate cancer, and rates appear to differ among treatment approaches "in a manner that is associated with

functional outcomes and patient expectations". While the Harvard study investigated men at 5 years post-treatment, a 2017 study investigated regret amongst long term survivors of localised prostate cancer. It evaluated men who were aged less than 75 years when diagnosed with localised prostate cancer between October 1994 and October 1995 in one of six American tumour registries and who completed a 15-year follow-up survey. The survey obtained demographic, socioeconomic, and clinical data and measured treatment decision regret, informed decision making, general- and disease-specific quality of life, health worry, prostate-specific antigen (PSA) concern, and outlook on life. It used multivariable logistic regression analyses to identify factors associated with regret. Factors associated with regret on multivariable analysis included reporting moderate or big problems with sexual function, moderate or big problems with urinary and bowel function, and PSA concern. Increasing age at diagnosis and report of having made an informed treatment decision were inversely associated with regret. It concluded that: "Lack of informed decision making was highly associated with regret, regardless of whether the patient reported being cancer free. Because treatment decisions for localised prostate cancer are preference sensitive, men should be made aware of treatment options, their respective risks and benefits, and be engaged with their providers in making value-concordant decisions. Not surprisingly, studies have shown that being unprepared for prostate treatment complications and their adverse effect on quality of life may lead to more regret. This is particularly noteworthy given the high proportion of men who are diagnosed with low-risk disease for whom active surveillance is now considered an appropriate option given concerns about overtreatment. Encouragingly, it addressed perceived overtreatment as a source of regret: "Regret expressed by our participants, who were surveyed in 2010, could reflect awareness of these recommendations. In this context, men who had no treatment complications or cancer recurrence might express regret if they came to realize that their treatment was unnecessary. Studies have also shown that men with passive roles in decision making had more decision regret than those with more active roles. Finally, a 2021 study of treatment regret following focal therapy showed that focal therapy is well accepted by patients. Over 80% of patients in the study reported that they would make the same choice if necessary again, and less than 10% regretted their decision to undergo focal therapy. The experience of our patients supports much of the research findings about decision regret in prostate cancer treatment. The majority of our patients come to us for a second opinion following initial consultations, diagnostics and treatment recommendations for their prostate cancer. They are well informed, open-minded and motivated to optimise their treatment whilst avoiding side effects that will negatively impact their sexual, mental and urinary health and enable a smooth recovery. As these studies show, treatment regret is reduced significantly if not eliminated when patients are informed and engaged. And while there are many, many resources available to provide both information and engagement on managing a prostate cancer diagnosis, many men encounter fear, anxiety and doubt when faced with these choices. This is something that we aim to continually address as we reach out to individuals and communities across the country to inform them of the options they have in treating localised prostate cancer. 2021 Covid Pandemic and Prostate Cancer Like its predecessor, the second year of the Covid pandemic brought new challenges and opportunities to patients and staff at The Focal Therapy Clinic. Cancellations of diagnostic and treatment procedures in the NHS continued to build throughout the year, and in a very uneven pattern across the country. This became a dominant theme amongst conversations with our patients, and for some it had a profound impact on the course of their treatment and recovery. Several of our patients also spoke openly about this, with Michael Anthony expressing his gratitude to the pandemic for causing the cancellation of his prostatectomy and his subsequent treatment with focal therapy. We spoke with cancer specialists such as Prof Gordon Wishart about the backlog in cancer diagnostics and treatment within the NHS and discussed its impact with our own consulting Urology team about how they saw the backlog impacting their work and their patients' health. TFTC Consulting Urologist and Andrologist Raj Nigam was particularly concerned with the number of men coming to him who had been prescribed hormone therapy while waiting for other treatments, and were encountering the side effects of that, something reinforced by patient advocate and educator Andrew Gabriel, who saw many men in his support groups struggling with exactly this situation. On a more positive note, the past year saw more evidence on the benefits of focal therapy coming to light. Early in the year a groundbreaking study was published which compared oncological outcomes of focal therapy and radical prostatectomy in over 800 men, and concluded that "In patients with non-metastatic low- intermediate prostate cancer, oncological outcomes over 8 years were similar between focal therapy and radical prostatectomy." This was particularly noteworthy at a time when the gold-standard RCT was difficult if not impossible to undertake, and researchers looked to alternative

methods to conducting robust studies. In addition to the aforementioned study on focal therapy v prostatectomy, a study using this data source assessed the change in functional outcomes after a second focal HIFU treatment compared with outcomes after one focal HIFU treatment, and concluded that a second focal HIFU procedure causes minor detrimental effects on urinary and erectile function. These data can be used to counsel patients with non-metastatic prostate cancer prior to considering HIFU therapy. We engaged with a number of campaigners, specialists and thought leaders on the issues of sexual health, urinary & pelvic health, and mental health which are of paramount concern to our patients as they consider alternatives to treat their prostate cancer. Health Care practitioners Lorraine Grover, Jane Simpson and Asanga Fernando offer valuable experience of supporting prostate cancer patients with the side effects they encounter from their diagnosis and treatment. Campaigners Elvin Box and Tony Collier have inspired many men and their partners through their personal journeys with prostate cancer and their advocacy for change through organisations such as Movember and Prostate Cancer UK. Health inequalities have become a highly discussed challenge in the wake of Covid19 as the pandemic exposed high levels of variation in access to healthcare and health outcomes. This of course is something already familiar to us and our patients who have faced variability in information and access to treatment for prostate cancer based on their age and race for many years. We spoke with several patients from the black community about this and how it has affected the management of their prostate cancer, and note in particular our interview with former patient Marcus McKenzie, who spoke to us openly about the heightened risk of prostate cancer that Black and mixed race men face, how this impacted his personal experience and what all Black and mixed race men need to know about managing their prostate health. We've also strengthened our commitment to addressing ageism in the management of prostate cancer, and discussed this with our consultants and patients to understand the experience of older men diagnosed with prostate cancer. Conversations with clinicians like Raj Nigam, and patients like Peter Hall continue to help us understand the needs and desires of older men who are diagnosed with prostate cancer, and, most importantly, to challenge the concept of "old age". Wishing you all a very Happy Christmas and New Year.

Decision Tools provide evidence to support Prostate Cancer decisions : Marc Laniado

Joining OnFocus today is Marc Laniado, Consultant Urologist with The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a dedicated practitioner and vocal advocate for the rights of patients to be informed about their treatment choices from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital. He's here today to talk with us about how patients can be supported in understanding their diagnosis and choice of treatment through decision tools such as Predict Prostate. <https://prostate.predict.nhs.uk>

Clare Delmar Hello and welcome to OnFocus. Brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Joining me today is Marc Laniado, consultant urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a dedicated practitioner and vocal advocate for the rights of patients to be informed about their treatment choices, from his base at Frimley Health. He's here today to talk with me about how patients can be supported through decision tools. I'm really excited to hear about you empowering your patients with some of these interesting tools. It's always good to be with you. Clare Delmar Yeah, we're getting used to this now, aren't we? So, Marc, before we go into what the tools are, I just want to set the stage a little bit and ask you about this mental state that your patients are typically in when they come to you for consultation following a prostate cancer diagnosis. Marc Laniado Well, often they come to me to get the diagnosis, so they don't even have it. Obviously, as you can imagine, they're a bit anxious, sometimes very quiet, sometimes contemplative. When I start talking about the results of biopsies I usually give patients a bit of a warning shot to try and make them aware that maybe there's some serious information coming for them to understand. And then when we deliver the sad news that someone has prostate cancer, obviously, that's quite a shock to people. So even though most of them will have been coming through a diagnostic pathway where actually we're trying to work out whether prostate cancer is there or not - many men and their families are still somewhat shocked or surprised when they actually hear they do have prostate cancer. With it comes sometimes a bit of denial or disbelief or the words go through their ears, but it doesn't seem to make any sense at that point. So this is quite a difficult time for patients when they get the news. Clare Delmar I mean, one of the things I guess I was alluding to when I said about following a diagnosis is because often they come to you for a second opinion. And I guess that's one of the reasons why it's difficult to actually give this information and to have it sort of processed quickly. Marc

LaniadoSo, when I've told them and maybe they've come back a second time, but men are very obviously anxious at that point. But mostly it's hope and a gusto for trying to get something done with the least amount of potential carnage as a consequence of that treatment. Clare DelmarSo one of the things that I'm hearing a lot from a lot of our patients is that when they have received a diagnosis elsewhere, they're sort of handed a whole packet full of brochures and other things. I think when you've told me about something called a decision tool, and specifically one that you use developed here in the UK, called Predict Prostate, you've said that that can really change the process of making a decision. And traditionally, we've been, as doctors, not been able to tell people exactly how well they'll do just by no treatment, how well they'll do with treatment. So there's been some fantastic work in developing the prostate tool available on the NHS online to all people who want to go to it. That tool really empowers men when they're deciding about what sort of treatment they're going to have? So, for example, you can imagine if you're told that you've got cancer and you may have a year or two to live or something of that nature, you might say, well, I'll take whatever treatment you can give me, as drastic as it may be, to give me the maximum amount of life expectancy that's possible. But your attitude might be slightly different if it turns out that, well, actually, the chance of dying from this disease in the next ten or 15 years is actually relatively low. And so armed with that knowledge, that the disease perhaps may not be as threatening as you first thought, you might think of things or think of common treatments in a slightly different way. And you might be more willing or open to consider other options that could come up. Clare DelmarHow does it work? We use the word tool and you mentioned doing it online in some of your descriptors, but can you talk me through how you actually use this with a given patient. Marc LaniadoYeah, well it's very easy. So you need to know the patient's age, the PSA value, the Gleason score, the number of cores with cancer if you have it, the number of cores without cancer. You need to know also whether the patient has any other serious health conditions, like having had a heart attack or been in hospital in the last two years for some serious condition. But the data are readily available to most people who've recently had diagnoses of prostate cancer. So for people who don't know, tumours are graded by Gleason score or grade group with increasing severity. So Gleason score three plus four is actually grade group two, which on a scale of one to five. And most people given that diagnosis, and that information would think, well, actually, I need to rush into treatment, have treatment that's fairly soon, not realising, in fact the chance of dying; I don't have a calculator right in front of me now, but chance of dying is probably around 4% or 5% at ten years. And even if you have treatment, the impact isn't that great as much as people might think anyway. So if you take 100 men, that means of those 100 men, four might die from prostate cancer, maybe another ten or 15, maybe less, would die from some other cause. And if you have treatment, that's radical treatment, I mean, surgery, radiotherapy, it doesn't actually give you 100% cure. It still seems that about half the men who have the treatment, unfortunately still succumb to the disease. Well, if you're thinking, should I have a really radical treatment, like a surgery to remove the prostate or six weeks of radiotherapy and hormonal therapy for a disease in which you take 100 people like me, only four or five of them might die from it. And yet of those 50 men, a significant proportion might get side effects, and so the benefit to side effect ratio, many men might think, isn't that great? Isn't there a way of having some form of treatment which hopefully pertains most of the benefits yet doesn't have so much toxicity, so much side effects. And that's why people tend to actually start thinking, well, maybe focal therapy, partial ablation, maybe focal therapy is the way to go, because you can then get treatment to the tumour, yet you can avoid most of the side effects associated with treatment. Clare DelmarThat's interesting, so are you suggesting that for men that have the relatively stage two, the grade two lower Gleason scores, localised cancer, that this tool is a way to avoid over treatment. Is that a fair statement? Marc LaniadoYeah, well, lots of men when they look at those numbers say, Well, I should go onto active surveillance. I'm not saying that this is a blanket statement for every man I can describe right now should definitely have no treatment. But the main point of this is that for most men who have intermediate risk or favourable intermediate risk prostate cancer, they're not that likely to die from it, certainly not in the near term. And it's worthwhile looking at some of the other options that can be used to treat people who have prostate cancer. So if you have a small focal cancer, cancer in one part of the prostate, why not just ablate or destroy that area realistically and do that alone rather than treatment to the whole prostate? Clare DelmarAbsolutely. I guess what I'm driving at, though, is that a patient could reach that conclusion and make that choice based on a straightforward conversation with you on his own. But what I'm interested in is how the tool helps that decision. Marc LaniadoWell, it helps that decision because most patients when you tell them they've got cancer, they're going to die from it immediately. If you can show this, the good thing about the tool is it gives you great graphical ways of looking at the data. They can do their own calculations and see how

what they put in effects the outcomes. Clare Delmar That is fascinating. And something I wanted to share with you is maybe you're aware of this, but I did some digging around before having this interview, and there's actually been quite a number of studies looking at these decision tools. I mean, this is around the world, mainly in the United States as well as here in the United Kingdom, and one which I found, and for our listeners, I will put this on the programme notes. It compared these tools amongst men with localised prostate cancer, and it compared a few, and it showed that the ones that were the most simple actually led to choices of less aggressive treatment and also less treatment regret. But is that you've been your experience with Predict Prostate because that's fascinating. Marc Laniado It's definitely revealing for patients, and they certainly when they understand whether they have serious disease or not, and they can see it in terms of life expectancy relative to the cancer, but also to the other health conditions. Because what I didn't say is that if you've got a lot of other health conditions, maybe prostate cancer is low down on the list of things that might cause you, unfortunately, to die. So yes, it does make a big difference to patients, certainly helps a lot. Clare Delmar So something else that I'm just picking up from what you're saying is that patients can access this themselves. Do you find that that's as effective in terms of ultimately their choice and their treatment, or is it something that you encourage doing sort of collaboratively as it were with you? Marc Laniado Well, I do it in the clinic with my patients anyway, so I put the data in and I go through the results with them. Now it's not to say it's extremely simple, but you need some knowledge of how to go around the website, but the information is written in the way that patients can understand. So yes, I would strongly recommend that patients get their own data, go onto the website, plug it in and see the outcomes, and then use that information to decide on whether they want to have treatment, whatever treatment that is or they want to perhaps not have any treatment, but also to see that if their risk of dying is not high, then maybe consider either active surveillance or you can consider focal therapy, which will give you all the benefits of treatment without so many of the side effects. Clare Delmar So this is called Predict Prostate and it's actually online at prostate.predict.nhs.uk. I will put this on the programme notes, but that's really helpful, Marc, and often we hear clinicians tell us that when patients come to them armed with various information they've gathered online, it can serve as a double edged sword, but it sounds like in this case that's not the reality at all. It's probably one of the more useful things that people can look at when they're deciding what to do. Clare Delmar Well, on that note, I'm just going to say thank you so much for sharing that. And I think it's been really helpful to talk about this and we'll probably come back to talking about this again and maybe even using a patient example. Thanks again. Clare Delmar A transcript of this interview is available on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Thankyou for listening and from me, Clare Delmar see you next time.

A team approach to precise and personalised treatment

"In our experience up to 70% of men with organ confined prostate cancer are suitable candidates for Focal Therapy." Mr Raj Nigam, Urological Consultant at The Focal Therapy Clinic

WHO IS SUITABLE FOR FOCAL THERAPY?

The general criteria for suitability are as follows: In general, men with early to intermediate stage prostate cancer that is confined within the prostate gland, and have a Gleason score of 7 or less, and a PSA of less than 20, are likely to be suitable for Focal Therapy. However, an individual assessment is made for each patient based on a detailed review of their clinical files and their personal priorities. Beyond these initial criteria there is a need for the careful review of each patient's case to make sure the objectives of cancer control and minimal side effects can be achieved. In order to do this our consultants will review all of your clinical records, MRI images and biopsy results to make an assessment of suitability for Focal Therapy treatment, including HIFU and NanoKnife IRE. HIFU is suitable for the majority of focal therapy patients. Where the prostate gland is relatively large or the position of the tumour is located at the anterior of the prostate, NanoKnife IRE technology may be more suitable. Each case is reviewed by our multidisciplinary team to confirm suitability and to work with Dr Clare Allen to prepare a treatment plan. The decision on suitability is made on clinical grounds but also takes into consideration the values and personal priorities of the patient. Beyond these initial criteria there is a need for the careful review of each patient's case to make sure the objectives of cancer control and minimal side effects can be achieved. In order to do this our consultants will review all of your clinical records, MRI images and biopsy results to make an assessment of suitability for Focal Therapy treatment, including HIFU and NanoKnife IRE. HIFU is suitable for the majority of focal therapy patients. Where the prostate gland is relatively large or the position of the tumour is located at the anterior of the prostate, NanoKnife IRE technology may be more suitable. Each case is reviewed by our

multidisciplinary team to confirm suitability and to work with Dr Clare Allen to prepare a treatment plan. The decision on suitability is made on clinical grounds but also takes into consideration the values and personal priorities of the patient. Beyond these initial criteria there is a need for the careful review of each patient's case to make sure the objectives of cancer control and minimal side effects can be achieved. In order to do this our consultants will review all of your clinical records, MRI images and biopsy results to make an assessment of suitability for Focal Therapy treatment, including HIFU and NanoKnife IRE. HIFU is the best option for the approximately 75% of men whose prostate cancer is in the lower part of the prostate gland. NanoKnife is suitable for the 25% of men whose prostate cancer is in difficult to reach regions of the prostate gland. "High quality information (the MRI scan and report) leads to highly informed discussion (the MDT), which leads to optimal diagnostics and treatment for each patient." Mr Alan Doherty, Urological Consultant at The Focal Therapy Clinic Dr Clare Allen is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK. "As a uro-radiologist, I integrate the results of the MRI scan and biopsies to create a detailed treatment plan for each Focal Therapy patient." Dr Clare Allen, Uro-Radiologist at The Focal Therapy Clinic Dr Clare Allen is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK. "High quality information (the MRI scan and report) leads to highly informed discussion (the MDT), which leads to optimal diagnostics and treatment for each patient." Mr Alan Doherty, Urological Consultant at The Focal Therapy Clinic

PERSONALISED TREATMENT PLANS

The Focal Therapy Clinic multidisciplinary team (MDT) of urologists, oncologist and uro-radiologists work together to develop the best possible treatment plan for your prostate cancer. Our MDT meets to present, review and agree on the diagnosis and treatment options for each and every patient, taking into account a complete set of clinical and personal, patient-specific issues. MRI scanning and precision biopsy underpins Focal Therapy. Since the early 2000s, multiparametric MRI scanning has allowed us to identify the location within the prostate gland that has cancer. Precision biopsies, especially trans-perineal biopsies, mean that we can now definitively confirm which areas have cancer and which do not. With this information, personalised treatment plans can be created to ensure that the areas of clinically significant cancer are fully ablated using HIFU, with an appropriate margin to minimise any risk of recurrence. Dr Clare Allen creates detailed treatment plans incorporating the patient's MRI sequences with MIM software that allows the surgeons to confidently treat the affected area of the gland plus a small margin. "High quality information (the MRI scan and report) leads to highly informed discussion (the MDT), which leads to optimal diagnostics and treatment for each patient." Mr Alan Doherty, Urological Consultant at The Focal Therapy Clinic Dr Clare Allen is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK.

Prostate Cancer Podcast:

Interviews with patients, doctors & campaigners

On Focus – The Focal Therapy Clinic Audio Series

Download Free Info Pack

On Focus – The Focal Therapy Clinic Audio Series

Download Free Info Pack

A new audio series brought to you by The Focal Therapy Clinic, where our host, Clare Delmar, explores some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about.

New approaches to delivering Focal Therapy

April 19, 2022 Focal Therapy – a view from across the Pond

March 30, 2022 Prostate Cancer Recovery and Music Therapy

March 21, 2022 Prostate Cancer patients deserve Personalised Care.

An interview with Mr Raj Nigam: Consultant Urologist

March 3, 2022 Conversations About Prostate Cancer

Active Surveillance

Age & Longevity

Anxiety & Depression

Charities & Campaigns

Erectile Function

Ethnicity

Focal Therapy

MRI Scans

Prostate Biopsies

Prostatectomy

Surgery

PSA Testing

Radiotherapy / Hormone Recovery

After Prostate Cancer

Relationships & Partners

Research & Innovation

Testosterone Suppression

Urinary Continence

Conversations About Prostate Cancer

Conversations About Prostate Cancer

Active Surveillance

Age & Longevity

Anxiety & Depression

Charities & Campaigns

Erectile Function

Ethnicity

Focal Therapy

MRI Scans

Prostate Biopsies

Prostatectomy

Surgery

PSA Testing

Radiotherapy / Hormone Recovery

After Prostate Cancer

Relationships & Partners

Research & Innovation

Testosterone Suppression

Urinary Continence

Search

April 19, 2022

Read More

March 30, 2022

Read More

March 21, 2022

Read More

March 3, 2022

Read More

February 18, 2022

Read More

1 2 3 ... 14

Next Page »

Prostate Cancer News: Latest Updates and Information

News & Views – The Focal Therapy Clinic Blog

Download Free Info Pack

NanoKnife, enhanced patient choice and the case for prostate cancer

screening February 15, 2023 The NPCA Annual Report 2022: some questions answered, many questions raised February 1, 2023 What is Men's Health? January 17, 2023 HIFU Treatment for Prostate Cancer December 23, 2022 [knm_simple_news_posts] News & Views Active Surveillance Age & Longevity Anxiety & Depression Charities & Campaigns Erectile Function Ethnicity Focal Therapy MRI Scans Prostate Biopsies Prostatectomy Surgery PSA Testing Radiotherapy / Hormone Recovery After Prostate Cancer Relationships & Partners Research & Innovation Testosterone Suppression Urinary Continence News & Views News & Views Active Surveillance Age & Longevity Anxiety & Depression Charities & Campaigns Erectile Function Ethnicity Focal Therapy MRI Scans Prostate Biopsies Prostatectomy Surgery PSA Testing Radiotherapy / Hormone Recovery After Prostate Cancer Relationships & Partners Research & Innovation Testosterone Suppression Urinary Continence February 15, 2023 Read More February 1, 2023 Read More January 17, 2023 Read More December 23, 2022 Read More December 23, 2022 Read More 1 2 3 ... 22 Next Page » Decision Tools Supporting Treatment Selection for Early Stage Prostate Cancer How decision aids help men to be more informed and have a more active role in choosing their treatment Perhaps one of the most understated and underappreciated aspects of a prostate cancer diagnosis is the impact it has on a man's mental and emotional wellbeing. "Knocked for six" and "state of shock" are often-heard descriptors of the experience and, while each man is unique in how he receives and processes the news, all men will face mental & emotional challenges in how they embark on the next steps in the diagnostic pathway to select and prepare for treatment. For some men, these challenges are particularly onerous if their decision process is compromised by anxiety, misinformation, brain fog or all of the above. Several decision tools have been developed and tested in recent years to support men in their decision-making on treatment and to enhance the communication between doctor and patient. A Canadian study which assessed the impact of decision aids on the treatment decisions of over 31k cancer patients found that: "Decision aids reduced the proportion of undecided participants and appeared to have a positive effect on patient-clinician communication. Moreover, those exposed to a decision aid were either equally or more satisfied with their decision, the decision-making process, and/or the preparation for decision making compared to usual care." It concluded: "Compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making and more accurate risk perceptions. New for this updated is evidence indicating improved knowledge and accurate risk perceptions when decision aids are used either within or in preparation for the consultation. Further research is needed on the effects on adherence with the chosen option, cost-effectiveness, and use with lower literacy populations." A more recent study on decision tools focused on two types specifically for men choosing treatment for prostate cancer. It tested the impact of a complex medical oriented DA compared to a more simplistic decision aid designed to encourage shared decision making in men with clinically localised prostate cancer. The study demonstrated that a simple decision tool led to an increased desire for shared decision making and, significantly, for less aggressive treatment. The positive impacts of Predict Prostate Here in the UK we have a widely available decision tool to support men in choosing treatment for prostate cancer called Predict Prostate. According to David Thurtle who helped to develop the tool with the Urology Foundation: "Every patient who is diagnosed with localised prostate cancer has to make a decision about what to do next, whether to monitor the cancer carefully or to pursue upfront treatment. Providing accurate survival predictions is one of the hardest things a clinician is asked to do. As part of his research David surveyed nearly 200 prostate cancer specialists to assess perceptions around survival following prostate cancer diagnosis, and likelihoods of recommending treatment. The results demonstrated huge variations in clinician perception of long term survival, with predictions of prostate cancer death ranging from 5-95% in some clinical scenarios. Counselling patients with the best information available isn't always straight-forward, but this tool hopes to inform and standardise that process. TFTC consultant urologist Marc Laniado is a strong advocate for Predict Prostate and has seen the positive impact it has on his patients: "When a man is told he has prostate cancer, often the first things in his mind are how long have I got to live? And traditionally, we've been, as doctors, unable to tell people exactly how well they'll do just by no treatment, how well they'll do with treatment, and what are the potential side effects from the treatment that they might receive? So there's been some fantastic work in developing the prostate tool available on the NHS online to all people who want to go to it. That tool really empowers men when they're deciding about what sort of treatment they're going to have, and how much treatment they're going to tolerate." He describes how Predict Prostate helps shift the conversation with patients from the drastic to the realistic. "You can imagine if you're told that you've

got cancer and you may have a year or two to live or something of that nature, you might say, well, I'll take whatever treatment you can give me, as drastic as it may be to give me the maximum amount of life expectancy that's possible. But your attitude might be slightly different if it turns out that, well, actually, the chance of dying from this disease in the next ten or 15 years is actually relatively low. And so armed with that knowledge, that the disease perhaps may not be as threatening as you first thought, you might think of things or think of common treatments in a slightly different way. And you might be more willing or open to consider other options that could come up." A multicentre randomised control trial of the clinical impact of Predict Prostate was published in September. Its main objective was to assess the impact of the tool on patient decision-making and disease perception. It concluded: "Predict Prostate reduces decisional conflict and uncertainty, and shifts patient perception around prognosis to be more realistic. This randomised trial demonstrates that Predict Prostate can directly inform the complex decision-making process in prostate cancer and is felt to be useful by patients." Evidence increasingly shows that using an individualised risk communication tool, such as Predict Prostate, reduces patient decisional conflict and uncertainty when deciding about treatment for localised prostate cancer. Precision enables better choices

Marc Laniado, consultant urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer, joins OnFocus to discuss the concept of precision in the diagnosis and treatment of prostate cancer, why it's important and how it's achieved. Marc has been a dedicated practitioner and vocal advocate for the precision diagnostics that support focal therapy from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital and has contributed to several pivotal clinical studies and trials on prostate imaging, diagnostics and focal therapy. Marc Laniado explains why precision diagnostics are important and how they are achieved. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar Hello and welcome to OnFocus, brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer, that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this number fact comes a multitude of challenges and opportunities. Joining me today is Marc Laniado, consultant urologist at The Focal Therapy Clinic, and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a dedicated practitioner and vocal advocate for the precision diagnostics that support focal therapy. From his base at Frimley Health, where he is a prostate cancer lead at Wexham Park Hospital and has contributed to several pivotal clinical studies and trials on prostate imaging, diagnostics and focal therapy. He's here today to discuss the concept of precision in the diagnosis and treatment of prostate cancer, why it's important, and how it's achieved. We hear about precision in treatment, and I think it means a lot of things to a lot of people. So I think one of the reasons I wanted to chat to you today was to try to put something straight in a more simplistic and honest way. So, let me start by suggesting that we all agree that the more precise the diagnosis, the more options for treatment that men have. And then you're being told that you're suitable for treatment, which involves perhaps the whole prostate or doesn't involve any treatment at all. But then if you try to draw down and look at more focal treatments or treatments which are more bespoke to the individual, that's not enough. So it's not just that cancer somewhere in the prostate, but we know it's at the front of the prostate or the back of the prostate. When we know where the cancer is located, exactly, what type of cancer you have, we can then dissect out the various types of treatment that might be suitable for that man. Treatments that might enable him to preserve those structures important for erections and to be able to stay continent, et cetera. So precision diagnosis means knowing exactly the location, the volume, the length and the type of cancer you have in minute detail. Well, I mean, like, if you're about to go out fishing, we could cast our nets or cast our hook to try and find fish somewhere in the lake. And in the old days, we did that when we were trying to find prostate cancer, we'd shoot our needle somewhere into the prostate. And we'd miss significant cancer sometimes and sometimes hit incidental cancer and misrepresent it. And the MRI gives you that map, it gives you that, if you like geo positioning of where your targets are, and tells you exactly the nature of the prostate so that you can plan treatment. So, for example, you might do an MRI scan that shows that there's a cancer in the back of the prostate, on the right hand side towards the base of the prostate, so that you know, when you're going to do your biopsy, you're going to target your needle into that area there specifically. But not only does it give you that information, it tells you whether you're suitable for one type of focal therapy or another. And then it also tells us about whether cancer is just confined to the prostate or if the cancer has gone outside the prostate. There might be times when people examine the prostate and think, prostate feels really suspicious or feels really

abnormal. But then you might have a high quality MRI scan that shows actually the borders of the prostate are pristine. It tells us whether you're suitable for treatment, amongst many, many things, and there are other useful aspects of MRI that should be used to. So I guess maybe when I asked my original question, I should have separated the scan from the actual scan report or the radiology report. And do you think that there's more variation in those, which could affect the precision that we're talking about? We also need an MRI report, and that MRI report by the radiologist ideally would be done by a radiologist, who has a special interest in identifying and evaluating men who might be suitable for focal therapy. So that radiologist would give you a diagram of where the cancer is located in the prostate. The MRI scan has to be decent quality, but also you need to have a very good radiologist reporting it. And the better your MRI scan, the better your radiologist, the more likely you are to be able to choose a focal therapy treatment with reliability. Or, on the other hand, you'll be able to say, well, look, the focal therapy clinic necessarily going to be the right treatment for you and that you might need to have another treatment. So apart from having a really high quality MRI scan with all the bangs and whistles, it helps to have good reporting. These can be built in to the MRI scans, that very urologist can do the report accurately and well at that time, or it can be done afterwards. But the software used to fuse the MRI scans together, to give you that bill that enables the radiologist to give his or her fantastic report. So it's really several elements that they should be aware of, and rather than hang about on that, because that's important. Marc Laniado The biopsy at the end of the day is what gives you the proof that cancer is present or not. And without the biopsy, the MRI scan tells you that cancer is likely or not likely, but it's not enough to make a firm decision on treatment. Ideally, biopsies be done in a way that target the abnormality present in the prostate reliably, but also hit other areas of the prostate to make sure the cancer is either present or not present there. So in recent times, there's been a new technique of doing biopsies where you put a little tube through the skin to put your needles through, and then you can direct the needle through the little tube into various areas of the prostate that needs to be sampled. So what we like to do when we're doing our biopsies, if you want to get them as accurate as possible, is to take our live ultrasound image and then fuse it with the MRI scan that we've had taken before. And when you do that, it means that you can then direct your needles into the appropriate part of the prostate and be sure that cancer is present. Now, that may seem easy to do, but actually it requires some technical and very sophisticated software to do that, and they're not all equal. Furthermore, the other problem is that some techniques from doing biopsies results in quite a lot of manipulation of the prostate during the biopsy itself. And if you do that, then it means that the fusion isn't quite so accurate, so you get less accurate biopsies. There are software tweaks you can try and make it work better, but actually, it's pretty hard. If you want the best quality standard of biopsy, in my opinion, is that you have the biopsies under a short general anaesthetic so that you don't feel the thing, so you're completely still. And then you very accurately fuse the MRI scan with the ultrasound and then direct the needles through to the prostate gland without moving the prostate during the process. Clare Delmar Again, there's several elements, and I'm interested that some of it's very much technology led, i.e. I mean, do you want to say a few more words about the difference between those five or six techniques that use a general anaesthetic versus those that use a local and how they impact precision? Although you can take the biopsies on the local anaesthetic, there's no doubt you can definitely do that. It doesn't lend itself to precise diagnostics because of the constraints of having to do the biopsies, often through a single channel on each side of the prostate. So it's difficult to direct the needle into exactly the correct part of the prostate, because the geometry doesn't match up. So when you're doing these precision biopsies this way, then you think the needle goes one way, but in fact, it's going another, and the MRI doesn't fuse as well with the prostate, so you can't be 100% certain of where you've put your needle, despite what anyone says. Clare Delmar So that's a lot of information about a lot of elements that ultimately need to a precision diagnosis. And I think what you've described or began to describe is what you would probably agree is the gold standard. But where the improvements have been have been largely in the delivery of transperineal biopsies rather than transrectal biopsies. So most places in the country are doing transperineal; well, not most, but many places are doing transperineal biopsies, but they're still not quite the highest standard in terms of MRI fusion. So there's still usually a large degree of a urologist or some other person trying to mentally fuse the MRI images with the live ultrasound. And then often, not only is that difficult to do, but then if you're also trying to take the biopsies through a single channel, put through the skin between the anus and the scrotum, through the perineum, that single channel means that you have to alter the angle of the needle going in so many times, that it's very hard again for people to triangulate in their head the complex geometry of the prostate and the MRI scan. Although that's to some extent available and is getting more available, it's still about the best

you can get in most parts of the country. So when we come back to where we started, that really high precise or precision diagnostics is not widely available in the country at the moment, but it is growing, but it's still not typically what we see. So in our clinic we see many patients who've come from other parts of the country who've had MRI scans and biopsies done, which largely, I'd say, are inadequate really, for deciding on whether someone is necessary suitable. And so it's always best if you have a diagnosis or have a suspicion you have prostate cancer, you seek out the best MRI scan that's possible and seek out the best diagnostic technique. If you can choose those two things, it puts you in a very powerful position to make decisions about your treatment. Because with that high level knowledge, you can then reliably or much more reliably decide if you need to have a whole gland treatment, that is treating the whole prostate or whether you might be suitable for partial ablation or focal therapy. Thanks so much for speaking with me about this, and I will direct people in the programme notes as to how to get in touch with you if they want to discuss it further. A transcript of this interview is available on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Thank you for contacting us. Thank you for filling out this form. One of our patient advocates will call you shortly. Click here to download our brochure. Providing men with access to the best possible Prostate Cancer Treatments Revolutionary treatment based upon advanced diagnostics. Best Prostate Cancer Treatment Building on developments in imaging and diagnostics, Focal Therapies allow men with early to intermediate stage prostate cancer to be treated in a minimally invasive way, eliminating their prostate cancer whilst maintaining their full quality of life. To provide men in the UK with access to these life-changing therapies, our founder, Brian Lynch brought together the SonaCare HIFU system and a group of world-class clinicians to create The Focal Therapy Clinic to offer HIFU Prostate Cancer Treatment. As of autumn 2022, we added NanoKnife IRE prostate cancer treatment to the minimally invasive therapies we offer our patients at The Focal Therapy Clinic. NanoKnife IRE treatment is useful for the 20% of men with tumour lesions predominantly in the Anterior portion of the Prostate Gland. This development is a significant step in our commitment to providing all our patients with the best possible focal therapy approach for them. Mr Tim Dudderidge, Mr Marc Laniado, Mr Raj Nigam, Mr Alan Doherty and Dr Clare Allen have been pioneering precision diagnostics and Focal Therapy for 20 years, and have supported the research and clinical trials at UCLH and Imperial Hospital. We believe that Focal Therapy is a powerful alternative to Radical Prostatectomy, Hormone / Radiotherapy treatments and Active Surveillance — offering effective cancer control while preserving sexual and urinary function in patients. These are often seen as a trade-off, and we have developed and supported an approach to managing prostate cancer that preserves patient's overall quality of life. Our clinicians have practised Focal Therapy with great success on hundreds of patients and are major contributors to clinical trials demonstrating its effectiveness. The Focal Therapy Clinic and clinicians have been working to support Focal Therapy treatments across the major private medical groups in the UK. "We aim to provide men and their loved ones with information to help them make the right decision for them." Brian Lynch, Founder & Patient Advocate, The Focal Therapy Clinic Marc Laniado, Consultant Urologist MARC LANIADO Marc is the prostate cancer lead at Wexham Park Hospital, Berkshire. He graduated from Guy's Hospital Medical School in 1989, and following specialist urology training in London, he became a Fellow of the Royal College of Surgeons (Urology) in 2000, going on to complete his MD in prostate cancer research, Fellow of the European Board of Urology in 2002. Before taking up his career as a consultant, Marc extended his knowledge and skills on a Visiting Fellowship at the Cleveland Clinic Foundation in the USA, where he trained in minimally invasive surgical techniques. His specialist skills involve precision diagnostics of the prostate gland using enhanced MRI scans and MR-US Fusion Biopsies, Focal Therapy, and Nerve Sparing Robotic Prostatectomy. Marc advocates the use of minimally invasive treatments powered by precision diagnostics and has interest in supporting prostate cancer patients struggling with mental health issues. He strongly believes in providing patients with sufficient information to allow them to make informed choices based upon their personal circumstances and objectives and the need for enhanced prostate cancer screening services. <https://vimeo.com/394413599> <https://vimeo.com/393915229> A PATIENT OF MR MARC LANIADO: Listen to one of Mr Marc Laniado's patients, Bruce, discuss his experience with The Focal Therapy Clinic and his successful HIFU Focal Therapy treatment. Raj Nigam, Consultant Urologist RAJ NIGAM Raj is a consultant urological surgeon based at the Royal Surrey County Hospital in Guildford. He was appointed in 2000, and has a range of experience in general urology, andrology and urological oncology practice in NHS hospitals. He underwent his basic surgical training at University

College and Middlesex Hospitals, and completed his MD thesis on the basic sciences of cancer metastasis at the Royal Postgraduate Medical School. He became a Urological Registrar at St Marys Hospital in London, before becoming a Senior Urological Registrant at St Bartholomew's and the Royal London Hospitals. Raj has held several management positions, including formerly serving as Clinical Director of Urology at Royal Surrey County Hospital. He is widely published in urological and oncological fields, and currently focuses on advanced prostate cancer diagnostics and focal therapies. In addition to his focus upon Prostate Cancer, Mr Nigam is a leading specialist in Male Sexual Function. He campaigns on the issues of Age Discrimination and the overuse of Hormone Treatments in Prostate Cancer treatment in the UK. <https://vimeo.com/394413341> A PATIENT OF MR RAJ NIGAM: Listen to one of Mr Raj Nigam's patients, Steve Wright, discuss his experience with The Focal Therapy Clinic and the HIFU Focal Therapy procedure. Steve was reluctantly preparing for Radical Prostatectomy when his wife came across HIFU Focal Therapy. It seemed too good to be true, but Steve has had a successful HIFU treatment. <https://vimeo.com/394410801>

Alan Doherty, Consultant Urologist ALAN DOHERTY Mr Alan Doherty completed his undergraduate training at Middlesex Hospital, London, before undergoing his surgical training at the Royal Marsden and Charing Cross Hospitals. Mr Doherty also studied at the Institute of Urology before taking up his position as a Consultant Urologist at Queen Elizabeth Hospital, Birmingham, in 2001. Queen Elizabeth Hospital is the largest urological cancer centre in the West Midlands. He is one of the most experienced surgeons in prostatectomy within the UK, having undertaken a total of more than 1,200 procedures. Mr Doherty's commitment to using minimally invasive techniques based upon precision diagnostics where appropriate includes all major specialties in urological surgery, including Laparoscopic Cystectomy (bladder removal) and Laparoscopic Nephrectomy (kidney removal), both of which are only performed by a small number of UK surgeons. He has published extensively on prostate cancer, including articles in the Lancet. Alan believes that Focal Therapy is the new standard for the care of early prostate cancer and that is often preferable to the Active Surveillance protocol. Mr Doherty was recently voted one of the UK's top ten prostate cancer surgeons in a poll of urologists for the Daily Mail. You can hear Alan here in the fourth of our audio series, where he discusses the advances in imaging and radiology that now make Focal Therapy a preferable treatment to Active Surveillance. [player id=8356]

Tim Dudderidge, Consultant Urologist TIM DUDDERIDGE Tim is a Consultant Urological Surgeon and lead of prostate cancer surgical trials at University Hospital, Southampton. Tim specialises in prostate cancer and is one of a handful of clinicians combining an interest in imaging and precision diagnostics with skills in both focal therapy and robotic surgery for prostate cancer. He received his Doctorate of Medicine in 1998, and more recently, a Research Doctorate, both from the University of Bristol. He trained in London and spent time undertaking research at University College London, gaining an MSc degree. He went through urological training at all the leading cancer centres including Kings College Hospital, University College Hospital, Imperial Healthcare and the Royal Marsden Hospital where he also worked as a consultant. Tim was awarded a Royal College of Surgeons Uro-Oncology Fellowship at Imperial in 2009 and subsequently was the UK's First Robotic Surgery Fellow at Royal Marsden Hospital. Tim has research interests in urine based cancer diagnosis and surgical trials for prostate cancer. He has been principal investigator for all the prostate diagnosis and focal therapy trials in Southampton and collaborated with colleagues as a founder member of the UK focal therapy users group. Tim's clinical approach is one of careful assessment and explanation of prostate cancer treatment options. Enabling men to fully understand the difficult choices they must make is a challenge, but also, the key to delivering treatments without patient regret. <https://vimeo.com/394413250> <https://vimeo.com/394225458> A PATIENT OF MR TIM DUDDERIDGE: Guy was recommended to go on Active Surveillance but he didn't want the uncertainty of not knowing how fast the cancer might be growing. Guy was successfully treated with HIFU Focal Therapy by Tim Dudderidge and back on his bicycle within 3 weeks. Prostate Cancer Patient Stories Please find below some patient stories highlighting how focal therapy has successfully treated their prostate cancer. <https://vimeo.com/394410801> Steve's story (04:15) STEVE'S STORY Steve was ready to have a radical prostatectomy and then he found The Focal Therapy Clinic. 'My hope is that men in my situation look at the other options that are open to them' Here we present Steve's HIFU Focal Therapy treatment journey. REQUEST A CALLBACK DOWNLOAD FREE INFO PACK <https://vimeo.com/394216419> Dave's Story (03:34) DAVES' STORY – UK HIFU FOCAL THERAPY PATIENT Dave was on Active Surveillance but did not wish to spend the next 20 years as a patient anxious about the progress of his prostate cancer. HIFU Focal Therapy has treated his prostate cancer and given him peace of mind. Dave is a patient of The Focal Therapy Clinic's Tim Dudderidge. Graham

Ogilvy's story (16:30) **GRAHAM OGILVY'S STORY** Journalist and publisher Graham Ogilvy joins OnFocus to discuss his recent experience with a prostate cancer diagnosis in Scotland that ultimately led him to seek treatment in England, and offers strong advice for men in Scotland to question the "blunt instruments" that are the default diagnostic and treatment offer there. Press play in the audio player below to hear the interview. Graham Ogilvy was diagnosed with prostate cancer and had to choose between having the prostate gland removed or destroyed with radiation and hormone treatment. He was interested in a third option, brachytherapy, but experienced a delay in accessing it. During this time, he researched high-intensity focused ultrasound (HIFU) and eventually found a consultant who performed the procedure. He underwent HIFU and had a positive experience with a quick recovery. Graham also expressed concerns about the biopsy procedures used in Scotland, which he considers to be inherently dangerous and potentially not accurate enough, and questioned why prostate cancer screening is not more widely available. Read Less Video Transcript <https://vimeo.com/394408946>

Barry and Jackie's story (03:34) **BARRY & JACKIE'S STORY** When Barry was diagnosed with prostate cancer the treatment options he was given were unappealing. Jackie believes that although Barry is 75 he should not be pushed towards hormone/radiotherapy treatment as he has many years of active healthy life ahead of him. Barry is a patient of The Focal Therapy Clinic's Raj Nigam. REQUEST A CALLBACK DOWNLOAD FREE INFO PACK <https://vimeo.com/394225458>

Guy's story (03:34) **GUY'S STORY** Guy received a diagnosis of early-stage prostate cancer based upon a well man check. He was encouraged to consider Active Surveillance but he wanted to put the diagnosis of prostate cancer behind him and to get on with his active life. Two weeks after his HIFU treatment he was back on his bike. Guy is a patient of Mr Tim Dudderidge <https://vimeo.com/393915229>

Bruce's Story (03:17) **BRUCE'S STORY** Bruce was not a candidate for Active Surveillance and needed treatment because of the fact that his cancer was close to the edge of his prostate gland. HIFU Focal Therapy was a great option for him allowing him to avoid the trauma of a Robotic Radical Prostatectomy. Bruce is a patient of The Focal Therapy Clinic's Mark Laniado. <https://vimeo.com/394410371>

Dr Harrison (08:32) **DR HARRISON – HIFU FOCAL THERAPY PATIENT** HIFU Focal Therapy patient Dr Harrison says, "It was one of those situations where you think, how could this happen to me. I then got on the internet, like anybody would, and began to search what my options were... and I discovered HIFU." **HIFU PATIENT PROFILE – PERRY LETCHER** My name is Perry Letcher. 5'9 ½, 11 stone 6 and an active sportsman – Cycling and running between 7-12 hours a week, considerably more when cycle touring. **HIFU PATIENT PROFILE – PATRICK O'MARA** Patrick O'Mara, an accountant from Kent, is 55 and a dedicated Wimbledon FC fan. Like WFC, he values second chances and the support of his fans. In 2012 his employer, KBR, offered him an overseas assignment in Saudi Arabia. With his children grown and his partner supportive of the idea, he decided to go for it. A routine medical review was required to undertake the assignment, during which Patrick was offered a PSA test — which he declined. **MARK STUBBS – UK HIFU FOCAL THERAPY PATIENT** TFTC patient Mark Stubbs discusses how seeking a second opinion for his prostate cancer diagnosis and treatment led to an unforeseen approach and better outcome. Press play in the audio player below to hear the interview. **HIFU PATIENT PROFILE – GRAHAM DOUBTFIRE** Graham is 75 and lives in Haslemere with his wife Diane. They enjoy walking and travelling, following his action-packed career in international banking which involved living in multiple cities across the USA and Asia. As Graham puts it, he was sent on these overseas posts to fix problems needing fixing – experiences he drew on when he was diagnosed with prostate cancer in 2015. **HIFU Prostate Cancer Treatment Clinical Evidence** HIFU Focal Therapy is a NICE approved treatment for prostate cancer which has undergone numerous clinical trials. At present the most extensive, evidence-based study on the outcome of Focal Therapy for prostate cancer is the 'Multicentre Study of 5-year Outcomes' which was published in October 2018 – the key findings of which are outlined below. A recently published landmark study comparing the outcomes of Focal Therapy and Radical Prostatectomy treatments for prostate cancer is also outlined on this page. **CLINICALLY PROVEN OUTCOMES MULTICENTRE STUDY OF 5-YEAR OUTCOMES FOLLOWING FOCAL THERAPY** In this 10-year clinical trial, conducted between 2006 and 2016 in the UK, 625 men were treated with HIFU Focal Therapy, giving a median follow up of 5 years. The results of the trial, which were published in 2018, showed that the therapy is an effective treatment with a low probability of side effects. Cancer control 100% cancer-specific survival rate 88% failure-free survival (FFS) rate – defined as freedom from radical or systemic therapy, metastases and cancer-specific mortality. 74% needed no further treatment after their initial Focal Therapy treatment 19% needed at least one additional Focal Therapy treatment 7% required Radical Treatment following Focal Therapy Urinary continence 98% had no issue with urinary continence after the treatment 2% needed

pad use for a couple of weeks Sexual potency*75% had no issues20% needed ongoing over-the-counter medicine) but may have been using this before treatment5% needed some ongoing additional support.*For men with erectile function pre-treatment ConclusionThe overall conclusion was that HIFU Focal Therapy for select patients with clinically significant, non-metastatic prostate cancer is effective in the medium term and has a low probability of side effects.It is important to note that as the study was conducted with a follow up of 5 years it can only include the 'medium term' in its conclusion, as long term is defined as a 10 year span.This study is the biggest of its kind and demonstrates why Focal Therapy should be part of any treatment consideration process for early-stage prostate cancer.Download the full report here:Review our Patient Stories FOCAL THERAPY COMPARED TO RADICAL PROSTATECTOMY FOR NON-METASTATIC PROSTATE CANCER This landmark 8-year study led by Imperial College London and co-authored by TFTC consultant urologists Tim Dudderidge and Raj Nigam, compared the oncological outcomes of 246 Focal Therapy and 246 Radical Prostatectomy patients at 3, 5 and 8 years post treatment.The patients were matched according to their year of surgery, age, PSA, Gleason score, maximum cancer core length, use of neoadjuvant hormonal therapy, and T-stage.The results of the study, published in 2020, have shown that for patients with low to intermediate prostate cancer, Focal Therapy provides similar cancer control and better post-op function compared to Radical Prostatectomy.Cancer control The rates of failure-free survival (FFS) – defined as freedom from local salvage therapy or systemic therapy or development of metastases – for the two treatments were as follows: Functional outcomes The rates of erectile function* and urinary continence post treatment were as follows: *Erectile function scores include men who did not have erectile function pre-treatment Conclusion The key finding of the study was that 'In patients with non-metastatic low- intermediate prostate cancer, oncological outcomes over 8 years were similar between Focal Therapy and Radical Prostatectomy'.This study is the biggest of its kind and demonstrates why Focal Therapy should be part of any treatment consideration process for early-stage prostate cancer.Download the full report here:Review our Patient Stories

The New Foscote Hospital, Banbury THE NEW FOSCOTE HOSPITAL The New Foscote Hospital is a world-class private hospital in Oxfordshire, serving the Cotswolds and Warwickshire regions and beyond with highest quality hospital treatments and aftercare.It is a small hospital, committed to the provision of individualised care and attention from the whole team.The New Foscote Hospital is located on the outskirts of the historic market town of Banbury, in a quiet residential area just off the Oxford Road and Hightown Road.It is easily accessible from Banbury and the surrounding region.Mr Alan Doherty offers HIFU and NanoKnife treatments at this hospital.Hospital phone: 01295 252281

Consultant at The New Foscote Hospital: Mr Alan DohertyConsultant Urologist Spire Parkway Hospital, Birmingham SPIRE PARKWAY HOSPITAL Spire Parkway Hospital is a leading provider of private hospital treatments for patients across the Midlands and beyond, offering specialised healthcare supported by advanced imaging and diagnostic technology.Spire Parkway Hospital is located in Solihull town, just a few miles south of Birmingham city centre, with easy access from the M42, M6, M40 and M5.It is close to both Birmingham International and Solihull Train stations, each within a ten-minute taxi journey from the hospital.Hospital phone: 0121 756 0442

Consultant at Spire Parkway Hospital: Mr Alan DohertyConsultant Urologist The Princess Margaret Hospital, Windsor THE PRINCESS MARGARET HOSPITAL The Princess Margaret Hospital is part of the BMI group of hospitals that specialise in the highest quality of private healthcare, with 59 hospitals nationwide and more than 85 years of experience.The Princess Margaret Hospital provides facilities for advanced, cutting-edge surgical procedures together with friendly, professional care.The Princess Margaret Hospital is located 20 miles west of London and 8 miles from Heathrow airport.Sitting on the edge of Windsor Great Park, within sight of Windsor Castle, the hospital is a 5-minute taxi ride from both Windsor Eton Riverside station and Windsor Central station.Hospital phone: 01753 395222

Consultant at The Princess Margaret Hospital: Mr Marc LaniadoConsultant Urologist Mount Alvernia Hospital, Guildford MOUNT ALVERNIA HOSPITAL Mount Alvernia Hospital is part of the BMI group of hospitals that specialise in the highest quality of private healthcare, with 59 hospitals nationwide and more than 85 years of experience.Mount Alvernia provides facilities for advanced, cutting-edge surgical procedures together with friendly, professional care.Located close to Guildford town centre, Mount Alvernia Hospital is a 12-minute taxi ride from Guildford train station.Hospital phone: 0844 589 2610

Consultant at Mount Alvernia Hospital: Mr Raj NigamConsultant Urologist Spire Southampton Hospital SPIRE SOUTHAMPTON HOSPITAL Spire Southampton Hospital provides world-class private hospital treatments, procedures, tests, scans, and aftercare, attracting patients from across the South of England, nationally, and internationally.It is a part of Spire Healthcare, the second largest provider of the private healthcare in the UK, with 38

award-winning hospitals nationwide. Spire Southampton is just a 10-minute taxi ride from Southampton Central train station, or 15 minutes from Southampton International airport. Hospital phone: 023 8255 0301 Consultants at Spire Southampton Hospital: Mr Tim Dudderidge Consultant Urologist

Understanding Your Prostate Cancer Diagnosis Understanding what your results mean Understanding what your results mean **YOUR RESULTS** If you have had an MRI scan and biopsy and have received a diagnosis of prostate cancer you will now have some results to consider. These results will contain information which tells you: How aggressive the cancer is, indicated by the Gleason Grade. The progression, size and location of the tumour, indicated by the TNM Stage. This page will help you to understand what these terms mean and will help you to get a clearer picture of your prostate cancer and the best treatment options for you. In almost all cases however we recommend that men seek a second opinion before accepting treatment.

GLEASON SCALE The Gleason Scale or Grade is used to evaluate how aggressive the cancer is and how likely it is to spread outside of the prostate. Many people with a new diagnosis of prostate cancer will want to know their outlook and to understand the treatment options that are likely to be appropriate for them - the Gleason Grade helps to determine both of these. The Gleason Grade refers to the pattern of cancer cells in the prostate. The pattern structure of these cells indicates how quickly they are likely to grow. The different patterns are graded 1 to 5, with Grade 1 being very similar to typical prostate tissue, and Grade 5 being very different to typical prostate tissue. The Gleason Score is derived from adding the most common grade in the samples to the second highest grade.

Grade group 0: below Gleason Score 3 + 3 = 6 This is a finding of normal prostate cells in the prostate gland with no prostate cancer cells detected.

Grade group 1: Gleason Score 3 + 3 = 6 Gleason Score 6 is considered early-stage prostate cancer and may not progress further or may progress very slowly. Men with a low volume of Gleason Score 6 this diagnosis would commonly be advised to follow the Active Surveillance protocol. In cases where prostate cancer cells with Gleason Score 6 are found with a volume of 4mm or more then the option of Focal Therapy can be considered. For these men HIFU or NanoKnife Focal Therapy treatment are a viable treatment option depending upon the location of the prostate cancer cells.

Grade group 2: Gleason Score 3 + 4 = 7 This is considered early-stage intermediate prostate cancer and is unlikely to cause harm in the short term. Men may be offered Active Surveillance or radical treatments such as Radical Prostatectomy or Hormone / Radiotherapy treatment. Men under the age of 70 who are in good health are likely to be encouraged to have a Radical Prostatectomy. Men with a Grade Group 2 prostate cancer are highly likely to be suitable for HIFU Focal Therapy and ought to consider this treatment option.

Grade Group 3 : Gleason Score 4 + 3 = 7 Gleason Score 7, 4+3=7 is considered to be a higher disease stage. This means that higher risk cancer cells with a score of 4 have been more visible than less dangerous score 3 cancer cells. For men with Gleason 4+3=7 Focal Therapy can be an attractive option in cases where the prostate cancer cells are clearly identified on MRI, have a low volume, biopsy results are in agreement with the MRI scan and a PSMA PET CT has confirmed that the prostate cancer cells are confined within the prostate gland. For men with higher volume Gleason Score 4+3=7 which is present throughout the prostate gland then the well established radical whole gland treatments are recommended.

Grade group 4 & 5: Gleason Score 4 + 4 = 8 and above These are considered advanced-stage prostate cancer and men with these prostate cancers benefit substantially from radical treatments such as Radical Prostatectomy or Hormone / Radiotherapy treatment. HIFU Focal Therapy would not be suitable in these cases. If you have received your Gleason results and would like to discuss what they mean for your diagnosis and treatment options, call us on 020 3820 2282 and we would be happy to offer advice and information.

TNM STAGE If conclusive, the TMN Staging system can indicate the tumour's size, location, and whether it has spread to the lymph nodes or another part of the body (metastasis). These results will have a combination of the letters T (tumour), N (node) and M (metastasis) and a number to indicate the stage of each, or an X if the result cannot be evaluated. In general terms T1, T2, and some T3a tumours where the cancer is still confined within the prostate gland, can be considered for NanoKnife or HIFU focal therapy.

Understanding my TNM stage results

Tumour (T) The number next to the T describes the size and spread of the cancer.

T1: The cancer is too small to be felt during a digital rectal examination (DRE) of the prostate but may be visible on the MRI scan.

T2: The tumour is found only in the prostate, not other parts of the body.

T2a: The tumour involves one half of one side of the prostate.

T2b: The tumour involves more than one half of one side of the prostate, but not both sides.

T2c: The tumour has grown into both sides of the prostate.

T1 and T2 tumours are known as localised prostate cancer. Treatment options include Active Surveillance, Radical Prostatectomy, Hormone / Radiotherapy or Focal Therapy, including HIFU Focal Therapy.

T3: The tumour has spread outside the prostate and may be growing into tissues or organs close by.

T3a: The

prostate cancer tumour is abutting the edge of the prostate capsule and there is a risk that it may have infiltrated the wall and spread into the surrounding tissue. T3b: The tumour has spread to the seminal vesicles that produce some of the fluid for semen. T3 prostate cancer is considered to be a relatively advanced stage and radical treatment is necessary. Nodes (N) The number next to the N describes whether or not the cancer has spread to the lymph nodes. N0: There is no cancer in the lymph nodes near the prostate. N1: There is cancer in 1 or more lymph nodes close by. NX: There is no information about the nearby lymph nodes, or they can't be assessed. Metastasis (M) The number next to the M describes whether or not the cancer has metastasized, ie spread to another part of the body. M0: The cancer has not spread to another part of the body. M1: The cancer has spread to another part of the body. MX: It is unknown if cancer has spread to distant sites. For a patient to be able to consider HIFU Focal Therapy as a viable treatment option, the cancer tumour must reside only in the prostate gland and not have grown outside the prostate. For patients whose cancer has a TNM stage of T3 or above, the tumour is also located outside of the prostate gland and is not suitable to be treated with HIFU Focal Therapy. If you have received your TNM Staging results and would like to discuss what they mean for your diagnosis and treatment options, call us on 020 3820 2282 and we would be happy to offer advice and information.

QUESTIONS FOR YOUR DOCTOR Now you have your prostate cancer diagnosis results and before starting treatment you should talk to your doctor about your options. You may want to seek a second opinion, or even talk to several doctors about all treatment options, their side effects, and the expected results. Here are some questions to ask your doctor: What are my treatment options? Why? What are the expected benefits of each kind of treatment? What are the risks and possible side effects of each treatment? The Prostate Cancer Diagnostic Process: PSA, MRI, Biopsy MRI imaging has revolutionized prostate cancer diagnosis Download Free Info Pack MRI imaging has revolutionized prostate cancer diagnosis Download Free Info Pack

DIAGNOSIS When caught early, prostate cancer is readily treatable. Over the last decade, developments in MRI imaging and biopsy procedures have made it possible for significantly enhanced diagnostic precision. This combined with extra PSA screening means that prostate cancer can be detected at an earlier stage than before. Early detection and precision diagnosis have laid the basis for minimally invasive focal treatment. This page explains the ways in which prostate cancer is detected and diagnosed in the UK. If you compare that to standard TRUS biopsies, which we know to be about 30%, it's a completely different league." Dr Clare Allen, Uro-Radiologist at The Focal Therapy Clinic

DIAGNOSIS When caught early, prostate cancer is readily treatable. Over the last decade, developments in MRI imaging and biopsy procedures have made it possible for significantly enhanced diagnostic precision. This combined with extra PSA screening means that prostate cancer can be detected at an earlier stage than before. Early detection and precision diagnosis have laid the basis for minimally invasive focal treatment. This page explains the ways in which prostate cancer is detected and diagnosed in the UK.

PSA TESTING A PSA test measures the levels of prostate specific antigen (PSA) in the blood. Levels of PSA in the blood can be higher in men who have prostate cancer. It is a screening tool used to determine whether or not an investigation for prostate cancer is needed. PSA test for detecting prostate cancer PSA in the serum of men with healthy prostates is present in small quantities but is often elevated in the presence of prostate cancer or other prostate disorders such as prostatitis or benign prostatic hyperplasia. There can also be other reasons why your PSA level may be raised, due to things like a urine infection or age-related reasons. Your doctor will usually see a PSA reading of 3 or more as a sign for further investigation. In the UK, men with a raised PSA will usually undergo a DRE (digital rectal exam) test to check for any obvious abnormalities and will be offered an MRI scan of their prostate gland. Men who have a higher risk of prostate cancer may be asked to have further investigations even if their reading is lower than this. Men are at higher risk of prostate cancer if: There is a family history of prostate cancer They are of Black ethnic origin They are overweight

PSA tests for ongoing monitoring If you have been diagnosed with prostate cancer and are on the Active Surveillance protocol you will be having regular PSA blood tests to monitor the PSA levels in your blood. This will usually be in combination with other tests to assess the progress of your cancer. You will also likely be having regular PSA blood tests if you have already had treatment for prostate cancer, to assess if the cancer has returned or increased. If you are unsure what the best options are for treating your prostate cancer, and are having regular PSA blood tests, we are here to help with confidential advice.

DRE (DIGITAL RECTAL EXAM) A digital rectal exam is a test that is done when a doctor or nurse inserts a gloved, lubricated finger into the rectum to estimate the size of the prostate and feel for lumps or other abnormalities. The DRE is used to help diagnose prostate cancer and for other prostate problems such as benign prostatic hyperplasia (BPH) or prostatitis. If the results of early detection tests like the PSA

test or the digital rectal exam suggest that you might have prostate cancer, your doctor will conduct further testing. The PSA may be repeated, or you may be sent to a specialist for more tests such as a MRI scan and a prostate biopsy.

Close Discover More MRI SCANS An MRI (magnetic resonance imaging) scan is used to identify areas of suspicion within your prostate gland that may need further investigation. It uses magnets to create an image of your prostate and the surrounding tissues. The image from your scan gives your doctor information about whether there are any cancer cells in your prostate and how likely they are to grow. The radiologist reviewing your MRI scan will identify areas of suspicion shown in the scan and will assign them a PIRADS score. A PIRADS score of 4 or 5 indicates a need for a biopsy, and a significant number of men with a PIRADS score of 3 will also be biopsied.

What is an mpMRI scan? A multi-parametric magnetic resonance imaging (mpMRI) scan creates a more detailed picture of your prostate than a standard MRI scan: it does this by combining four different types of image. In the UK, an mpMRI scan should be carried out for men with an elevated PSA level before any biopsy. The information from the mpMRI pinpoints exactly where any areas of interest are located and allows for more targeted biopsies.

Close Discover More “The big change has been the advent of MRI and its use in prostate imaging. If you compare that to standard TRUS biopsies, which we know to be about 30%, it’s a completely different league.” Dr Clare Allen, Uro-Radiologist at The Focal Therapy Clinic

PROSTATE BIOPSIES A prostate biopsy involves using thin needles to take tiny samples of tissue from the prostate gland. The tissue is then examined under a microscope to check for cancerous cells. If cancerous cells are found, the biopsy will also show how aggressive the cancer is, whether it has already spread, and how likely it is to spread outside the prostate. Whenever possible, it is preferable for men to have a modern trans-perineal biopsy rather than a traditional trans-rectal biopsy. Consequently, there is a greatly reduced risk of infection (less than 1 in 1000) and significantly improved accuracy, thus providing a broader range of treatment options in the event of a positive diagnosis.

Trans-rectal ultrasound biopsy has a relatively high risk of infection (approximately 1 in 30) and lower accuracy.

MRI-Ultrasound Fusion Transperineal Biopsy MR-fusion biopsy plan: fusing MRI images and ultrasound permits very precise biopsies. MRI-Ultrasound fusion transperineal biopsy is the state-of-the-art technique for prostate biopsy and allows surgeons to get a precise understanding of the extent of prostate cancer within each section of the prostate gland. Computer registration (or ‘fusion’) of the mpMRI image onto an ultrasound image, which currently guides biopsy, allows accurate targeting through direct visualisation of the lesion. This technique is typically carried out under general anaesthetic and takes between 30 and 50 minutes. The number of cores taken can range between 5 – 30. The difference with this type of prostate biopsy is that it involves using a grid (or template) with tissue samples extracted through holes in the grid by several needles. Each hole correlates to numbers and letters, in the same way as grid references are located on maps.

Transperineal Prostate Biopsy A transperineal biopsy of the prostate is a type of needle biopsy in which a very fine needle is inserted into the prostate through the skin between the testicles and the rectum (back passage) – an area known as the ‘perineum’. Here, the man is typically lying on his back with his legs in the air, and the samples are taken through the skin of the perineum. This procedure can be done under local or general anaesthetic. The principal advantages of the transperineal biopsy technique over the more traditional transrectal biopsy are improved diagnostic accuracy and a substantially reduced risk of infection.

Transrectal Ultrasound ‘TRUS’ Guided Prostate Biopsy A transrectal ultrasound guided biopsy of the prostate (TRUS) is a type of needle biopsy done through the wall of the rectum using a transrectal ultrasound scanner probe. The patient lies on their side with their knees up while the doctor pushes a fine needle through the probe and into the prostate gland in order to get samples of prostate tissue. Different areas of the prostate are sampled with approximately 8–14 biopsy cores. This is typically done under local anaesthetic. TRUS biopsies are being increasingly replaced in the UK with Transperineal biopsies as they offer an improved level of accuracy and significantly reduced risks of infection.

“A high-quality mpMRI scan combined with a targeted biopsy allows us to know the location and grade of your prostate cancer. We can then treat it with minimal damage to surrounding organs and reduced side effects.” Mr Raj Nigam, Urological Consultant at The Focal Therapy Clinic

“A high-quality mpMRI scan combined with a targeted biopsy allows us to know the location and grade of your prostate cancer. We can then treat it with minimal damage to surrounding organs and reduced side effects.” Mr Raj Nigam, Urological Consultant at The Focal Therapy Clinic

Dr Clare Allen is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK.

Our Prostate Cancer Consultants Meet Our Team Our urologists Mr Tim Dudderidge, Mr Marc Laniado, Mr Raj Nigam and Mr Alan Doherty, along with our uro-radiologist Dr Clare Allen, have been

pioneers in the areas of precision diagnostics and focal therapy for the last 20 years. Based in the UK, they have led the development of focal therapy through clinical trials and treated hundreds of patients with these ground-breaking technologies. They along with industry expert Brian Lynch have created The Focal Therapy Clinic to widen the awareness of focal therapy as a viable treatment option to prostate cancer patients in the UK.

Mr Tim Dudderidge Consultant Urologist MB ChB, MSc, FRCS (Urol) Tim is a urological consultant at University Hospital Southampton, where he specialises in prostate and bladder cancer. He is one of a handful of clinicians combining an interest in imaging and precision diagnostics with skills in both focal therapy and robotic surgery for prostate cancer. Read more about Tim and see his video here

Mr Marc Laniado Consultant Urologist MD, FRCS (Urol), FEBU Marc is the prostate cancer lead at Wexham Park Hospital, Berkshire. He has been a consultant since 2002, working with patients in both Windsor and Harley Street. Marc specialises in MRI to identify areas of suspicion and is a pioneer in the use of targeted biopsy techniques. Read more about Marc and see his video here

Mr Raj Nigam Consultant Urologist MBBS, MD, FRCS, FRCS (Urol), FEBU Raj is a consultant urological surgeon based at the Royal Surrey County Hospital in Guildford. He was appointed in 2000, and has a range of experience in general urology, andrology and urological oncology practice in NHS hospitals. Read more about Raj and see his video here

Mr Alan Doherty Consultant Urologist MBBS, BSc, MD, FRCS (Urol), FEBU Alan completed his undergraduate training at The Middlesex Hospital before undergoing his surgical training at the Royal Marsden and Charing Cross Hospitals in London. Mr Doherty also studied at The Institute of Urology before taking up his position as a consultant urologist at Queen Elizabeth Hospital Birmingham, the largest urological cancer centre in the West Midlands, in 2001. Read more about Alan and hear his interview here

Dr Clare Allen Consultant Uro-Radiologist Clare qualified from Oxford and is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK. She was lead radiologist on the Promise Trial which proved the efficacy of mpMRI for prostate cancer globally.

Brian Lynch Founder and Patient Advocate Brian has been involved in the world of prostate cancer diagnosis and focal therapy for over 10 years. He is an advocate both for the use of MRI and targeted biopsies for the precise diagnosis of prostate cancer and for the use of focal therapy wherever appropriate.

Princess Grace Hospital, London THE PRINCESS GRACE HOSPITAL NOTTINGHAM PLACE, LONDON The Princess Grace Hospital is one of the UK's best equipped, multidisciplinary, acute private hospitals. It is part of the international division of HCA (Hospital Corporation of America), which is the world's largest private healthcare company. Based in Marylebone, The Princess Grace is located in the Harley Street medical district, Central London, just off Marylebone Road. Hospital phone: 020 7486 1234

Consultant at The Princess Grace: Mr Marc Laniado Consultant Urologist HIFU : Soundwave-Based Treatment Focal Therapy: Fight prostate cancer with unmatched, targeted precision FEES £250 Consultation £13,000 Procedure HIFU and NanoKnife treatment based upon advanced diagnostics. FEES £250 Consultation £13,000 Procedure "In Focal Therapy, the aim is to get rid of the cancer that is causing concern whilst ensuring that the patient does not become incontinent and has a much lower chance of losing erectile function."

Mr Tim Dudderidge, Urological Consultant at The Focal Therapy Clinic Focal Therapy for Prostate Cancer? Day case procedure : rapid recovery Excellent cancer control No incontinence Preservation of erectile function An estimated 1 in 8 white men in the UK will be diagnosed with prostate cancer in their lifetime. Men with organ confined, localised prostate cancer with a Gleason score of 7 or less can be considered for Focal Therapy. At The Focal Therapy Clinic, we offer precise, non-invasive and successful treatments for localised prostate cancer with minimal side effects. These treatments are High-Intensity Focused Ultrasound (HIFU) and Irreversible Electroporation (NanoKnife IRE). HIFU (High-Intensity Focused Ultrasound) treatment is the most popular and well-evidenced type of focal therapy treatment for prostate cancer with over 20 years of clinical use, over 50,000 patients treated and multiple successful clinical trials. Focal HIFU treatment is effective in treating medium to large-volume prostate cancers in the lower part of the prostate gland where over 75% of prostate cancer occurs. More recently Focal NanoKnife treatment is being used to treat the 25% of prostate cancer tumours which occur in the front of the prostate gland which were often not possible to treat with HIFU treatment. HIFU is an ultrasound wave-based treatment for prostate cancer that uses a pair of high-intensity ultrasound beams to heat targeted areas of the prostate, destroying cancer cells and preserving sensitive prostate tissue and structures which do not have cancer cells. The HIFU procedure is carried out under general anaesthetic and sophisticated 3D MRI Fusion software is used to guide the treatment of the targeted prostate cancer cells. Extensive clinical trials have shown that HIFU provides effective cancer control whilst preserving erectile function and urinary continence. A UK based clinical

trial of 625 men who had the HIFU procedure was reported in 2018 and 2021 and its results were very encouraging. 100% of men had no urinary problems within 2 weeks of treatment and 95% of men had a normal erectile function at 6 weeks after treatment. At 8 years after treatment, cancer control amongst the men treated on the trials was equivalent to a group of similar men who had undergone Robotic Prostatectomy. Download Free Info Pack HIFU Treatment Versus Nanoknife / IRE Treatment Am I Suitable Listen to Mr Dudderidge discuss HIFU Focal Therapy with Dr Mark Porter of the Times on Radio 4's Inside Health Programme. <https://vimeo.com/394228009> "Using precision diagnostics, we are able to pinpoint and treat the specific area of cancer. Traditional prostate cancer treatment is like using a sledgehammer to kill a flea." Mr Alan Doherty, Urological Consultant at The Focal Therapy Clinic Am I Suitable "Using precision diagnostics, we are able to pinpoint and treat the specific area of cancer. Traditional prostate cancer treatment is like using a sledgehammer to kill a flea." Alan Doherty, Urological Consultant at The Focal Therapy Clinic Am I Suitable Am I Suitable <https://vimeo.com/394410801> Steve's story (04:15) STEVE'S STORY Steve was ready to have a radical prostatectomy and then he found The Focal Therapy Clinic. 'My hope is that men in my situation look at the other options that are open to them' Here we present Steve's HIFU Focal Therapy treatment journey. READ MORE STORIES BENEFITS OF HIFU FOCAL THERAPY The main benefit of Focal HIFU prostate cancer treatment for localised prostate cancer is the clinical precision with which it can be performed. Targeting only the prostate cancer cells, the HIFU treatment enables the other tissues and structures of the prostate and surrounding area to remain completely untouched. This ensures that any damage to healthy tissue is avoided — something that typically increases the risk of the debilitating side effects associated with traditional prostate cancer therapies, such as urinary incontinence and erectile dysfunction. Unsurprisingly, these side effects can significantly affect your quality of life, even after the cancer has gone. Other key benefits of HIFU therapy for prostate cancer include: Effective cancer control — similar to radical prostatectomy or radiotherapy treatments Minimally invasive — non invasive surgery, no radiation, no hormone therapy A day (outpatient) procedure — meaning you can go home the same day and often as little as 90 minutes after your procedure Quick recovery time (within 2–3 days) Minimal post-operative pain and discomfort Minimal risk of incontinence (98% of patients fully continent at 2 weeks) Preservation of erectile function (95% of patients maintain erectile function) Can be repeated if necessary Does not exclude further treatment with radiotherapy or surgery if required Read Clinical Evidence Watch Patient Stories <https://vimeo.com/394218914> Getting Focal HIFU Prostate Cancer Treatment The prospect of cancer treatment can be daunting, but it can help to ease your worries if you know what to expect. Here's everything you need to know about before, during and after HIFU prostate cancer treatment. Before the procedure Before you can have Focal HIFU prostate cancer treatment, you'll first need to have your suitability for the procedure assessed to ensure that it is the right treatment for you. This will involve a consultation with your consultant urologist / surgeon, where you'll discuss your medical history and cancer diagnosis, and talk about what you hope to gain from your treatment and any worries that you have. The critical point that your consultant will focus upon is to ensure that the MRI scan and histopathology biopsy results produce a detailed image of the area of the prostate that has prostate cancer cells and confirms that the rest of the prostate does not have clinically significant prostate cancer. We may need to carry out some tests such as MRI scan and a biopsy to find out more about the tumour in your prostate. Your consultant will explain why each test is necessary and what to expect at each step of the process. Physical preparation for your treatment has been shown to be a contributing factor in its success and your recovery. Your surgeon will explain to you the importance of eating well before and after your surgery. They will also talk to you about the various steps you'll need to take to prepare for the Focal HIFU procedure, such as if there are any medications you should stop taking before treatment and when you should stop eating and drinking before your general anaesthetic. Your surgeon and specialist nurse will be able to answer any questions you have so that you understand all that the treatment involves. They'll tell you how long the surgery will take, what you can expect from your recovery and when you can get back to your usual daily activities such as exercising or going to work. During the Focal HIFU prostate cancer procedure HIFU is a non-invasive treatment for prostate cancer. This means that there are no incisions made into the skin and no wounds to care for afterwards. This will make it easier for your surgeon to see the images of your prostate clearly, ensuring the accuracy of your treatment. The HIFU treatment is performed under general anaesthetic, which will put you into a deep sleep before it takes place. This probe will emit a high frequency, ultrasound energy to heat and destroy the cancer cells in the prostate. It treats just a very small area at a time, and your surgeon will move the beam around to ensure all the cancer cells are targeted. HIFU recovery and aftercare Every patient is unique and recovery from your HIFU

procedure will depend on multiple factors, including your age and fitness level. You should expect it to take up to 48 hours for the effects of the general anaesthetic to wear off, so you should not drive until this time has passed, although you will still be able to return home the same day. You'll be fitted with a catheter as part of your surgery, and you will need to wear this for up to seven days. Patients can expect to be able to pass urine easily and with good bladder control as soon as the catheter is removed. Your surgeon will talk to you about the importance of taking enough time to rest and recover following your surgery. You will be advised to avoid heavy lifting or strenuous exercise for at least a week, and sexual intercourse until your catheter is removed. It's important to follow all aftercare and follow-up appointment instructions provided to you by your surgical team.

HIFU prostate cancer treatment success rates

HIFU prostate cancer treatment is a very popular and successful therapy. For many people, most importantly it has been shown to have no impact on the healthy tissues and structures surrounding the prostate. By keeping these tissues healthy and intact, HIFU treatment almost eliminates the side effects associated with traditional radical whole gland prostate cancer treatments. Currently, HIFU prostate cancer treatment is not an option available on the NHS except under limited clinical trial conditions. Typical risks and side effects include bleeding, infection, infertility, urinary incontinence and erectile dysfunction. A less targeted approach, hormones weaken cancer cells and radiotherapy blasts them with radiation to destroy them. There are also side effects associated with radiotherapy including erectile dysfunction, bowel incontinence, depression and fatigue. Hormone therapy doesn't cure prostate cancer alone, but it can be used to slow the progression of advanced cancer and relieve your symptoms. It blocks testosterone, but this too has side effects including low libido, erectile dysfunction, depression and more. At The Focal Therapy Clinic, we offer Focal Therapy treatments for prostate cancer (HIFU and NanoKnife) as an alternative to these more traditional treatments.

HIFU side effects

Any cancer treatment can pose a risk of side effects and HIFU is no exception. However, when compared to the treatments currently offered by the NHS, HIFU side effects are mild and much less frequent. As you know, you'll need to wear a catheter for a few days following your procedure, but once this is removed, you shouldn't experience any long-term effects. The side effects associated with HIFU include:

- Temporary urinary symptoms
- The risk of contracting a urinary tract infection
- Some blood and seminal fluid in your urine in the days and weeks after surgery as the cells in the tumour break down
- A small risk of infertility due to decreased/absent ejaculatory fluid
- Erectile dysfunction issues, but this is rare

However, most men will experience minimal to no side effects at all. In fact, recent clinical studies have shown that following HIFU Focal Therapy treatment, 98% of patients had no issue with urinary continence and 95% maintain erectile function. The cost of your HIFU treatment at The Focal Therapy Clinic will be broken down into an initial consultation, and then the procedure, medicine and aftercare. The cost of an initial consultation, which includes a review of your medical history and a second opinion on diagnosis and treatment options is £250 including VAT. The package cost of a HIFU procedure, including treatment, medicine and necessary aftercare usually starts from £14,000 including VAT. It's also worth noting that your treatment is likely to be covered by a private medical insurance policy if you have one. The cost of the initial consultation involving a review of your medical files and a second opinion on your diagnosis and treatment options is £250, including VAT. This detailed consultation can be conducted in person or by video call and typically takes between 30-45 minutes. The cost of the HIFU Focal Therapy procedure including treatment, medicine, and after-care is from £14,000, including VAT. The relevant CCSD Code for the HIFU Focal Therapy treatment option is: M6770

How long is the HIFU Focal Therapy procedure? Usually lasting between 90 and 140 minutes, it is a largely well-tolerated procedure that allows men to leave the hospital within 90 minutes of completion. Patients are able to return home within a couple of hours of having Focal Therapy treatment. The risks and benefits of any procedure are different for everyone - your doctor will be able to explain in detail the risks that may affect you. There is a small risk of side-effects and complications following HIFU Focal Therapy, the most common of which are temporary urinary symptoms and the risk of contracting a urinary tract infection. The objective of Focal Therapy is to treat only the areas of the prostate gland that contains cancer and leave the healthy tissue intact. This non-invasive approach avoids damaging the erectile nerves or the urethra thus minimising the risk of urinary incontinence or erectile function. Recent clinical studies have shown that following HIFU Focal Therapy treatment: 98% had no issue with urinary continence 95% maintain erectile function although 20% of men may need pharmaceutical support

[Click here to review the statistics on sexual function and incontinence in detail.](#) The mission of The Focal Therapy Clinic is to make this option as broadly available as possible and to ensure that men have a good understanding of all their treatment options before they make a decision. Provided that your diagnostic results are of sufficient quality your consultant will be able to give

you a definitive answer regarding your treatment options and suitability for Focal Therapy. Once you are comfortable that Focal Therapy is the right option for you, treatment can be arranged in a matter of weeks. One of the major benefits of Focal Therapy is that it does not preclude the subsequent treatment options of further Focal Therapy, surgery or radiotherapy. Around 74% of men will not need any further treatment for their prostate cancer after Focal Therapy. Listen to Consultant Urologist Tim Dudderidge provides a clinical overview of focal therapy "In delivering the treatment we avoid the patient having progressive disease, but, importantly, we preserve their functional status, meaning the patient does not become incontinent and has a lower chance of losing erectile function." The Harley Street Hospital, London THE HARLEY STREET HOSPITAL The Harley Street Hospital is located at the centre of London's most prestigious medical district. Leaders in specialist healthcare and day surgery, The Harley Street Hospital offers the highest quality of personalised care and state-of-the-art facilities with a focus upon focal therapy for prostate cancer. Located at the Oxford Street end of Harley Street, The Harley Street Hospital is a short walking distance from both Oxford Street and Bond Street tube stations. Hospital phone: 0844 589 2610 Consultants at The Harley Street Hospital: Mr Raj Nigam Consultant Urologist Mr Tim Dudderidge Consultant Urologist Mr Marc Laniado Consultant Urologist Our Focal Therapy Treatment Locations Spire Southampton Hospital Chalybeate Close, Southampton BMI Mount Alvernia Hospital Harvey Rd, Guildford The Harley Street Hospital Marylebone, London BMI The Princess Margaret Hospital Osborne Rd, Windsor Spire Parkway Hospital Damson Pkwy, Solihull The New Foscote Hospital Foscote Rise, Banbury The Princess Grace Hospital Marylebone, London OUR CLINIC LOCATIONS The Focal Therapy Clinic offers Focal Therapy in seven state-of-the-art private hospitals across London and the UK - in Southampton, Guildford, London, Windsor, Banbury and Solihull. All our partner hospitals have the highest standards of patient care, along with the cutting-edge technologies and expertise required to carry out HIFU Focal Therapy treatment. Cost Of Focal Therapy Treatment We wanted the diagnosis of prostate cancer gone, in the best and easiest way possible... and we found focal therapy SELF-PAY PATIENTS Cost of Consultation £250, including VAT. Your initial consultation with one of our senior consultants will involve a detailed review of your medical files prior to the consultation. At the consultation you will have a comprehensive discussion with your consultant reviewing your diagnosis and all of your treatment options including your suitability for HIFU/NanoKnife IRE focal therapy treatment package. We have many patients who have utilised a combination of self-funded and NHS diagnostics and treatments. As many of our patients are self-funded, we have made sure that the costs of HIFU and NanoKnife IRE procedures are as affordable as possible. NanoKnife treatment price in the UK is £15,000 for the treatment, medication and aftercare. The excellent rates we achieve with our partner hospitals are based on the high volume of patients we can help with these pioneering prostate cancer treatments. A range of tailored funding options and price-plans are available to help you with the cost of your treatment, though it's worth noting that all of the major health insurance providers will fund the cost of HIFU/NanoKnife IRE treatment for prostate cancer. Our team is on hand to provide further information on self-pay or insurance-funded Focal Therapy options. Advice is free and without obligation, so do not hesitate to get in touch to discuss your prostate cancer treatment options today. Close Discover More INSURED PATIENTS Focal HIFU Prostate Cancer Treatment costs and Focal NanoKnife Prostate Cancer Treatment costs are reimbursed by all the major health insurance companies in the UK (such as BUPA, AXA PPP, Aviva, and others). If you have been diagnosed with prostate cancer your diagnosis and treatment journey may have started via your GP and NHS pathway. Alternatively, you may have private healthcare insurance and received your initial consultation, tests and diagnosis via this route. Patients with private insurance will have access to all the precision diagnostics and modern treatments relating to prostate cancer including HIFU Focal Therapy costs and NanoKnife IRE costs. In addition, all the latest and ground-breaking diagnostics tests such as 3T mpMRI scanning and precision biopsies can be covered by these providers. With our years of experience and partnerships with healthcare insurers, we can advise you on what is available to you within your specific policy. Whatever stage you are at in your diagnostics or treatment journey regarding your prostate cancer, we can help and advise you on all the available options and help you choose the best one for you and your circumstances. Close Discover More Before & After Treatment "The treatment itself was as smooth and easy as anything" "The treatment itself was as smooth and easy as anything" GETTING READY FOR TREATMENT We want to involve you in all the decisions about your care and treatment. Before your focal therapy treatment proceeds, either by HIFU or NanoKnife, your consultant and your specialist nurse will spend time explaining to you all the risks, benefits and alternatives so that you understand all that the treatment involves. If you are unsure about any aspect of your proposed treatment, please do

not hesitate to speak with a senior member of staff

again.<https://vimeo.com/639089349><https://vimeo.com/639089349> THE DAY OF YOUR TREATMENT

You will be asked to not eat anything for at least six hours before the HIFU/NanoKnife IRE procedure. You should NOT drink anything for at least two to four hours before the procedure. On the day of the procedure, you will arrive at the hospital about 2 hours before your scheduled treatment time and will be met by the specialist nurse who will bring you to your room. After you have changed she will discuss the procedure itself including the urinary catheter, how you can expect to feel after the treatment and in the following days. At this stage you will meet with your consultant urologist who will discuss the procedure with you again and confirm that you have understood the proposed procedure. You will confirm that you wish to proceed by signing the legal consent form. Shortly afterwards the consultant anaesthetist will meet with you. The anaesthetist will explain the anaesthetic options available to you and make sure that your preferred option is both appropriate and safe. The anaesthetic will usually be a general anaesthetic (which puts you into a deep sleep during which you cannot feel anything). This is so that you do not move during the procedure, so that the HIFU/NanoKnife IRE treatment is effective. Just prior to going to the operating theatre the specialist nurse may give you an enema to ensure that your bowel is unobstructed. After this you will be brought to the anaesthetic room where you will promptly be put to sleep. Both the HIFU and NanoKnife IRE treatment use a probe, slightly larger in size to the one used when you had your first prostate biopsies taken, that is placed into the rectum (back passage) by the surgeon. During the HIFU treatment, the HIFU device is directed towards the prostate area so that the ultrasound waves can target your prostate gland through the rectum. HIFU treatment normally takes between one and two hours. The NanoKnife IRE treatment is administered by a series of needles that are inserted into your prostate gland, through the perineum, surrounding the cancerous areas. [Close Discover More](#) More detail on the urinary catheter here An indwelling catheter can either drain into a bag attached to your leg, which has a tap at the bottom so it can be emptied, or they can be emptied into the toilet directly, using a valve. It is inserted into your bladder through your urethra which is a little opening through the penis. It is not usually a painful procedure but can be a little uncomfortable – a local anaesthetic gel is generally used to minimise any discomfort. Once inserted, indwelling catheters are held in place by inflating a small balloon at the tip of the catheter in the bladder with sterile water, either already in a pre-filled chamber within the catheter or by using a syringe, so it can't fall out of the bladder. You should empty the bag before it's completely full (around half to three-quarters full). Valves should be used to drain urine at regular intervals throughout the day to prevent urine building up in the bladder. The bag can be attached to your right or left leg, depending on which side is most comfortable for you. At night, you'll need to attach a larger bag. It should be placed on a stand next to your bed, near the floor, to collect urine as you sleep. Single-use night bags are usually used to reduce the risk of infection. The catheter itself will be removed after 5 or 6 days. This is usually done by a doctor or nurse at the hospital or at your local GP surgery however it is possible to learn how to do this yourself if you so wish. [Close Discover More](#) AFTER THE TREATMENT Once the HIFU/NanoKnife IRE treatment is complete your anaesthetist will wake you up. When you wake up after the procedure you can expect to be a little groggy for up to an hour. You are unlikely to have any discomfort although you will have had the catheter fitted. You will be visited by your consultant to confirm that the procedure has gone as planned and he will confirm that you can proceed to leave the hospital. Most men will be able to go home about three to four hours later, provided there is someone to escort them and stay with them overnight. Occasionally, there will be the need for an overnight stay after treatment if your medical team think it is safer. Also, under no circumstances should you drive a car on the day of treatment. You will be taught all about your catheter and how to look after it. A contact number will be given if you have any problems at home. Most people recover from their HIFU/NanoKnife IRE treatment within one or two weeks. Most people can return to work after the catheter has been removed. Your urine may be blood stained whilst you have your catheter. Rarely, the bleeding may continue in which case you should seek advice from your doctor or local emergency department. Your bladder emptying will be assessed once the catheter has been removed in clinic (trial without catheter clinic). This will allow time for the catheter to be removed and for an assessment to be made that you are able to empty the bladder. [Close Discover More](#) FOLLOW UP AND AFTERCARE At 3 months after the procedure you will have a formal consultation with your consultant to confirm that you have had no side effects and that your PSA level has been significantly reduced. At between 9 months and 1 year you will have an mpMRI scan done to confirm that the prostate cancer has been fully ablated and that there is no clinically significant prostate cancer remaining. At between 9 months and 1 year you will have an mpMRI scan done to confirm that the prostate cancer has been fully

ablated and that there is no clinically significant prostate cancer remaining. At this stage, men will be discharged back to their GP with their detailed clinical notes confirming that the treatment has eliminated their prostate cancer diagnosis. AI tools are improving Prostate Cancer Diagnosis and Treatment AI as the key to the future of prostate cancer diagnostics and treatment. As the backlogs in cancer referrals, diagnostics and treatment continue across the country, new tools and technologies that drive increased throughput and potentially deliver better outcomes seem highly attractive. Artificial Intelligence, or AI, is often talked about in such terms, and is seen by many to be elemental in the future of healthcare. Indeed, Eric Topol, a globally recognised medical researcher and author of the Topol Review which examined how the NHS can deliver a digital future for staff and patients, believes AI will be key to improving healthcare in the UK: "By augmenting human performance, AI has the potential to markedly improve productivity, efficiency, workflow, accuracy and speed, both for [physicians] and for patients ... What I'm most excited about is using the future to bring back the past: to restore the care in healthcare." Imaging now plays a critical role in the diagnostic pathway for prostate cancer and continues to advance in both technology and clinical practice. While there has been significant growth in the use of mpMRI for the diagnosis of prostate cancer, this has manifested in considerable variability in quality. This means that reliance on specially trained radiologists is high – and is already compromised by a shortage of radiologists. The information collected in an MRI scan provides the basis for large datasets that can train an AI algorithm to undertake many of the tasks that both radiologist and urologist perform when assessing a patient's MRI scan: gland segmentation, cancer detection and localisation, assessment of lesion aggressiveness, local staging and pre-treatment assessment, and prediction of biochemical recurrence. As is often the case, the development of AI tools for prostate imaging is far ahead of their adaptation and implementation, and evidence continues to build on their effectiveness in clinical settings. What's interesting about integrating AI into prostate imaging is that the imaging itself is still evolving, both technologically and in its implementation. As mentioned earlier, there is considerable variability across the spectrum of prostate imaging - interpretation and reporting. Professor Mark Emberton of UCLH believes this is key to the role of AI in prostate imaging. In a recent European symposium, he argued that imaging is likely to be simplified in coming years, and that this will facilitate the integration of AI with imaging which will be expected, therefore, to have an increasing role in helping clinicians maximize the clinical utility of imaging studies. Alan Doherty, Consultant Urologist with the Birmingham Prostate Centre and the Focal Therapy Clinic, believes that as AI becomes integrated into imaging there will be more support for the increased use of focal therapies: "Focal therapy is a targeted treatment to an identifiable area of cancer in the prostate. Precision diagnostics are essential, and currently the technique of choice is high quality MRI. Unfortunately, accurate interpretation of MRI scans by clinicians requires years of experience and training. Computer algorithms will improve rapidly as they are taught to interpret the signals of an MRI scan, giving clinicians reliable information on the location and extent of prostate cancers. This will further support the use of focal therapies in routine clinical practice." The practice of pathology in prostate cancer is already seeing benefit from AI. This product, called Paige Prostate, improved detection of cancer on individual slide images by 7.3% on average compared to unassisted reads, according to its developers. In its review of the product, the FDA said that the risk for false negatives and false positives with the program is lessened because it is used along with a doctor and by the pathologists' consideration of patient history, laboratory studies, and other clinical information. AI tools are not only detecting the presence of prostate cancer in laboratory slides but are also showing they can perform accurate grading based on the Gleason scoring system. Do you have questions about how AI might impact diagnostics and treatment, and ultimately the experience for men with prostate cancer? Michael's story Michael Anthony, a recent HIFU patient at The Focal Therapy Clinic, had just turned 50 late last year when he was diagnosed with localised prostate cancer - quickly followed by a bout of Covid. As he says, "I got cancer for my birthday and Covid for Christmas", and his ultimate treatment was a direct outcome of these memorable "gifts". He joins OnFocus to tell his story about managing a prostate cancer diagnosis in the Covid era and to share his learnings from this experience with our listeners. Michael Anthony's story Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar Hello and welcome to OnFocus, brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, and sometimes ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this number of facts comes a multitude of challenges and opportunities. I'm Clare Delmar and joining me today is Michael Anthony, a recent HIFU patient at The Focal Therapy Clinic. Michael had just turned 50 late last year when he

was diagnosed with localised prostate cancer, which was quickly followed by a bout with COVID. As he says, "I got cancer for my birthday and COVID for Christmas", and his ultimate treatment was a direct outcome of these memorable gifts. He's here to tell the story about managing a prostate cancer diagnosis in the COVID era and to share his learnings with our listeners.

Clare Delmar I'm sort of mentioning how you were bestowed with these slightly unwelcome gifts late last year and particularly at the age of 50, which is incredibly young to be diagnosed with prostate cancer. And when I was there, because I was 50 in a month's time and I'm due a prostate check when I turned 50, the doctor starts discussing exactly that - about the fact that I need to have my prostate checked. And then about four or five days later, I got a phone call from a doctor I hadn't seen, and he told me there was an irregularity with my PSA test on my blood test. And then I was woken up on Monday morning with a phone call to tell me that there was something on my MRI. I was told when I was there that the cancer team, they have a meeting every Wednesday, and I would be discussed at the meeting. I said, so what if haven't got my results and the nurse explained that because you're in today, you will get discussed whether we've got your results or not. So I had a nervous Wednesday waiting for a phone call to tell me whether I did or didn't have cancer. And then I had a 45 minutes phone call the next day on the Friday, which I think was November 20 last year. Not that you particularly would want to, but if you wanted a family member or someone, you could have them. Even when I went in there, it wasn't that boring hanging about because it was all really kind of quick. Fortunately, you had actually had the PSA test, as you said, you had no symptoms or anything. And when I turned 50, they would have contacted me and said they wanted me in to check my prostate, to do my bloods and all that. And because I'm not a regular visitor to the doctor, that's why I think the lady was like, we might as well sort this out now. I mean, she's nursed people; when she was a district nurse, she nursed people who died of prostate cancer. Tell us about the COVID and what happened next and about what kind of treatment options were actually offered to you?

Michael Anthony Well, my treatment options were having on the 45 minutes phone call on the 20 November to tell me that I had cancer. And she then explained to me about the long term effects after...the after effects of a prostatectomy. Did it occur to you to question any of those treatment options, or did it sort of incentivize you to go learn a bit more about what this all meant? I was cold all the time, and I actually rang one of my cancer team up on the first time I engaged with them because I wasn't really engaged with the cancer team. And then suddenly, because when you get diagnosed with cancer, you get bombarded with mail like Macmillan and stuff and hospital appointments and just stuff that's like it's just a bit too much. So I was sitting in the front room with my thermals on, with the heating on, with clothes on, with my coat on, and I'm still feeling cold. And at the end of the conversation, I asked the radiotherapy doctor what they would choose. And that's really a prostatectomy, because obviously, at 50, if I had radiotherapy or chemotherapy, there's a strong chance that it'll give me cancer by the time I'm 60. So I'm left with just a prostatectomy, which is what I was booked in for on the 21st January. I went in and at pre-op, they asked you lots of questions about have you had MRSA or this and that? And it was the day that Boris had brought in a rule that cancelled all operations on COVID patients or people within 28 days of COVID got their operations cancelled. Michael Anthony To be honest, I was elated because they weren't going to give me a prostatectomy. And I think of all the after effects of a prostatectomy, and I think they weren't going to do that to me.

Clare Delmar So that had been on your mind, like the side effects that you had been made aware of were actually on your mind the whole time you just hadn't had an opportunity to really kind of voice them.

Michael Anthony I got told in a 45 minutes phone call when I was told I had cancer, they told me what a prostatectomy was because I had no idea. And to sum it up in my world, she was saying they're going to cut some length off the cock. They're going to make it so they never come again and you're going to be incontinent and have erectile dysfunction for the rest of your life. But I went in for my pre-op on a Monday, and funnily enough, the Saturday before the Monday, I filled an application form in online about whether I was eligible for focal therapy or not having read about it on one of the cancer sites. But after six weeks of doing nothing and just doing nothing to do with cancer, I posted a question on a cancer site, and within ten minutes, a guy called Chris had answered it. And then I kind of spent the whole next 48 hours just reading stuff and asking questions and getting it answered. And in the process of that over the next sort of four weeks, which is between then and when I have my prostatectomy booked, I read a piece where somebody had posted a question. Once I read that, I then read up more stuff about focal therapy and the side effects, which were compared to prostatectomy, it's just another world, isn't it?

Clare Delmar So then you contacted the clinic and began to explore if you'd be eligible or suitable for that kind of treatment.

Michael Anthony Yeah, I did that on the Saturday and on the Monday, I went in and my prostatectomy was cancelled. So Monday night I get a phone call from a guy from The Focal Therapy

Clinic, and I start talking to him, but he loses me because he's talking about cancer. They have a long conversation, and afterwards they get off the phone and she was like, this is perfect for you. But, yeah, I wanted him to see all the stuff anyway, before I had the consultation, just because of the first conversation with the guy from The Focal Therapy Clinic, I knew he'd ask me stuff that I wouldn't know the answer because I didn't really understand it. So when I had my consultation with him, which was the Monday a week after my previous had been cancelled, I had a consultation with him. But as treatments go... As cancer treatments go, and if this kills my cancer or cures my cancer, I mean, it's unbelievable. What a prostatectomy would have done to me mentally and what this did, is not even a comparison. Clare Delmar And, Michael, do you feel that you mentioned that when you were initially given your diagnosis of prostate cancer, you were counselled - if that's the right word - on what the potential, if not likely side effects would be of a prostatectomy? In retrospect, and given not just what you've experienced, but also what you experienced in your own head, mentally and emotionally, do you think that that discussion was handled well? What wasn't brilliant was the fact that focal therapy never got mentioned to me at any point. Whereas, like, my cancer was 85% on the right hand side of my prostate and 1% on the left and millions and millions and millions of men live with 1% on their prostate. Why would you put me through all of the stuff you would have put me through when I've only got cancer on one side? It's almost as if having the COVID was kind of what saved you from not having to undergo the radical treatment. So I would have probably got a phone call that night by The Focal Therapy Clinic and not been as engaging because I would have just gone through pre-op that day for an operation that's happening the following Thursday. And my partner who took the call, I don't think she would have been into taking that call, because she would have known that your prostatectomy is booked next Thursday Michael. It's all sorted. Clare Delmar I think what's really interesting about your story and your personal experience is that so much of how you take in this information and your sort of readiness to look at the other options is based on how emotionally secure you feel about it. Suddenly you are now ready to hear about something else which proved to be the right choice for you. Michael Anthony Yeah. I think it's wrong that I had to read it on a forum on the Internet to find out about it initially in the first place. I mean, there's not that many different cancer treatments, you know, however many there are. And if my cancer was perfect for focal therapy, in the words of Doctor Nigam, then my hospital should have been telling me that. And this could - if I go there in February, and Doctor Nigam says that my cancer is gone and I haven't got cancer anymore - then this has saved my life. Clare Delmar So would you then share that with other men and try to spread the word that if your cancer is localised, or certainly to understand exactly where the cancer is, and to seek second opinions? Already, my mum rang me to tell me her friend, Phil, he's been diagnosed with prostate cancer, and I got him on focal therapy straight away. And there's so many places you can get information on focal therapy now that I've had it, and now that I know a little bit about it. And I directed Phil in that direction, my mum's friend, and that's the direction he's going in, apparently. And actually, the whole benefit of doing an interview like this is that we'll put this out there for other people, too. So, Michael, I really very much appreciate you coming in to talk to me, and I know this will be helpful and really inspiring for other men. Clare Delmar A transcript of this interview is available on our website, along with further information on diagnostics and treatments for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. VIEW OUR FEES FEES £250 Consultation From £14,000 Procedure HIFU and NanoKnife treatment based upon advanced diagnostics. FEES £250 Consultation From £14,000 Procedure PRECISION TREATMENT For Prostate Cancer Focal Therapy is a general term for minimally invasive treatments for men with early-stage localised prostate cancer. These treatments have been pioneered and advanced in the UK by clinicians committed to offering men precision treatment options that effectively control their cancer and preserve their quality of life. The Focal Therapy Clinic offers patients HIFU Focal Therapy, and NanoKnife IRE Focal Therapy. More About HIFU Focal Therapy More About Nanoknife IRE Focal Therapy "Where appropriate Focal Therapy provides effective cancer control with minimal impact upon sexual potency or urinary continence." Mr Marc Laniado, Consultant Urologist at The Focal Therapy Clinic Download Free Info Pack Click here We are delighted to be selected as a finalist in the Health Outcomes category in this year's Laing Buisson's Healthcare Awards <https://laingbuissonawards.com> Download Free Info Pack <https://vimeo.com/394228009> SUITABILITY FOR FOCAL THERAPY EXPLAINED Focal Therapy is a general term for non-invasive techniques such as High-Intensity Focused Ultrasound (HIFU) and NanoKnife IRE. It has been shown to be as effective in controlling prostate cancer as radical treatments but with less side effects. Am I Suitable Prostate Cancer Facts Focal Therapy: Fight prostate cancer

with unmatched, targeted precision Download Free Info Pack HIFU and NanoKnife treatment based upon advanced diagnostics. Download Free Info Pack “For men who have been diagnosed with prostate cancer there is tremendous hope that they’ll be able to live out their disease with fewer problems than their fathers or grandfathers did in the past” Mr Marc Laniado, Urological Consultant at The Focal Therapy Clinic

WHAT IS PROSTATE CANCER?

Prostate cancer is cancer that begins in the prostate gland. The prostate is a walnut-sized gland located beneath the bladder and surrounding the upper part of the urethra – the tube that carries urine from the bladder. The gland is a part of the male reproductive system that makes most of the semen that carries sperm. Prostate cancer is the most common form of cancer found in men in the UK, with over 47,500 men diagnosed each year. Most men (78%) who are diagnosed will survive their prostate cancer for ten years or longer. When diagnosed as early stage prostate cancer 100% of men will survive their disease for five years or more. This is compared with around half of men, when their disease is diagnosed at the latest stage. Tumours can be benign (not cancerous) or malignant (cancer cells). In localised prostate cancer the cancer cells are confined within the prostate gland and can be treated, often in a way which preserves the gland and its functionality. While some prostate cancers confine themselves to the prostate gland, other types of prostate cancer cells can grow aggressively and need decisive treatment. Like all cancers, the risk to life from prostate cancer is based on the cancer cells spreading out of the prostate gland and into lymph nodes, bones, and other vital organs. The earlier cancer cells are detected, the better the chances are of the treatment being successful. Close Discover More

“For men who have been diagnosed with prostate cancer there is tremendous hope that they’ll be able to live out their disease with fewer problems than their fathers or grandfathers did in the past” Mr Marc Laniado, Urological Consultant at The Focal Therapy Clinic

WHAT IS PROSTATE CANCER?

Prostate cancer is cancer that begins in the prostate gland. The prostate is a walnut-sized gland located beneath the bladder and surrounding the upper part of the urethra – the tube that carries urine from the bladder. The gland is a part of the male reproductive system that makes most of the semen that carries sperm. Prostate cancer is the most common form of cancer found in men in the UK, with over 47,500 men diagnosed each year. Most men (78%) who are diagnosed will survive their prostate cancer for ten years or longer. When diagnosed at its earliest stage 100% of men will survive their disease for five years or more. This is compared with around half of men, when their disease is diagnosed at the latest stage. Tumours can be benign (not cancerous) or malignant (cancerous). In localised prostate cancer the lesions are confined within the prostate gland and can be treated, often in a way which preserves the gland and its functionality. While some prostate cancers confine themselves to the prostate gland, other types of prostate cancer can grow aggressively and need decisive treatment. Like all cancers, the risk to life from prostate cancer is based on the cancer spreading out of the prostate gland and into lymph nodes, bones, and other vital organs. The earlier the cancer is detected, the better the chances are of the treatment being successful. Close Discover More

SYMPTOMS OF PROSTATE CANCER

During early stage prostate cancer, many men will not experience any symptoms therefore a raised Prostate Specific Antigen (PSA Blood test) level is often the first indication of suspicion. There are a number of quite common prostate symptoms, risk factors, which can indicate an increased risk of a prostate cancer diagnosis:

Race: Black men have double the risk of white men

Family history: Increased risk if a brother or father had prostate cancer

Age: Impacts men from 50 but average age at diagnosis is 66

Increased frequency of urination

Increased urgency in the need to urinate

Weakened or interrupted flow

Straining to urinate

Erectile difficulty

Painful ejaculation

Blood in urine or semen

While these symptoms may indicate other non-life-threatening conditions such as Benign Prostatic Hyperplasia (BPH) or Prostatitis, it is vital that the possibility of prostate cancer is ruled out. If the cancer has spread beyond the prostate gland, your symptoms can also include the following:

Fatigue

Change in bowel habits

Unexplained weight loss

Swelling or fluid build-up in the legs or feet

Numbness or pain in the hips, legs or feet

Persistent bone pain which may lead to fractures

These symptoms can also be caused by prostate conditions other than cancer, such as BPH or an enlarged prostate. What to do if you think you have prostate cancer

It is vital if you are experiencing these symptoms to speak with a doctor and have a thorough check-up to determine the underlying causes. Your physician will want to know how long and how often you have experienced these symptoms to help with your diagnosis. Part of this check-up will include a Prostate Specific Antigen (PSA) test to see whether there are elevated Prostate Specific Antigen levels in your blood. In the UK, men with a raised PSA, typically above 4, will be offered an MRI scan of their prostate gland. They may also have a digital rectal exam carried out by your GP to test for hardness or protrusions. Close Discover More

PROSTATE CANCER RISK FACTORS

While there are no known direct causes of prostate cancer, there are some known factors that increase your lifetime risk of

developing it - mainly family history and ethnic origin. For example, if a man's father or a brother has had it, his chances of also getting it are higher (and it would be strongly advised to have his PSA tested regularly from 50 years old and /or if he were showing prostate-related symptoms). In addition, if you have a family history of genes which increase the chances of developing breast cancer (BRCA1 or BRCA2), or a strong family history of breast cancer, your risk of prostate cancer may be higher. Prostate cancer rarely affects young men – affecting only around 1 in 10,000 men under 40 years of age. The ratio increases to 1 in 38 for men between 40 and 59 years of age, and jumps again to 1 in 14 men between 60 and 69. The majority of such cases are men over 65 years old. Ethnicity Black men in the UK are twice as likely than white men to develop prostate cancer, with an average lifetime risk of 1 in 4 men developing the disease. Weight Those who are obese also may have a higher risk of prostate cancer, although studies have been inconclusive. In obese people, prostate cancer tends to be more aggressive and more likely to come back after initial treatment. Many studies have shown that certain behaviours and lifestyles can reduce the risk of developing prostate cancer. Some of these include:

- Exercising:** getting exercise most days of the week improves your overall health, helps you maintain your weight, and improves your mood. Beginners can start slowly and work their way up to more exercise each day.
- Having a healthy Diet:** eating a variety of nutrient- and vitamin-rich fruits, vegetables, and whole grains can improve your overall health, possibly even warding off prostate cancer.
- Maintaining a healthy weight:** aim to consume a constant and appropriate number of calories each day to keep your weight from fluctuating too widely. Consult your doctor to find your ideal weight and create a healthy weight loss plan.
- Taking proper medication:** your doctor may want to prescribe you certain medications if you are at a higher risk of prostate cancer. Drugs such as 5-alpha reductase inhibitors including finasteride and dutasteride can help bring down the overall risk. Quitting smoking can also reduce your chances of developing it.

Close Discover More <https://vimeo.com/394410801>

Steve's story (04:15) **STEVE'S STORY** Steve was ready to have a radical prostatectomy and then he found The Focal Therapy Clinic. 'My hope is that men in my situation look at the other options that are open to them' Here we present Steve's HIFU Focal Therapy treatment journey. **READ MORE STORIES**

DOWNLOAD FREE INFO PACK "Traditional surgery often leaves men with long-term erectile dysfunction – four in ten patients will still need a safety incontinence pad for urinary incontinence after a year and one in ten will be significantly incontinent. Focal Therapy would spare them these life-changing complications." Mr Tim Dudderidge, Urological Consultant at The Focal Therapy Clinic Dr Clare Allen is the uro-radiology lead consultant at University College London. She has pioneered the use of mpMRI imaging for prostate cancer since 2000 and has led the establishment of reporting standards for prostate cancer imaging in the UK.

TREATMENTS FOR LOCALISED PROSTATE CANCER ■ Choosing a treatment and health care team is an important decision. Take the time to get educated on all available options and potential negative side effects to make the best treatment decision for you. Depending on your diagnosis you may have a choice of treatments for your prostate cancer. The best treatment for one man may not be the best for another. The right treatment for you will depend on many factors including:

- Risk of the prostate cancer spreading
- Gleason grade of the tumour
- Your age and general health
- Side effects of the treatment

Treatments options might include:

- Active Surveillance** Active Surveillance involves the monitoring of prostate cancer through regular PSA tests, MRI scans and biopsies. The Active Surveillance protocol is offered to men with early-stage prostate cancer, that is confined within the prostate gland and not deemed at risk of escaping within the next 24 months. Usually this is a PSA test level of below 6 and a Gleason score of 3+3=6 or a small amount of low risk Gleason 3+4=7. There are many reasons why Active Surveillance is a part of the prostate cancer treatment journey, but in the main it is to delay radical treatments, which are likely to cause permanent side effects to the patient. For about 75% of patients this can allow a delay before having radical treatment of about 5 years, during which time many men can enjoy a good quality of life although others find the constant monitoring of their condition to be stressful.
- Surgery** Surgery, known as a radical prostatectomy, is the removal of the entire prostate by a surgeon. It is a major surgery which is an effective treatment for cancer however is invasive and has common side effects of erectile dysfunction and urinary incontinence.
- Radiotherapy with Hormone Therapy** Radiotherapy uses high energy waves similar to x-rays to destroy prostate cancer cells. The main types of radiotherapy administered for prostate cancer are External Beam Radiation Therapy (EBRT) – which directs radiotherapy beams at the prostate gland from a machine – and Brachytherapy (Internal Radiation) – which involves inserting radioactive seeds into the prostate gland. It is now standard practice in the UK to have three to six months of Hormone Therapy (Androgen Deprivation Therapy) before Radiotherapy. While this has the side effect of reducing libido and causing a loss of vitality and weight it

does significantly reduce the size of the prostate gland prior to Radiotherapy. Radiotherapy treatment is often offered to older men above 70 years old who are not considered strong enough to have surgery. For men with an estimated 10 years of healthy life span surgery is the preferred treatment option for localised disease in the UK NHS. Radiotherapy with hormone therapy is effective at treating prostate cancer however is invasive and exhausting and takes a significant amount of time to recover from. Possible side effects include a loss of vitality, erectile dysfunction and bowel issues. Within 10 years of Hormone / Radiotherapy treatment roughly 15% of men will have prostate cancer recurrence and will need further treatment. For many of these men, the only remaining treatment options are Hormone Therapy or Chemotherapy. Hormone Therapy Prostate cancer can be reduced and controlled using Hormone Therapy, often referred to as Androgen Deprivation Therapy or ADT. ADT eliminates testosterone from a man's body which significantly reduces the rate of growth of prostate cancer and shrinks the size of the prostate gland. Hormone Therapy on its own will not cure prostate cancer, rather the treatment aims to control the cancer and delay or manage any symptoms. Hormone Therapy has been demonstrated to significantly improve the effectiveness of all radiotherapy treatments by increasing the sensitivity of cells to radiation. Hormone Therapy has significant side effects including lethargy, loss of libido, depression, cognitive impairment and loss of memory. Focal Therapy Focal Therapy is a general term for minimally invasive treatments for prostate cancer that use a high dose of energy to kill cancerous cells. There are different kinds of focal therapy but all target only the area of the prostate gland with the aggressive tumour while leaving the rest of the prostate and nearby tissues and structures alone. At The Focal Therapy Clinic, we provide both High Intensity Focused Ultrasound (HIFU) and Irreversible Electroporation (Nanoknife) treatment for prostate cancer. They provide effective cancer control whilst minimising risks of erectile dysfunction and urinary continence. HIFU FOCAL THERAPY NANOKNIFE IRE Focal Therapy "Traditional surgery often leaves men with long-term erectile dysfunction – four in ten patients will need a safety incontinence pad after a year and one in ten will be significantly incontinent. Focal Therapy would spare them these life-changing complications." Mr Tim Dudderidge, Urological Consultant at The Focal Therapy Clinic Privacy Policy It is The Focal Therapy Clinic's policy to respect your privacy regarding any information we may collect while operating our website. This Privacy Policy applies to <https://www.thefocaltherapyclinic.co.uk> (hereinafter, "us", "we", or "<https://www.thefocaltherapyclinic.co.uk>"). We respect your privacy and are committed to protecting personally identifiable information you may provide us through the Website. We have adopted this privacy policy ("Privacy Policy") to explain what information may be collected on our Website, how we use this information, and under what circumstances we may disclose the information to third parties. This Privacy Policy applies only to information we collect through the Website and does not apply to our collection of information from other sources. Website Visitors Like most website operators, The Focal Therapy Clinic collects non-personally-identifying information of the sort that web browsers and servers typically make available, such as the browser type, language preference, referring site, and the date and time of each visitor request. The Focal Therapy Clinic's purpose in collecting non-personally identifying information is to better understand how The Focal Therapy Clinic's visitors use its website. From time to time, The Focal Therapy Clinic may release non-personally-identifying information in the aggregate, e.g., by publishing a report on trends in the usage of its website. The Focal Therapy Clinic also collects potentially personally-identifying information like Internet Protocol (IP) addresses for logged in users and for users leaving comments on <https://www.thefocaltherapyclinic.co.uk> blog posts. The Focal Therapy Clinic only discloses logged in user and commenter IP addresses under the same circumstances that it uses and discloses personally-identifying information as described below. Gathering of Personally-Identifying Information Certain visitors to The Focal Therapy Clinic's websites choose to interact with The Focal Therapy Clinic in ways that require The Focal Therapy Clinic to gather personally-identifying information. The amount and type of information that The Focal Therapy Clinic gathers depends on the nature of the interaction. For example, we ask visitors who sign up for a blog at <https://www.thefocaltherapyclinic.co.uk> to provide a username and email address. Security The security of your Personal Information is important to us, but remember that no method of transmission over the Internet, or method of electronic storage is 100% secure. While we strive to use commercially acceptable means to protect your Personal Information, we cannot guarantee its absolute security. Links To External Sites Our Service may contain links to external sites that are not operated by us. We strongly advise you to review the Privacy Policy and terms and conditions of every site you visit. We have no control over, and assume no responsibility for the content, privacy policies or practices of any third party sites, products or services. Aggregated Statistics The Focal Therapy Clinic may collect

statistics about the behaviour of visitors to its website. However, The Focal Therapy Clinic does not disclose your personally-identifying information. Cookies To enrich and perfect your online experience, The Focal Therapy Clinic uses "Cookies", similar technologies and services provided by others to display personalised content, appropriate advertising and store your preferences on your computer. A cookie is a string of information that a website stores on a visitor's computer, and that the visitor's browser provides to the website each time the visitor returns. The Focal Therapy Clinic uses cookies to help The Focal Therapy Clinic identify and track visitors, their usage of <https://www.thefocaltherapyclinic.co.uk>, and their website access preferences. The Focal Therapy Clinic visitors who do not wish to have cookies placed on their computers should set their browsers to refuse cookies before using The Focal Therapy Clinic's websites, with the drawback that certain features of The Focal Therapy Clinic's websites may not function properly without the aid of cookies. By continuing to navigate our website without changing your cookie settings, you hereby acknowledge and agree to The Focal Therapy Clinic's use of cookies. Privacy Policy Changes Although most changes are likely to be minor, The Focal Therapy Clinic may change its Privacy Policy from time to time, and in The Focal Therapy Clinic's sole discretion. The Focal Therapy Clinic encourages visitors to frequently check this page for any changes to its Privacy Policy. Your continued use of this site after any change in this Privacy Policy will constitute your acceptance of such change. The Focal Therapy Clinic is part of Nuada Medical Prostate Care Limited which is registered as a information controller with <https://ico.org.uk>. Full details of our company wide privacy policy can be found at <https://www.nuadamedical.com/privacy-policy/>.

Elvin Box talks about his work to eradicate Prostate Cancer taboos Elvin Box: on a mission to eradicate the taboos faced by men with prostate cancer Elvin Box, a popular and passionate advocate for men with prostate cancer, returns to OnFocus to discuss the Movember campaign which began earlier this month. Diagnosed in 2016, Elvin is a Movember UK ambassador and has written and campaigned extensively on a number of issues impacting men and their families as they experience a diagnosis of prostate cancer and navigate treatment options. Today he talks about his mission to eradicate the taboos faced by men with prostate cancer. Movember UK: <https://uk.movember.com> Clare Delmar Hello and welcome to OnFocus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men and in the UK, and with this number fact comes a multitude of challenges and opportunities. Joining me today is Elvin Box, a popular and passionate advocate for men with prostate cancer. Diagnosed in 2016, Elvin is a Movember UK ambassador and has written and campaigned extensively on a number of issues impacting men and their families as they experience a diagnosis of prostate cancer and navigate treatment options. He's here today to discuss the Movember campaign, which begins next week and his mission to eradicate the taboos faced by men with prostate cancer. I always like talking with you anyway, so to get to record it and to be talking about something that I'm so passionate about, very pleased to be given the opportunity. So let's start by talking about Movember, and maybe you could just tell our listeners a little bit about your role with Movember and most importantly, how you see the organisation and its campaigns making an impact. As you well know, I was diagnosed with prostate cancer in the June of 2016, operated later in August 2016, and on returning to work, I was then working in the corporate world and since early 2017 and I was asked if I would speak to lovely people from Movember who had come in to talk to somebody about Movember. And from there we had a wonderful discussion and we spoke passionately about my experience with prostate cancer and we were aligned completely. Elvin Box And then they showed me the DVD clip that they put out the year before as their campaign, which was to do with suicide prevention. And within 30 seconds of it starting, I was wailing, crying my eyes out and through the tears to keep playing it, it was around two minutes. So that's why I Mo, as they say, I've now come through well and truly prostate cancer, everything it can throw at you. I'm out there to smash prostate cancer and so it never kills and in the process it never takes men's mental health as well. And Movember is obviously all about prostate cancer, testicular cancer, mental health awareness and suicide prevention. Three key things that mean that men depart from this wonderful Earth earlier than their female counterparts, sometimes up to six years. Although there is some interesting research that says that 20% to 25% of men in the UK will not make it to 65. Clare Delmar And the impact that Movember is having is it mainly through awareness raising and various events? Or can you specify something that you have particularly been impressed with in terms of impacting men? Elvin Box So Movember is global, seeks to raise as many dollars, pounds and any other person's currency as possible. That money is then towards innovative programmes and research, all in the bid to reduce the impact the three causes

are taking upon men, specifically the mental health situation, because they're trying to knock that down by 25% by 2030. And it's well known... it's very very sad that this week, Michael Tyler, wasn't it, the American actor passed with prostate cancer? And he's been deeply moving because the video clips out there, you can see the agonising death he had. Elvin Box And.. and Dum dum dum, drum roll, have big enough cahoonas to let me talk in public through their media and they actually support me talking about the taboo. Clare Delmar Yeah, well, that's what I wanted to get on to next because you've had quite an impact. And I wanted to ask you how you and the campaign address what you and I have talked about this. I often call them the big three taboos around prostate cancer, which are not in any particular order, incontinence, sexual dysfunction and mental health. And so I actually ask everybody, is there anyone in the room who has suffered with prostate cancer? So I get the full backing of Movember on that and everybody who hires me in, knows that's what I'm going to talk about. I openly ask and almost beg, please bring in every gender possible, because it impacts everybody. I do everything I can to say to people, explain to people that if you look at in three ways, it can hit you. Prostate cancer can attack you and you can catch it nice and early, which you well know about. There's the big three and in no particular order, your continence, your potency, your ability to get and maintain an erection and how it affects your mental health. Clare Delmar The other thing I wanted to ask about the big three is we're calling it, is sometimes, well, not sometimes often these big three side effects, which we're calling taboos, just because no one likes to talk about them. So, yes, what you just said is absolutely true that as the prostate cancer develops and advances, sadly, those three effects will manifest, but equally, they can manifest with treatment. One of the organisations... they don't have to drag me, I run there, and I will open up, and this campaign there's a big bit about you do recognise the fact is, the earlier you catch it, the less damage that is caused in actually removing the tumour. I'd really impress upon people is that if you catch it and it hasn't hit the walls of the gland. If that tumour is eminently curable, and that means you will do little, I can't say none, but you're going to reduce dramatically the impact of the rest of that person's body, physically and mentally. And I wanted to focus on that for a second because what I'm really interested in is that often in the case with treatment. Back to your point, their quality of life would have been improved if there had been simple and straightforward information provided free and post events. And so I guess my question to you is, from your experience, how have these taboos been handled within the health system? Is this the root of this, or does it go back to something else that you've experienced personally and through your campaigning? As you will know, I talk online and actually on Zoom calls too, to learned people at various universities and the great guys out there who have suffered like me. So taking all of that in, it's not just me like thinking about it, one individual, but all that information. We as a nation in the United Kingdom and I've not heard it from elsewhere, do little or nothing to explain what we mean by impotency and incontinence. That information, that education should come way before you are diagnosed with prostate cancer, because there's such a high probability during your lifespan. Elvin Box If you're lucky enough to get to 80 and you were born with a prostate, there's an extraordinarily high probability it will be attacked through cancer. Clare Delmar Well, it's one in eight as we know in this country and one in four if you're a black man, you know that too. Elvin Box So the impact on your potency is that, well, you won't be able to ejaculate anymore and you'll not be producing any semen anymore. Now, what I just explained is everybody should be told that because they do err on the side of caution, anything with medical professionals, God bless them. There are certain things that will happen regardless of how you are treated and what stage the treatment was and how well you fared up. There's things that are just going to happen and that should be made clinically clear before you go anywhere near it. Elvin Box It's almost mentioned in passing, and it's very much dependent upon who is going to undertake your treatment. It's very inconsistent to use the Queen's English, too inconsistent, far too inconsistent in trying to explain to the person who's going to have the treatment, the extent of their incontinence and the extent of their impotence and the extent of their mental health, which is rarely mentioned. You'll be having a discussion with someone who is honest enough to say it depends how well I treat you, because if we get it up front and we can do something as early as focal therapy and that can be explained. Elvin Box And that is one of the key things that is explained, we have got a far, far greater chance of reducing impotency. In other words, you will get an erection like you used to do, which then leads on to the next bit. Don't forget to tell the people how strong were your erections before you got prostate cancer. I think that's something we're all doing quite consistently, as you say, quite passionately and particularly starting next week with Movember campaign. But other than raising awareness, what do you think can be done to ensure that all men who are diagnosed with prostate cancer understand how these issues may affect them and that support is there if they want and need it. You've just got to do something about informing those who are diagnosed

with prostate cancer. For instance, you will have a shrinkage of your penis if you go one route, one straight route through a prostatectomy. By the way, we're now going to tell you what best practise means for your penis rehabilitation, for want of a better term, because I found out by osmosis and that's five years on. Yes, I call it the resurrection because with relatively normal means, ie, I take five milligrammes of Cialis on a daily basis and without Viagra and without an injection, but with love and affection, I can now get an erection. Clare Delmar And is that what Movember is doing is trying to really reach the unreachable and try to get men to see that this is important? Their quality of life has been somewhat disturbing because we had our tumours removed, but because it was diagnosed at such a late stage. Elvin Box Thank you, Clare, for all the support you give me and the prostate cancer community that is out there online. We can only thank you from the bottom of our hearts for giving us the voice and for projecting on a regular basis the challenges because someone's going to have to listen soon because we're going to be banging down their door. Clare Delmar A transcript to this interview with links to Movember and Elvin's video of him discussing these issues with other men are all available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Precision Prostate Biopsies Improve Prostate Cancer Treatments: The MRI-Fusion Biopsy How fusion biopsies are revolutionising prostate care and opening the door to more precise treatments When it comes to choosing a treatment for prostate cancer, if you are going to have your whole prostate treated, e.g. However, if you want to maximise your chances to keep a normal sex life, stay dry and pad-free, yet treat the cancer, just knowing significant prostate cancer is present is not enough -- you need to know where the cancer is located and, critically, where it is not located, with as much certainty as possible. An optimised approach to identifying the location of cancer within the prostate means that treatment strategies that are highly targeted and minimally invasive become accessible to men with localised prostate cancer. The Focal Therapy Clinic Consultant Urologist Marc Laniado describes a recent experience that highlights how and why. And it all begins with an MRI scan: "I saw a 64-year-old man who had an MRI scan done in his local hospital and was told he needed to have his prostate taken out. Contrast is the "added juice" that helps make the scan just a bit more accurate for overall detection, but also necessary when deciding if focal therapy is possible or not and judging after if the treatment has been successful." He explains that an accurately produced MRI scan becomes the road map for an accurate biopsy: "We need the highest quality MRI scan possible combined with laser-sharp biopsies that match suspicious areas in the prostate seen on the scan. Taking biopsies under local anaesthetic gives you the information to know that cancer is present. However, limited sampling occurs because it can be pretty uncomfortable, and awkward positioning is often required. Also, it can be quite difficult to reach certain parts of the prostate, such as the lowermost part at the apex, where many vital structures come together". The accuracy of the biopsy is improved further when the patient undergoes a general anaesthetic: "In our practice, we overlay the MRI images live onto the ultrasound images, i.e. we fuse them and then very carefully sample the abnormal areas on the MRI scan," says Marc. "With the fusion, we can be very confident that we have precisely tested the prostate for cancer. Again, the reasons are that we need to know where cancer is present and be sure that there is no cancer in other parts of the prostate. Furthermore, the general anaesthetic means that we can very accurately sample the areas that are difficult to biopsy under local anaesthetic, and take more samples which can be painful under even the best local." Alan Doherty, Consultant Urologist at the Birmingham Prostate Centre and The Focal Therapy Clinic, concurs: "Finding and knowing where small early prostate cancers are located is difficult and needs precision diagnostics. Using a general anaesthetic approach is less painful, avoids patient movement and therefore more accurate biopsy needle placement". Alan is passionate about offering his patients choice in their treatment for prostate cancer, and helping them to maintain their quality of life. He explains how the biopsy technique and approach is integral to this: "Using a GATP (general anaesthetic, trans-perineal) fusion technique to perform prostate biopsies enables me to find the location, size and nature of the cancer precisely. In my experience this means fewer full prostatectomies and more targeted treatments and makes PSA screening completely logical." In the case of Marc Laniado's patient, both the MRI scan and the local anaesthetic approach provided suboptimal information. "My patient had had transperineal prostate biopsies under local anaesthetic, giving a general idea of where the cancer was. We had to wait a while after the first set of biopsies before getting a new higher-quality MRI scan, followed by biopsies that targeted the MRI abnormalities and then so-called systematic biopsies. A general anaesthetic was used to allow accurate and more comprehensive sampling." He continues, "with that new information, I could

tell my patient that he had cancer in just one part of the prostate without cancer elsewhere. He then became a candidate for focal therapy, which ultimately resulted in no detectable cancer on the post-HIFU MRI scan, normal erections with complete bladder control." Have you experienced different biopsy approaches?" "CancerCareMap.org" Robin Pritchard, co-director of Cancer Care Map, joins On Focus to discuss how the online map he provides works and how it is impacting the communities it serves. Cancer Care Map was designed to help people living with cancer find care and support services in their local area, anywhere in the UK. These services are wide-ranging and include counselling & support, exercise & fitness and financial advice amongst many others. Its aim is to make sure that no one goes unsupported because they are not aware of a service in their local area. <https://www.cancercaresmap.org> Clare Delmar Hello and welcome to OnFocus, brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this number fact comes a multitude of challenges and opportunities. Joining me today is Robin Pritchard, co-director of Cancer Care Map, an online resource that helps people living with cancer to find care and support services in their local area anywhere in the UK. These services are wide ranging and include counselling and support, exercise and fitness and financial advice, amongst many others. Its aim is to make sure that no one goes unsupported because they are not aware of a service in their local area. Robin joins me today to discuss how Cancer Care Map works and how it's impacting the communities it serves. And I think Cancer Care Map joins a whole range of digital mapping services that I seem to be aware of and no doubt you are as well. Robin Pritchard Yeah, I think it's becoming I mean, we launched our pilot site back in 2018 and went fully live with [cancercaresmap.org](https://www.cancercaresmap.org) in 2019, and we're starting to see more and more sort of people, and I think especially over the last 18 months, more and more people have turned online for help and support and to connect with other people. Clare Delmar So maybe that's a good way to just give us a little bit more detail about how the project got started. You mentioned it was in 2018 and then maybe just give us some examples of the kinds of support services that you're actually mapping. Robin Pritchard We are a charity, and the charity behind Cancer Care Map is the Richard Dimbleby Cancer Fund, which was set up in the 1960s following the death of broadcaster Richard Dimbleby. So we've worked in the field of care and support since that time, predominantly through our work at Guys and St Thomas's Hospital. And around 2015, 2016, the idea of the Cancer Map first was sort of talked about and it came very much from people approaching us personally saying, we know you've got a support centre in London, how do we find out about the support near us when people are affected by cancer? And so we commissioned some research with Guys and St Thomas' to a) sort of do some local mapping of support services in Southeast London, but also sort of to look wider to see how were people signposted to support services in their area? Some charities do have directories on their websites, but it's sort of tailored towards specific types of support or specific tumour group or a specific sort of brand of support. And I think quite often people are told, Don't Google it wait until you see your clinician. But actually, when you can't sleep and it's 03:00 in the morning, the first thing you do is pick up your phone and start Googling. I remember in one of our focus groups, a patient said to us, going to Google is like being given the key to the British Library and being told to go and find a specific book when you don't even know what that book is called or where to find it. We work with all the UK charities, all the community groups, all the NHS trusts around the country. And it's about putting all the information that's out there, all those amazing support services that are out there in the community and in the NHS trusts in one place where you can find them. I mean, I mentioned a few in my intro, but I'd like to hear from you what some of these services actually entail. There's the sort of psychological support, emotional support counselling, I think probably that's the thing that people initially think of when you think of sort of support. So all those kind of health and fitness, to do with people's awareness of their physical things that happen to them following surgery and treatment, all those sort of health and wellbeing support that's out there. It's things like you mentioned financial support, finding out about how to navigate the benefit system, things like travel and transport, how to get to and from, there's a huge financial impact if you're suddenly having to travel to and from hospital to appointments all the time. And there are so many amazing support services out there, charities and community groups, that offer help sort of taking people to and from their appointments. And another much more practical thing, there's a charity that we always talk about called The Cinnamon Trust. So if you're living alone and you have to go into hospital for a certain amount of time, they will foster your cat or your dog for you. And actually, you might not even consider that there could be a charity out there that would help you with these things. And sort of going right back to the beginning when we sort of held our first focus groups to try

and find out if we were going to develop something, what did people want? We brought together a group of patients, carers and clinicians, with a couple of GPs involved as well. And I think quite often as well the person themselves, especially at the early stages of diagnosis and treatment, you're so focused on what's happening to you and your appointments and what they're sort of practical. This is what I've got to do for the next, however many months and quite often it's the people around them. It's either the carers or their family and friends who are wanting to do something to help, who are feeling helpless, want to sort of offer some advice. How can I help my friend, my partner, by finding out about all that sort of extra additional support that's there. Clare Delmar I was going to ask you about that, too, because one of the things that we noticed with our patient group is that often it's not the cancer patient himself that is actually seeking care, seeking treatment, seeking advice. So it's interesting to hear that you obviously recognise that and that you've designed this map to support them. As a friend or a family member, you want to be helpful, you want to be able to sort of come up with things that they haven't thought of that can sort of be a real use, but also sometimes, especially if you are the primary carer you need support yourself. You need to... again through the work that we've done at Guys, very much it's that supporting the people who are supporting the people who are going through cancer. Because it's really important, because it has a huge mental, physical and financial impact on people. You mentioned a little bit earlier when you said that often people they don't know that they need certain kinds of services or support, and sometimes at least in our patient group, in prostate cancer. I think the reason they don't know this is because a) they don't talk about it and b) the reason they don't talk about it is it's kind of perceived as "taboo". And I'm aware that many of the services that you're mapping and by doing that, making accessible to people are addressing elements of cancer and cancer treatment that are seen as taboo. So I'm wondering how you think the map might help to break these taboos and possibly enable more cancer patients and their loved ones to access the services which will improve their quality of life. And again, I think there are so many ways in which cancer can impact you and impact your life and impact your family and those around you. And I think again, people have given so much information at the start that they're overwhelmed by all the information they're given. And actually, all they've heard is I've got cancer and I've got to have this treatment and this operation and it's possibly going to have this effect on me. And as you say, it can have a very physical sort of impact on someone depending on the type of cancer it is and whether that's urinary sort of cancers or I guess, as you say, affecting people's sexual functions. And again, that's possibly the kind of things that you wouldn't want to discuss with those closest to you. Actually, I think knowing that there are these amazing organisations out there that provide and again, it's something that we hear more and more, that provide a safe space where you can have the conversations about the things that are really worrying you that you don't want to have with your close friends and close family. Again, we've just been doing some interviews around the country with different people sort of around cancer care. And again, we keep hearing people referring to the cancer centres and support groups that they go to as a safe space for them to talk about things with other people who really know, understand what they're going through because they've gone through similar or going through similar themselves. I've just been looking editing his films yesterday, an Afro Caribbean guy in London who was diagnosed with prostate cancer when he was 50, and he talks very candidly with us around how men just won't talk about these things. There's a huge issue with the sort of black community not coming forward and presenting very late with things like prostate cancer because it is a taboo that you don't talk about, you kind of ignore these things. You just don't want to admit that, as he said in his interview, you've got an issue down there. And actually these support centres allow safe spaces for people to come along and actually talk about these things and actually get the help and the treatment that they need. Clare Delmar That's a really interesting example, because I've actually done a few interviews with two Afro Caribbean men about this. So yeah, maybe we'll have to touch base on that in another conversation, but it is very important one. And in fact, I saw something today about GPs engaging with black men in the early stages and sending them for more diagnostic treatment on prostate cancer. And it's a very pronounced differential because of how they get access to these services, which actually leads me on to another question that I think is something at the top of a lot of people's list the last few months, if not the last few weeks, and that's this concept of health inequalities. This has become more and more apparent and talked about certainly since our experience with Covid. And again defined as the variability in both health outcomes and the availability of services to people based on whether it's age, race, geography and I guess other factors as well. So I'm wondering how cancer care map might demonstrate these inequalities or how you might address them or how you might simply raise awareness of them. We work very closely with the NHS England Cancer Alliances, and it's something that we hear again and again around people are focused on health

inequalities and how you reach the hard to reach. And it's those communities that for so many different factors, whether it's cultural or financial or just so many reasons why certain communities don't access healthcare. We've seen it with the sort of the vaccine take up in the last 18 months and things as well. What we try and do with cancer care map is we're really pushing out there to everyone to keep it really simple as well, just so that people can just go on there and see what's around them. And again, part of our focus is reaching out to not just the patients themselves but those around them, because actually, sometimes the people around them have got more access information is more accessible to them. And so if we can get them on board, then they can then impart that information back to the person that they're supporting.

Clare Delmar I mean, do you have any recent examples of various cancer patients that have really benefited from your services? And a lot of people have approached cancer care with a lot more sort of fear and doubt and trepidation.

Robin Pritchard Back in September, we launched a digital campaign across Google and Facebook, and actually, the engagement that we're getting with people is painting quite a bleak picture, really. We know that we've got nearly 3000 organisations on Cancer Care Map that are offering amazing care and support, but people don't know about them. A lot of people just don't know or they have sort of one negative experience and it puts them off asking for help. How do you get the trust of people that they will access the services and will reach out for support when they need it?

Clare Delmar I guess on that note, my final question to you would be what would you say to a recently diagnosed prostate cancer patient, which is our community about identifying and accessing support other than sending them to your website, which I will put on our programme notes.

Robin Pritchard Yeah, we've got nearly 3000 local and national organisations are out there. Again, through the interviews that we've been doing recently, the two things we hear are people saying, Just ask for help, just don't be afraid, be honest, ask for help. The second thing is people saying, don't feel pressured, take your time, don't feel you have to tackle everything at once. And actually a lot of people sometimes it's maybe sort of six months after their initial diagnosis, after they've had their treatment and they're recovering and they've moved on or even if they're in palliative care. It's that later on, sometimes the impact of what's happened to them really hits them and that's hopefully by putting everything on Cancer Care Map, you can come back to it at any point. Again it goes back to that initial when people initially diagnosed, they're given a huge folder of information and leaflets and phone numbers and it's too much and it all gets thrown away somewhere or shoved in a corner. And actually in six months time when you think, actually, I'm really struggling now, I could do with some help. Actually, it's all there on Cancer Care Map and the thing to say as well with Cancer Care Map is that we check and verify all the information that goes on to the map. We also check and update information every two to three months, which again, is really important because things change so quickly, especially in the last sort of 18 months. The services have adapted and continue to adapt to the impact of the lockdowns and the restrictions. So, yeah, it's just knowing that that information is there and knowing that there's always help you wherever whichever part of the sort of, awful word to use, "journey" that you're on.

Clare Delmar That's a very positive message, which is one of the reasons why I wanted to bring you on the programme because there really are these services out there, and it's really wonderful to see you trying to consolidate them in a way that gives people access. There are all these amazing services, amazing centres that are sort of charity run and community led, and they do provide that safe space where you can go along and just have those conversations or just sit down and be angry or sit down and cry with people who really understand, who aren't your friends and family, who are people that have been through what you're going through.

Clare Delmar A transcript of this interview and links to Cancer Care Map are available in the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer, please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Prostate Cancer Issues need to be discussed openly Breaking the taboos around prostate cancer It's that time of year again – when moustaches are in and taboos around men's health are out. Movember starts this week, gearing up in its mission to break the taboos around mental health, prostate cancer and other diseases affecting millions of men across the globe. Elvin Box, Movember ambassador and prostate cancer survivor, is on his own personal mission to do this. He spoke to us earlier this year about how he uses his experience to inspire men across the country to speak openly and honestly about all aspects of their health. He says: "I am lobbying for what every person with a prostate should receive - better and quicker diagnosis of prostate cancer, that leads to undergoing treatment that results in just a minor impact upon the quality of life enjoyed by the victims." And he believes that one way to do this is to break some taboos around prostate cancer, and support men in understanding and voicing their experiences with the life-changing conditions that sadly

for many bring embarrassment and shame. It doesn't have to be this way. We can start with The Big Three – anxiety & depression, sexual dysfunction, and incontinence. These conditions affect many men who are diagnosed with and treated for prostate cancer, and despite the enormous impact they place on these men, they are rarely talked about. We've spoken with specialists in these areas about how the taboos placed on these conditions harm both the men experiencing them and their loved ones. Talking mental health, Oncological Psychiatrist Asanga Fernando told us: "I think a really damning statistic of our time is that 73 percent of cancer patients diagnosed with depression, and this is across tumour types in the UK a few years ago, don't receive any adequate evidence based treatment for their depression. Cancers across the board, about 17 percent of cancer patients suffer with depression at some point during their cancer journey. We know for prostate cancer, it's about that." He believes mental health support needs to be better integrated into clinical practice for cancer patients, and is dedicated to making this happen through his work at St George's Hospital London. "As a clinical community we need to drive a shift in culture towards measurement of patient quality of life as a marker of treatment effectiveness. It appears that despite recent developments in cancer treatment, many of which have improved patient survival, the clinical community has been rather myopic in failing to adequately consider how investing in the mental health of cancer patients can improve patient experience, Quality of Life, functioning, and even engagement. This involves doing things differently, namely thinking innovatively and more effectively integrating mental health and psychological wellbeing into routine cancer services." In terms of sexual dysfunction, we spoke with psychosexual specialist Lorraine Grover about what men have told her when they are diagnosed with prostate cancer: "A lot of men have said to me over the years that they would rather be sexually potent, whatever that definition is to them and alive, being sexually active, than not being sexually active and having their cancer cured because of the effect of the treatments of managing prostate cancer, which is so sad to hear when actually if the subject was raised with them, they would know that there are lots of things to be considering about sexuality and prostate cancer." She believes discussions about sexual health and practice need to happen upfront, and include partners too when appropriate. "People need a safe environment to be able to talk about their sex lives and to be able to have that discussed with the health care professional. Partners, and women in particular, need the opportunity to talk to somebody about the impact that prostate cancer has had on the man in their life's personality, their health, their fear, etc. It also allows a discussion to take place about ongoing sexual issues - It could be, I'm seeing a patient in their 50s where their partner may be in the menopause or premenopausal or has had her own ill health, has never had an opportunity to talk about sex with anybody. And I'm part of that team, hopefully, and I address it and they go, wow, I've never had this opportunity to talk about things." Addressing incontinence and urinary health, we spoke with pelvic health specialist Jane Simpson about the poor communication men receive about it. "A patient recently told me: 'My prostate first made its presence felt during my mid 50s when having a wee ceased to be what it was. What had always been a powerful jet dwindled to a mere trickle and three or four effortless tries where needed before my bladder felt empty. Like most men, when things go wrong below the belt, I was overcome with squeamish embarrassment and told no one.' I think that sums up about communication to do with men and incontinence." She added that the poor quality and availability of public loos exacerbates the embarrassment men feel around incontinence and reinforces their reluctance to talk about it. "I think that access to public loos for men, they don't ever think about it before they've had this particular issue and suddenly it becomes actually quite important. And interestingly, I've had a lot of conversations with guys about the fact that male loos don't have bins in them. If you go to a ladies loo, there's a sanitary bin to put your sanitary towel in, or your tampon or whatever. Men don't carry handbags!" We continually hear about public toilets as both a challenge to men living with incontinence and an opportunity to discuss it openly and provide support for these men. A blog we published last year about this attracted considerable attention from men whose lives had been compromised by their inability to access a toilet, and we continue to raise awareness about what is effectively another taboo. What are your experiences with taboos associated with prostate cancer? A View From the Frontline of Prostate Cancer Treatment Charlie LeBosquet, clinical application specialist for Prostate Care Limited joins the podcast to discuss his views from the frontline of prostate cancer diagnostics and treatment. Charlie has been a critical link in the theatres where men are biopsied and treated for prostate cancer for nearly two decades, supporting clinicians and operational staff alike, and he has a unique and valuable perspective on the advance and adoption of technology in the diagnosis and treatment of prostate cancer. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870 Clare Delmar Hello, and welcome to OnFocus,

brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Joining me today is Charlie LeBosquet, clinical application specialist for Prostate Care Limited. Charlie's been a critical link in the theatres where men are biopsied and treated for prostate cancer for nearly two decades, and he has supported clinicians and operational staff alike. He's got a unique and valuable perspective on the advance and adoption of technology in the diagnosis and treatment of prostate cancer.

Clare Delmar So you've been in this business for a long time, as we say, and hence why it's taken me with such persistence to get you here because I know you have a lot to share. I guess the first thing I just want to say is you've been, I love this term, clinical application specialist in the field of prostate cancer for well, I think I said almost two decades, but maybe you can clarify that and just tell us a little bit about what that role means. So what we do as clinical application specialists is the various companies that have work for provides the equipment and the technical expertise for the surgeons to use in their diagnosis and their treatment of prostate cancer. A good way of describing this as an analogy is in the same way that rock bands have roadies who set up all their equipment and manage their sound desk whilst they're playing their instruments and doing their stuff, we have a similar role within theatres. We're very knowledgeable in how the equipment works and the best ways of getting it to suit what the surgeon wants to do. They carry out the procedure, and our role is to help them get into the best possible position to be able to do the procedure itself. And I appreciate the analogy of roadies for rock bands, because I know that you actually are a rock musician yourself, so you're kind of operating on both sides, but that'll be for another interview, I guess.

Charlie LeBosquet I'm not big enough of a musician to have roadies ourselves.

Clare Delmar So basically you're there on the front line with the surgeon and the theatre team, and, of course, the patient. So what has changed since then, since you began, in terms of both the technology that you're talking about, that you set up and the theatre operations themselves.

Charlie LeBosquet When I first started, this is back in 2005, I was working with a company that provided HIFU equipment for treating prostate cancer using ultrasound. Now, at that time, the way I saw it from the technical point of view is the various technology companies were competing to come up with better ways of treating prostate cancer. Most of this, all of this is actually driven by the doctors and the technology companies are looking to find ways and ways of using the science to develop better ways of treating prostate cancer. And then it seemed to me there was a certain shift in where the technology expertise was focused. Previously it had been all about finding better ways of treating prostate cancer to get a really good level of cure but to reduce the level of side effects. Around about 2009, the technology companies started coming up with better ways of diagnosing prostate cancer. I say the technology companies, it's not the technology companies that come up with the ideas, it's the clinicians that come up with the ideas and the technology companies go away and work on how they do that. So the emphasis shifted from different ways of treating prostate cancer to different ways of getting the best possible diagnosis that you could for prostate cancer. From where I am, working in theatres, I see the technology when it actually is sufficiently developed to be able to be used in theatres. Whilst all this is going on a long time before you get to that stage, there's an awful lot of research going on in the background with technical companies, but mainly with the doctors and the first stage I think on that was to take biopsies from being a transrectal approach, i.e. putting a needle through the rectum into the prostate, which is a standard way of doing biopsies to using a transperineal approach, which is where the probe is still in the rectum, but the biopsy needles are actually put through the perineum and they're horizontal. Rather than doing fairly random biopsies, they could take very systematic biopsies covering the prostate to do the best they could to make sure they weren't missing anything. Now that kind of transperineal biopsy developed from brachytherapy and cryotherapy, where you had equipment that set up a grid on the perineum so you could put your needles through at specific intervals to be able to cover the whole of the prostate.

Charlie LeBosquet Yes, it's difficult to say as I wasn't involved in that part of it, but they were doing - I know when I first started - clinicians were doing cryotherapy and brachytherapy, which involves using these needle based setups. And then from there they began to use those, or they were using those in order to do transperineal mapping biopsies.

Clare Delmar OK Charlie LeBosquet What happened after that, or again, this will have all been being developed at the same time as the technical and clinical teams were working on developing the MRIs to such an extent that the MRIs could give an indication before the pre-diagnostic as to where the suspicious areas may be within the prostate. And one of the things I specifically remember when we first started providing this equipment to do transperineal biopsies, the surgeons were coming into theatres with MRI reports of MRIs that have been taken prior to the biopsy, and they were looking at these MRI reports and saying, okay, I'm going to do a full mapping set up, but

I want to focus on this area or these areas because the MRI reports were telling them that's where the suspicious areas were likely to be. And they came up with this term or the term that I heard all the time was 'cognitive fusion'. And cognitive fusion was effectively where the surgeons had all the equipment, which gave them a live ultrasound image. And they had equipment to effectively be able to put the needles exactly where they wanted to. Clare Delmar OK. Charlie LeBosquet But they had to take the written report of the MRI and work out in their heads, which holes they needed to put the needles through in order to get into that area because there was nothing on the live ultrasound image that could mark out that area. However often surgeons would say to me, what would be really great is if we could superimpose these diagrams that the radiologists are giving us as to where the likely areas of cancer are. If we could superimpose that on top of the live ultrasound image so we have the targets marked out. Charlie LeBosquet Yeah, just like to be written over the top - now that would have been in probably 2010, 2011. Clare Delmar OK. Charlie LeBosquet When I think it probably started effectively in efficient systems, probably in my experience, in around 2014. So this is where companies came up with software in order to actually do this process where you can superimpose the target on top of the actual ultrasound image. So the way they manage that is by various different software methods, but effectively, in the nutshell, what happens is the MRI is taken in slices. The software package, enables the radiologist to outline the prostate at each slice and then to outline all of the suspicious areas at each slice. And if you imagine that creates almost like a framework, like if you imagine an egg in an egg slicer, you have all of those various slices. You end up with a sort of cartoon of the outside of the prostate and where the suspicious areas are. What then happens is you have that loaded into your software before you start the procedure. The live ultrasound is linked into the computer, into the software and effectively, the live ultrasound is broadcast and via a series of captures and manipulations, you can manipulate your cartoon as it were, to fit the actual live image of the prostate. And then as the surgeon moves the probe in order to get to the areas that they want you to take the biopsies, the fusion goes with it. Clare Delmar So I'm gonna pick up on your funny, popular cultural analogy from earlier on and say it sounds like a video game. Clare Delmar In all seriousness, are there simulations for surgeons to actually learn how to actually superimpose this. I know the software does it, but then to actually practise exactly what you've just described. Now, elastic fusion is where you have a software programme that you outline the prostate with your mouse at various levels. And then the little cartoon that we talked about earlier fits itself around that shape of the prostate. And the various mathematical algorithms adjust the shape in order to predict where the suspicious areas are. You also have a method of rigid fusion, whereby the cartoon that you have is exactly the same shape as the MRI image of the prostate. Then it's more a question of making sure you're not squashing the prostate when you have the live ultrasound image and you overlay it. Clare Delmar Which are sort of using two technologies or two imaging technologies, I suppose? Charlie LeBosquet Exactly. Clare Delmar So I mean, what you're describing is it considered to be kind of the gold standard that everyone should have access to - this very sophisticated, very precise form of biopsy? Charlie LeBosquet That's not really for me to say, because we should perhaps have said this at the beginning: I'm not a doctor. Clare Delmar I guess where I was going with that is, do you actually see variations, do most hospitals do this procedure? Charlie LeBosquet Well, because I work for a private company and we take our equipment to hospitals who do these procedures, but don't do enough of them to necessarily warrant buying the equipment. I don't really see the areas where it's being used with people with hospitals that have already bought their equivalent. Clare Delmar But I mean, given that you've seen this advance from paper or sort of physical MRI images and the cognitive process that you described earlier. I'm not asking you to look into a crystal ball, but what do you think are the key technological trends that might be driving, you know, even more precision or more widespread adaptation and any thoughts on that? Charlie LeBosquet Well, again, it's difficult for me to say, because I don't see what the doctors are working on at the moment. If I put a patient hat on as it were and try to imagine what I would like to be able to see as a patient, what would be really fantastic is if the MRI could be definitive in its diagnosis of what is cancer and what isn't cancer. But one of the things that all surgeons would feel that it gives them a better indication, a better understanding of what's going on in the prostate is if they have technology that can not only tell them where the cancer is, but can also tell them with some level of certainty that there isn't any cancer anywhere else. But I don't think anybody could say I know that there is only cancer there and there's nothing anywhere else. But then, I suppose, go back many years, they probably wouldn't have been able to tell where anything was anyway. Things have developed quite significantly now, and if that carries on, then that may make life a lot easier for them. What I do know is once the surgeons that we've worked with have started using this technology,

they don't want to stop. So that is an interesting observation and final point, I guess, is we've talked about technology and adaptation. Are there fewer people that are required to undertake these procedures because of this technology? I'm not sure that much has changed because it revolves very much around the surgeon getting the needles into exactly those areas of the prostate that the surgeon wants to get the needles into. So I don't think the theatre operation has changed a great deal other than the areas of targeting that are clearly marked out for the surgeon.

Clare Delmar Charlie, I mean, you are somebody who's been incredibly devoted to the support of this incredible event of technology. You've seen so much and you know, I think it's important that all patients understand what the roadies are doing. Just as when you go and see the rock band, we know that all would not be possible without the roadies behind. I think it's really important, and it's really fascinating and you've been so devoted to it.

Clare Delmar A transcript of this interview is available on the programme notes on our website, along with further information on diagnostics and treatment for prostate cancer, along with additional interviews and stories about living and treating prostate cancer. Please visit the www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Four Questions on the Implications of Age in Developing Prostate Cancer

Ageing is the highest risk factor in developing prostate cancer, and its commonly accepted inevitability is often encapsulated in the comment "you don't die of it, you die with it". So entrenched is this mentality that it drives attitudes, behaviours and practices around the management of prostate cancer, to the point where we have seen blatant age discrimination in patient care. In an attempt to address this age discrimination, we produced a series of podcasts and blogs based on interviews with both patients and clinicians about their experience. In addition, we encourage all men and their loved ones to consider four key questions about age-related implications of developing prostate cancer. Is it exclusively older men that develop prostate cancer or are younger men developing it too? A recently published study from the USA showed that prostate cancer has been increasing amongst younger men "Prostate cancer in older adolescent and young adult men has increased in most countries. There is some evidence that this may be caused in part by underdiagnosis, prostate-specific antigen screening, and overdiagnosis. It also may be caused by trends in obesity, physical inactivity, HPV infection, substance exposure, environmental carcinogens, and/or referral patterns. How the biology of these cancers differs from that in older men and how the etiologies vary from country to country remain to be determined". Another US study showed the incidence of prostate cancer in younger men to have increased by 6x over the last twenty years. It emphasised the aggressiveness of the disease in younger men as compared to their older peers, and highlighted that those with family histories and of Afro-Caribbean descent are most at risk. Is prostate cancer different in older vs younger men? A recent review in the Lancet of five main cancer types concluded that yes, it is, and this needs to be better understood to develop more personalised care to patients. "To conclude, although most tumour subtypes and molecular alterations seem to be present in all age categories, there are clear shifts in the distribution of these characteristics with increasing age. The biological explanation as to why some subtypes and alternations are more frequent in older people has yet to be elucidated. Cumulative DNA damage with increasing age and immunosenescence might play a role, but are insufficient to explain all the observations summarised in this Review. A better understanding of these biological processes is needed and might help to better understand cancer biology globally, and as such improve personalised cancer care in both young and old people with cancer". How does one define "old"? From an NHS point of view, the age of 70 is a demarcation line in characterising someone as "elderly", and approaches to patient care derive from this based on years of practice. Yet anecdotally we see wide variation in the cognitive, attitudinal and physical characteristics of men aged 70+ who come to the Focal Therapy Clinic, many of whom tell us they've have more energy and better quality of life than they did at age 50 (and sometimes 40). Scientifically we can now differentiate between chronological age and biological age using several approaches, including those based on cell senescence and epigenetics. Each of these approaches are likely to have implications for prevention and treatment of disease, and have influenced a growing body of researchers and clinicians, some of whom have recently launched a campaign through the Lancet to reclassify "Old Age". "Chronological age is of limited use for diagnosis, prognostication, and treatment guidance. Additionally, age by itself is of limited use for the assessment of population health, for the evaluation of initiatives designed to promote healthy aging, and for health or social care planning. Ageing might predispose to some chronic medical or mental health conditions with other factors playing a much greater role in the disease causation than age alone". If we can manage and control our biological age, will that reduce the risk of getting prostate cancer? This is not yet fully understood, although researchers continue to investigate links between specific aspects of ageing and

certain diseases. A recent UK study has shown links between cell senescence and prostate cancer, which coupled with evidence on interventions that reduce or curtail cell senescence could lead to new approaches to managing the disease. More immediately, some of this research could help us to understand and improve recovery for men after they have had treatment for prostate cancer. Advances in epigenetics have encouraged some researchers to apply these techniques in developing prevention and treatment strategies for some cancers. Outdated assumptions about age can lead to misinformation and poor treatment choices, and we are committed to dispelling these in our approach to patient care. This is underpinned by three continued practices: Raising awareness of prostate cancer among younger men and providing screening if they are at particular risk – eg. prostate cancer is present in their family and/or they are Afro-Caribbean. Providing “older” men access to a wider range of treatments, appropriate to their biological v chronological age. Advising all men of the opportunity to improve both biological age and healthspan through a range of adaptations and interventions, which we have discussed in podcasts [here](#) and [here](#).

Meet The Focal Therapy Clinic Experts Supporting a world-class clinical team to deliver personalised patient care Focal Therapy, by its very nature, demands a whole person approach to patient care and a thorough interrogation of each patient’s values, priorities and quality of life. This requires a detailed, open and honest conversation with him about all treatment options, and how these will impact his mental health, sexual health and urinary health. The process of assessing a patient’s suitability for focal therapy is culminated in the MDT, a finely tuned and deeply informed collaboration amongst our team of clinical specialists in urology, radiology and oncology, supported by state-of-the-art diagnostic technology and expertise, itself continuing to advance in precision and strength. The Focal Therapy Clinic is privileged to support a team of outstanding clinicians dedicated to both personalised care and clinical collaboration in the diagnosis and treatment of prostate cancer. So who makes up this team, and what is the expertise they contribute?

Dr Clare Allen, UroRadiologist Clare’s pioneering research and deep expertise in reading and interpreting prostate MRI scans is what underpins the review of each patient’s case in the MDT. Her approach to reporting on each patient scan is state-of-the-art and widely regarded as best practice in the UK if not the world. “Excellent prostate cancer care involves a multidisciplinary approach, which they excel at here at the Focal Therapy Clinic,” says Clare. “Prostate cancer is an interesting cancer because there is such a wide spectrum of disease. A lot of tumours we detect can be safely monitored, as they pose no danger to the patient, while others are very aggressive and need to be treated very quickly in order to save the patient’s life. MRI scans can help determine what type of tumour the patient might have, so it’s an area where it has been possible to make hugely beneficial changes for the patient. About 50 per cent of men here have an MRI scan before having a biopsy, and this number is rising each year, while in the US, for example, it is around 7 per cent. “At our biweekly MDT, we discuss the scans and any biopsy results, and work out the options for each patient’s treatment. This multidisciplinary approach is best for patient care and offers a personalised approach to their cancer treatment,” Marc Laniado, Consulting Urologist

In addition to focal therapy, Marc has developed deep expertise in robotic surgery. He is also known for his holistic approach to patient care and, in particular, his attention to sexual, urinary and mental health in prostate cancer patients. He explains this in a recent interview. “Many years ago I went to medical school like everyone else, and I wanted to be a doctor to understand the human body, to be able to help people. I was very much involved in trying to understand why prostate cancer spreads from its local site in the prostate gland to going out into the bones. And then during my training, we used to do lots of open operations to remove prostates and send patients for radiotherapy. And I was always struck by the seeming difference between the severity of the disease and the consequence of the treatments that they received. So I was always wondering how we could make our treatments fit the struggle or problem that the patients had. And so whilst I tried to improve my surgical delivery of treating prostate cancer through robotic prostatectomy, eventually, the keyhole way, there was always a feeling that I had that many of our patients probably could be helped by other means. And so I looked for treatments that could be focused literally on the cancer itself and an area around it, rather than necessarily treating the whole prostate. So the basis has been trying to keep men as healthy as they are with their normal way of life, treat the cancer, but not to give them so many side effects as we had experienced in the past.”

Tim Dudderidge, Consulting Urologist Tim is widely recognised as an innovator in the management of prostate cancer, and this year was appointed a Clinical Champion by Prostate Cancer UK. He has undertaken pioneering work on non-invasive treatments for prostate cancer, including HIFU, cryotherapy and now focal laser ablation. He describes the challenges and opportunities he sees in introducing new technologies for patient care. “I think the first and probably the easiest is the technical skills. I mean, I think as surgeons, we’re naturally inclined towards learning new technical skills and

that's what we're good at. Whenever you're doing something new as the pioneer, you feel, I guess, individually convinced of the merits of doing this new thing and you feel that there's an advantage. But there's so many other people that you interact with who sort of need to be similarly inclined. And so you end up in some conflict." "I think the first phase of introducing this new technology is to kind of go through that process and learn to deal with the conflict and manage it. Certainly with prostate cancer, it's full of uncertainties and learning how to explain the risk of different competing issues. And I think when you're introducing something new, which perhaps is a useful challenge to some of the difficulties of existing treatments, you need to explain, yes, this is a new and untested treatment. And so that process of explaining that, so that patients are making a decision to enter a trial or try a new treatment, that they're doing that fully informed of the pros and cons, and that again, takes a lot of time. And after a few years of doing it, I really feel like I'm quite good at that now." Raj Nigam, Consulting Urologist and Andrologist

Raj's specialism in Andrology gives him a powerful perspective on the impact of prostate cancer and its treatments on sexual health, and he has a particular interest in how hanging perceptions of ageing are affecting how men are treated for prostate cancer. "Many observers have noted that the various biases and issues that we have in medicine generally have been brought to the fore with Covid and how, for example, elderly people were managed and treated with this potential diagnosis, particularly in Western countries, and that was sanctioned at the highest level. People who have now begun to think, well, hang on, do these sorts of issues and criteria for diagnosis and management apply in other conditions? And we've known for a while that in cancer management, that age and ageism has played a role. You know, for example, in breast cancer management, there have been several studies which have shown that the outcomes of more elderly women with breast cancer is worse, where ageist attitudes have been brought in. So within prostate cancer, the pervasive notion that you're much more likely to live with it than die from it is one that is actually influenced even in the earliest stages of diagnosis. They will be denied further investigation to even diagnose what type of cancer they have because they say, look, even if you have it, it won't affect you in your lifetime. And even when it is diagnosed, far more men are given this management term of what we call watchful waiting, which is an old term and it's a little bit parochial and probably has a bit of unconscious bias attached to it. But we have to recognise that the mental effect on a lot of men who are diagnosed with this is quite great no matter what their age. And we know, again, the outcomes are worse than men who are affected mentally by the diagnosis than those that are not. So I think it's something that we all have to take a step back and take on board, that we really must not have our subconscious biases regarding age when we're either trying to diagnose or manage the condition. Alan Doherty, Consulting Urologist

Alan comes to the Focal Therapy Clinic having been voted top urological surgeon by Daily Mail based on many years of experience as a practicing clinician. He was drawn to practice focal therapy as the evidence base built and brings a fresh approach that is no nonsense and robust. "I often ask myself, how do patients choose any particular treatment? So you often find that engineers, for example, like a solution to their problem, are quite enthusiastic about choosing surgery as that solution. You'll get other people who are much more concerned about their quality of life and their sex life, for example. And you say, well, it's not up to me and I'm not you, so you need to sit down with your family and write a list of your priorities, see what you could live with and what you couldn't live with. And then the urologist is there to help patients through that journey to highlight to them. And my experience, and I think I've been guilty of this as well, is that we are very much taught to treat cancers with a curative obsession. But we now have a range of treatments that can slow down cancers with none of the side effects that destroy a man's quality of life, and these need to be included in the offering". Would you like to discuss anything with our clinical team?

Raj Nigam, Consultant Urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy Clinic is an andrologist with a special interest in the impact of prostate cancer treatment on sexual and mental health, and has spoken several times before on the podcast about age-related implications of prostate cancer treatment. He's here today to discuss how advances in ageing research could potentially aid in recovery from prostate cancer and its treatment. Or, in other words, if the biggest risk factor in developing prostate cancer is ageing, what can we do to mitigate that risk?

Clare Delmar Hello and welcome to OnFocus, brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Raj Nigam, consultant urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy Clinic. Raj is an andrologist with a special interest in the impact of prostate cancer treatment on sexual and mental health and we've spoken several times before about age related implications of prostate

cancer treatment. He's here today to discuss how advances in ageing research could potentially aid in the recovery from prostate cancer and its treatment. Raj Nigam Thank you Clare Clare Delmar So you're sort of my go to person to talk both about different types of treatments and how it impacts the sort of wider health elements for men and also how age factors into that. So I'm really excited that you're interested in talking about where this might be leading us. And I think before we start, it would just be good to sort of set the base case for what recovery needs and how different treatments lead to different recovery outcomes. So maybe you could just describe for our listeners how recovery does differ according to the type of treatment, whether it's an invasive treatment, an non-invasive treatment, what do you think and how would you describe recovery? Raj Nigam Essentially, it's important to be aware that the treatment options in prostate cancer are very varied. There is a spectrum of treatments ranging from surveillance alone, what's known as active surveillance or previously known as watchful waiting, ranging right through to the most radical surgery, what's called a radical prostatectomy and therefore recovery is very much dependent upon the treatment that you choose. And under treatment I do include active surveillance because although there is no intervention as such, it's important to be aware that the decision to go down the active surveillance route is not without its implications, both mental and physical and not just for the patient, but also the patient's partner or carers, and so on. But obviously, where you have done a major intervention, which may or may not have led to significant life changing complications in some cases, that will, of course, hamper one's recovery. And although we are talking about age as a factor in these recovery processes, we do know that age is a fluctuating spectrum now. We no longer think that because there's a clear distinction between chronological age and biological age. And this is a fascinating area of research that we're looking into not just in terms of prostate cancer, but in terms of ageing in general, we know that there's a massive amount of research going on in ageing in the brain and development of dementia and so on, and how people can reverse that. So, you know, like I said, ranging from the most extreme treatment intervention to the most basic, all of those will have different impacts upon their recovery. We know from scientific studies that the treatments that cause the greatest urinary or sexual or bowel dysfunction will lead to the most protracted of recoveries and the most difficult of recoveries. There are many, many surveys that can be done whereby regret is defined and regret is defined as a number, and then that number is allocated to an individual following questionnaire analysis. And we do know that decision regret is highest in the most severe form of intervention, i.e. In fact, there's a paper from my own institution, which is a large institution that carries out radical prostatectomies, which showed that after 18 months, 30% of men who had undergone a radical prostatectomy had a high degree of regret. Raj Nigam Under multivariate analysis, actually, age was not a factor, although one would think that intuitively that it might be that older men perhaps would cope with a greater degree of dysfunction than young men who might be working, for example, have good sexual function prior to the treatment. But what was more important, it seems, is the involvement of the individual in the decision making. And this is repeated across the scientific literature that if you involve the man and discuss all the treatment options in detail, then the level of decision regret is less than it would be because they go into it completely with their eyes open, knowing what they may or may not expect. And I think age is a role in this, too, in terms of even having the questions initially and actually being able to tell those conversations with the doctor. Raj Nigam And I think that is partly a cultural thing in that perhaps that the older man may not ask as many questions, may have a greater degree of deference to the doctor or the nurse who is informing him about his or her treatment options, and may not necessarily question what other treatment options may or may not be available. The other important factor to note regarding age is that traditionally a lot of older patients, so I put that in inverting commas, have been denied certain interventional treatments, and that hopefully is changing, not just with the older male or the ageing male having knowledge of what is available, but also the fact that older patients now with their comorbidities that they may or may not have being managed better will be able to cope with interventions much more so. Whereas a lot of older men might have just been put on the so called watchful waiting protocol, a lot of these men are now seeking an active treatment for their prostate cancer, and I think that's a good thing, because they should not be denied purely on the basis of chronological age, their particular treatment. Clare Delmar Do you think they'll come a point where this chronological age versus the biological age will actually be a) measured and then b) applied in these decisions? Again, there are scientific measures that are being produced whereby you can distinguish between the two, between chronological and biological age. But we, as doctors, can often do that simply by talking to the patient and knowing a little bit more about our patients and their lifestyle and what is important to them and so on. So I think a lot of it is part of the doctor - patient and the nurse - patient relationship and understanding the involvement of the patient in

the decision making process. Clare Delmar So in that case, it becomes a little bit more subjective because you have kind of the tools and the experience and the interest to build that relationship. I guess what's interesting me is that in terms of bringing some objectivity to it, you can see that our understanding of ageing is advancing all the time, and even at the cellular level we're hearing people talk about longevity, and without getting into that, I'm interested in how you think that this might impact our approaches to both the treatments offered and then therefore the recovery from prostate cancer treatment. Do you think that this will get better informed so that everybody will have access to a more age appropriate pathway? I think that certainly age will have an important impact on the recovery process following whichever treatment we do. For example, a patient who might have had an open radical prostatectomy procedure previously will now be having a minimally invasive approach. We know that if we prepare that patient well that the patient will be discharged from hospital earlier and therefore will have hopefully less immediate post operative complications. And whereas previously, age might have been a complete contraindication to carrying out such interventions, that should no longer be a barrier as long as the physiology of the patient is such whereby we know that they're going to recover and recover relatively quickly. Clare Delmar Ok. Raj Nigam Your second question relating to recurrence, however, is a much more controversial one, and it's an interesting area of science on whether age and indeed the recovery process will impact upon future recurrence. It's an interesting area of science, but at present, we're lacking in evidence on whether recovery actually does impact upon future recurrence of cancer. Clare Delmar I mean, if I kind of go back to putting it bluntly at the most basic level, if you look at the biggest risk factor for developing prostate cancer, it's ageing. It sounds like stating the obvious here, but I could then ask and I will ask, how do you think we can better mitigate this risk? And there is a concept called cellular senescence, which actually is a double edged sword because we think that cellular senescence, which basically means that our cells which are constantly proliferating and undergoing what's called a cell cycle, are for some reason arrested, and they stop at that point in time. And we think that is beneficial in terms of tumour development, for example, that certain tumours may only get to a certain size and then not grow any further. But we also know that the other edge of that sword is that we think that leads to ageing because our cells are no longer being renewed as they were when we were younger and therefore we develop wrinkles, our organs age, etc. So it's an interesting area of science on how you can mitigate the advantages of cellular senescence, but actually decrease the disadvantages. There's a lot that's been studied in terms of diet, in terms of various factors that can influence ageing at a cellular level to our advantage without losing the benefits of ageing. Because anecdotally we all know that, for example, in very elderly patients, there may be some tumours that are extremely slow growing and prostate cancer is often one of those, not in all cases, but is often one of those. So it's a case of how can we harness those effects and single out a particular organ, for example, that that particular organ will undergo cellular senescence, but that it won't have a wider impact on the rest of our bodies. I mean, it's almost like, you know, good cop, bad cop in training it to do the right thing. Raj Nigam I'm not a trained cell biologist, but my basic understanding of it is that there is this constant battle going on within us with cell turnover, cell proliferation and also cell senescence. Clare Delmar So in the meantime, I think people should keep an eye on what this research is leading to, and it's always advisable anyway to have a healthy diet and to exercise and do the things that are going to reduce inflammation and basically keep you healthy. So I think that the concept of diet in ageing is really important, and we understand a lot more about it now than we used to, and we understand what supplements are important and which are not and also, like I said, which supplements may be helpful in reducing cell turnover so that we do not develop tumours and so on. So there's a lot of research that is going on in there, and I think that those are the sort of interventional factors that are constantly being studied. And we know exercise also is extremely important in needing a generally healthy life, but also in the non development of psychological, mental and physical problems. Clare Delmar I mean, we could talk forever about this, and it's really interesting because it becomes a multidisciplinary approach, doesn't it? I mean, we're kind of integrating cell biology with gerontology and oncology and that gets to be an exciting but often a very controversial and even dangerous area to comment on. I think you're absolutely right and there are actual journals that are dedicated towards this. Obviously there are gerontology journals, there are psycho-oncology journals, and so on, so I think being wider understood that dealing with cancer is not just a unique specialty process. It is, like you say, quite correctly, a multi-disciplinary process and particularly in prostate cancer, because our treatments are so varied, ranging from doing very little to hormonal treatments, for example, the impact of hormonal treatments, particularly in ageing men. Clare Delmar Well, indeed, on that note, I think we'll finish, but only to add to be continued as the evidence builds. And we get a little bit more understanding

of how our older patients are coping with these different treatments. So I want to thank you so much, Raj, because it's always fascinating to talk to you about this. Clare Delmar A transcript of this interview and links to Raj's practise are available on the programme notes, along with further information on diagnostics and treatment for prostate cancer and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Most of us have never heard the phrase "health inequalities" until it suddenly exploded in its use over the last year, describing a range of circumstances in which health outcomes and the delivery of healthcare are inequitably distributed across communities, population groups and the nation. Covid exposed the inequality of health outcomes across regions, towns and even neighbourhoods and made many of us focus on the underlying determinants of good health. A wide consensus has developed on the need to address these health inequalities, and the government has recently established a new department to focus exclusively on it. But for those affected by prostate cancer, health inequalities have been with us for a lot longer than Covid. There are of course obvious inequalities in risk factors that underly developing the disease – being a man for starters and after that one's age. But did you know that if you're a black man you have twice the likelihood of developing prostate cancer? That's right – while 1 in 8 men in total will develop prostate cancer, 1 in 4 black men will. Cancer Research UK provides a breakdown of how prostate cancer incidence is distributed across the UK. And did you know that if you're 70 or over you may not get offered the same treatment than if you were younger? Inequalities in prostate cancer care exist across geography, too – sometimes described as a postcode lottery. With regard to black men, research is being undertaken to understand the biological and physiologic and genetic roots of this inequality. But it's also important to look at access to care within the black community, and to understand if this differs from other communities. We've spoken with several men about this over the last year who have described personal and community-wide experiences that are different from the experience of non-black men. We continue to support many individuals and organisations that are raising awareness and campaigning for more research on prostate cancer in black men and improving access to screening within black communities. In terms of age, we embrace the changing attitudes to ageing that we see partially driven by living longer and the very question about what constitutes age. As the science underlying our understanding of ageing continues to advance, we hope to see more personalised treatments emerging for older men with prostate cancer, based on their overall health and quality of life and not simply their biological age. And as for the postcode lottery, all men have the right to access the care they want regardless of their geographical location. Educating and informing men about treatment options and encouraging second opinions will help them to exercise this right. We aim to help men develop their individual health advocacy, and believe that knowledge and transparency are paramount to accessing the best healthcare available to them. Raymond's Prostate Cancer story Today's guest is Raymond Poole from Co Wicklow in Ireland, who is both campaigner and advocate for better treatment and more honest discussion about the impact of prostate cancer on men's lives. Following his prostate cancer diagnosis and subsequent treatment, he has used both poetry and prose to express his emotions, communicate his experience with honesty and humour, and inspire others to develop their voice and make better choices about their prostate cancer support and treatment. He's Irish, so that may not come as a surprise. In our conversation today, he'll comment on some of his experiences with prostate cancer by drawing on passages from his books 'Nothing's So Bad That It Couldn't Be Worse' and 'Taking the Pi55 Out of Cancer'. You're in for a treat. Follow Ray on twitter @Aladinsane40 Taking the Pi55 Out of Cancer: <https://www.raymondpoole.com/taking-the-pi55-out-of-cancer> Nothing's so Bad that it Couldn't be Worse <https://www.raymondpoole.com/nothing-so-bad-that-it-couldnt-be-worse> Clare Delmar Hello and welcome to OnFocus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided, or even ignored. Prostate cancer is the most commonly diagnosed cancer amongst men in the UK and with this sombre fact because a multitude of challenges and opportunities. Joining me today is Raymond Poole from County Wicklow in Ireland, who is both campaigner and advocate for better treatment and more honest discussion about the impact of prostate cancer on men's lives. Following the prostate cancer diagnosis and subsequent treatment, he has used both poetry and prose to express his emotions, communicate his experience with honesty and humour, and inspire others to develop their voice and make better choices about their prostate cancer support and treatment. In our conversation today, he'll comment on some of his experiences with prostate cancer by drawing on passages in his books. It's wonderful to be talking to you and great to get advice out there about prostate cancer in men because it's not spoken about enough. And you are my first Irish guest, so I want to commend you for

that and it's very exciting. Clare Delmar I do, indeed, without further ado, let's just launch into the very beginning of your journey and ask you to give a short summary of when and how you were diagnosed with prostate cancer and what happened afterwards. And in July 2016, when I was 53, my PSA rose and he asked me to come back four weeks later and had risen again. Then later that year towards the end of that year, the December time frame, I got biopsies done, which was a journey in its own right, because although I got over 20 biopsies from the prostate, none of them were cancerous, but I ended up with sepsis and that brought me on a journey into numerous infections. So if I hadn't got sepsis, I would have thought it was okay and I could have ended up with stage four cancer. Raymond Poole Yeah, well, what happened then, when I went in, I ended up going to hospital for eleven days just before Christmas in 2016, and my PSA in July was at 9.5. So they knew at that stage things were going in the wrong direction, you know, but look, listen, as you well know, men can have a PSA reading in the hundreds, and it still doesn't mean that they're going to have to get radical prostatectomy or anything. Well, I would prefer to be followed up by an MRI and then targeted biopsy rather than a random biopsy like I had first, you know. Raymond Poole Actually, I ended up with a different consultant who very skilfully managed me. And it was only in hindsight and reflection, I realised just what he was doing and he was managing really my expectations, my concerns and my worries. And he gave me an in depth talk about what the prostate was all about, how bad the cancer was and the options that were open to me. And then the ones that were open to me, he made sure I went and visited each individual specialist consultant to talk about those options. Of course, me being the man that I am thinking I can't move, I've just had major surgery, but I had this lovely lady, I called her Maid Marion. She was a lady that looked to me as if she was in her sixties, she was like a health care worker. And I suppose you're worried you've got tubes coming out of you everywhere and you're worried they are going to fall out or something. The surgeon did his job, and that's the thing I think about and not just prostate cancer, any major illness, cancer, in particular, having seen so many people have different forms of cancer. I remember saying to the nurse at the very early stages, you have a bag on you for a week and then you go in after a week of surgery and then they remove the bag from you and they lay you down on a table and they say, breath in and they take the bag off. And then they say, no, get up very slowly because you may leak when you get up and of course they give you some pads or whatever to wear as you're getting up. But I think on my second visit to that urology nurse I said, please stop calling it leakage. I ended up for just over three months having to wear full nappies because my bladder just lost all control. But the wonderful thing was once I lay down in bed in the evening, I have no leak whatsoever. Clare Delmar So Ray, you've been through, gosh, sepsis and then you had erectile dysfunction and the incontinence. It ended up being a dialogue about two voices in my head, sort of sitting back and reviewing everything that was happening to me in a very... I call it sort of like the non PC book about PC because it's just pure dialogue, you know, in it before. So basically, it's two voices, and it's written very much in the sense of two Dublin lads having a conversation about me and I'm a third party, and they're just totally disregard for any of my feelings or anything. I remember saying to one guy, if we can only get them to show up now I'd be happy because every time I would sit down and do something, I get, oh, there's another I should write about that. I only intended it to span about six months, and actually I ended up finishing it... My dad during the book, at the end of it, he passed away. I just nickname this Nurse Jackie and it says: "Well, Nurse Jackie says the pill won't work, but you can get a pump. Now get this, she said, were you told it may get smaller after the operation as they have to move things about? They didn't care what they said about you because you can either hedge around it or you can hit it face on. I don't want anybody listening to this thinking they're going to end up with permanent erectile dysfunction and permanent incontinence and all that type of thing. And I said to her, as difficult as that is that's actually a good thing, because could you imagine having erectile dysfunction and not having a low libido? Raymond Poole She just looked at me and said, Well, it's you that it hasn't got the libido. Clare Delmar So Ray, your writing really does provide... Because I've seen you on Twitter and you're a big social media blogger, and developed quite a following, and I can see that it provides support and comfort, certainly humour to many men. But the one thing when people meet me and I talk about it, it does take them back a bit because I don't hide the fact... They are things that happen in your life that aren't anything to do with something that you haven't done or that you have done, they just happen to you. The fact that I've ended up with incontinence and with permanent erectile dysfunction, that just happened to me. Men are not the best people at talking about anything that happens below their belly button, you know. It's my wife, my two daughters, and then I was a real Irish man because I was a real Mummy's boy. And you know, when you look at their journey and when you look at the journey of an individual who is born with a womb, they encounter things much earlier in life, like they

have the menstrual cycle, very young in life. They have ended up going to the doctors very young in life for checks and smear tests and everything. In fact, one of the things I've definitely observed in some of the interactions I've seen with you and your followers is this idea that prostate cancer brings so many taboos and misunderstandings about the male body and its functions. And I'm wondering if you can give some examples of how this has helped some of the men you work with. And then I guess I'm interested in knowing how you think we can actually accelerate this process of better understanding, better acceptance, earlier engagement. There's a good few men in it and actually they're from Ireland, the UK and the US and Canada. And it was purely through interaction on social media we came about and we started talking about it and it breaks down that barrier. Like I've had men phone me who are going in for the surgery because and here's the strange thing, I have more women following me than I have men and have more women direct messaging me, asking me questions about prostate cancer than I do men. It could be their partner, it could be their father, it could be their grandfather or sibling, whatever, friend, whatever, you know. And some of them have actually bought the books to give us presents to their, whoever is going on that journey to try and help them with that. The one is to raise awareness around prostate cancer, break down the language and the vocabulary that we use when we're talking about prostate cancer. And the other thing is both books, and I'm finishing a third one at the moment on poetry, I don't take any money. It's like a number of people who have gone on the prostate cancer journey when they first of all, they tell someone they have cancer and there's a lot of sympathy. And it's almost like the sympathy is turned off on the person who's talking to them because they say things like aren't you the lucky one that it was just prostate cancer or aren't you glad it was just that. And it really frustrates and upsets them because they think, well hold on a minute, you've no comprehension what we're actually going through, particularly those... I read about another guy there, he was 36 when he was diagnosed with aggressive prostate cancer. I grew up thinking, yeah, prostate cancer when I'm seventy, I'll have a look at it, you know. And for me, one of the things that happened was I was sexually abused as a child and that revisited me after my prostate cancer examinations and everything. And one of the things I try to raise awareness about when a child has been sexually abused. People often say, Why does someone wait till they're 50 or 40 to announce they were sexually abused? The reason any individual does that is because as a child, you don't have the vocabulary to explain what's happened to you. You've been told by the perpetrator that it's a secret between you and them, or it's someone in society that nobody would believe would do it to you. Now, if you move forward ten or 40 years when you're an adult and you're 50 years of age like I was and you get prostate cancer and you look at that. The vocabulary and the language you need to talk about prostate cancer to another person is something men aren't that familiar with. I mean, how many men do you see sitting down at the pub talking about erectile dysfunction or how many of them will say, Gee, you know what strange thing happened to me last night, I had blood in my semen when I ejaculated. This is a strange encounter, because what happened with this book was, 'Taking the Piss Out of Cancer' I wrote first, and when I gave it to the publisher, they said, no, you better write an introduction to this. And then when I wrote the introduction, they said, no, can you just leave 'Taking the Piss Out of Cancer' to one side and write an entire book in the way you've written the introduction because we really like that descriptive passage. All these episodes that happened throughout my life are threads in the fabric that make me and their interwoven experiences formulate how I approach things in life, especially my journey with cancer. To understand anyone fully you first must understand their journey, their encounters, challenges, failures and successes they have. And I believe that the way I approached my prostate cancer and probably the reason I'm so outspoken about it, and I don't care what I say is because I was silenced as a child when I was sexually abused. You've had another traumatic experience in your life, and you're going to share that journey with others. And you're going to help others because you know as well as I do over 11,000 men die from prostate cancer in the UK every year. That's a staggering... We don't have the numbers for Ireland, but that's a staggering staggering amount. If you're a Caucasian male, you have a one in eight chance, if you're a black male, a one in four chance. So I also feel at times that the medical profession or general practitioners who we go for, who's our front line that we go to. They sometimes don't always think of prostate cancer for younger men because that's the common thread I found with younger men that I talked to. If you're having low libido, if you're having a problem getting an erection, well usually, let's give you one of those stiffening pills, that should help you. Most of the people I talk to, have found that to be the starting point that was hardest to achieve. Indeed, anyone even a transgender woman, because they still after prostate and helping them. So when they do go to their GP, they turn around and say, I have X Y and Z, do you think it might be prostate cancer? Clare Delmar So the power of words that you're helping to provide, I think, really does give lots of strength and lots of confidence to

these men. Raymond Poole Sure, I'll finish with a small poem that I wrote in 'Nothing So Bad That It Couldn't Be Worse'. It'll actually be inserted in the book of poetry that I've written now which will be called 'The Dark Side of Silence'. I do 90% of my writing under the light of the moon because that's when my brain gets most active on these things. And there's a stillness in the air and in the environment and everything seems to be asleep but me. And it gives me time to go to places that probably I wouldn't during the day because I'm too busy and there's so much going on. It's been such a pleasure and I know you're inspiring for lots of our listeners, so many thanks. Clare Delmar A transcript of this interview and links to Raymond's books are available in the programme notes and our website, along with further information on diagnostics and treatment for prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. When a Doctor Becomes a Prostate Cancer Patient

Joining me today is Dr Stephen Allan, a retired consultant anaesthetist and former prostate cancer patient. Stephen has a unique perspective on how men are diagnosed and treated for prostate cancer, and shares his wisdom and experience regularly through Tackle Prostate Cancer as a patient representative, and as an advisor to NICE and the National Prostate Cancer Audit. Clare Delmar Hello and welcome to On Focus, brought to you by the Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Dr Stephen Allan, a retired consultant anaesthetist and former prostate cancer patient. Stephen has a unique perspective on how men are diagnosed and treated for prostate cancer, and he shares his wisdom and experience regularly through Tackle Prostate Cancer as a patient representative and as an adviser to NICE and the National Prostate Cancer Audit. We've talked a little bit beforehand and you know that I tend to like the sound of my own voice, well that's what my wife tells me. I am really passionate about trying to change how prostate cancer is treated and how patients are treated as well. Perhaps I'm a little bit evangelical... Clare Delmar We need people like you Stephen and hopefully we'll be able to bring that out. And I guess the first question I'd like to ask is based on your experience as both the doctor and the patient, what is the good news for men with prostate cancer and what would be the bad news? Stephen Allan I think that undoubtedly the best news we've had has been multi-parametric MRI. And just as important as having that investigation is that it's now been accepted nationally on accepted treatment pathway supported by NICE. And we can now identify patients with these small, potentially very slow growing cancers that may never need radical treatment or indeed treatment at all. And they can go into active surveillance programmes and can be sensibly and accurately monitored, which again, we couldn't do, certainly not when I was diagnosed 13 years ago. So we've also identified patients for whom major surgery just might not be needed and you can use more localised treatments. If the treatment is as effective, but the potential is for much less side effects, why should we be doing radical major major surgery. I think, you know, what you're saying is as well, certainly what we believe at The Focal Therapy Clinic. But it's interesting to hear it from you who did not enjoy that advancement when you were a patient yourself. And I've got to say, as a traditional died in the wool old man and an old doctor, accepting newer techniques can be quite difficult for people. The reason for change is allowing men to have less side effects and to be able to go into these treatments for prostate cancer with less fear. I think we've got more sensitive investigations in addition to your conventional MRI and CT, they might sort of be described as static investigations. They look at the anatomy, the structure, the position of the tumour, but they can't show how active it is, how fast those cells are dividing. I describe that as an active scan, not only is it showing where it is, but the cell activity, those cells of high activity, which may well indicate that there are metastases. If there's cell activity where they shouldn't be, then you've got to find out what that is. Stephen Allan And, of course, that's so much more sensible; you'll be picking up men with very much smaller secondaries and at a stage when they will be easier to treat, much earlier than conventional scans could do. Stephen Allan Much of the bad news we've known about for a long time, to be honest, but there seems to be very little in the way of change. And figures show that the time of first diagnosis, barely 50% of men have the tumour confined within the prostate capsule. That spread may be very, very localised, but it is enough to have severe implications to influence your treatment options. Stephen Allan Well, the pandemic has influenced things such that fewer men have been diagnosed, fewer men have been referred for treatment, fewer PSA tests have been done. I mean, the figures that are being bandied around are things like 50% reduction in referral to urologists, up to 10,000 men not being treated either not being treated at all because they weren't referred or that their treatment has been delayed for whatever reason. Clare Delmar So I want to just pick up on something you said earlier about when you talked about the precision that multiparametric MRI affords patients and how that underpins less invasive and more accurate treatments that, and this

is the point, don't deliver the kinds of side effects that you have with more radical ones. So we've spoken before and you've spoken very openly about incontinence and its impact on men post treatment. So I guess I'm really interested in what advice you would give to men in making choices about treatments for prostate cancer and how you think that this particular debilitating side effect can be better managed? The second day was when I realised I was likely to be totally incontinent of urine for the rest of my life. There was my young granddaughter proudly telling me that she was now dry at night and didn't need to wear nappies, and there was me, her grandfather, barely sixty years old. Much of despair comes from not knowing how incontinence is produced and how it can best be managed. And because of my status as a consultant, many healthcare professionals found it very, very difficult to even talk to me about it. But talking to other patients in a support group, finding out how they coped was the best thing that I have done. I made decisions for myself and had a bit of a long journey which there's no time to go into. Firstly, discuss how you feel with everybody - doctors, nurses and especially other patients. How much information do they want and when will they take it in, particularly pre treatment. If it's a problem for you, then it's important.... Clare Delmar ...then it's a problem, absolutely. I spoke to somebody, a complete stranger I never met before about my artificial urinary sphincter. My experience now is that, I don't have any data that's published that gives specific time scales about when you should have surgical remedies. That said, my personal experience, speaking to men with severe incontinence like myself, after six months, you've got what you're going to end up with. So start earlier, start making a noise at six months because, you know, on the NHS, it's going to take so long to get a referral, it'll be year before they do anything anyway. Clare Delmar The other challenges, you mentioned the word fear earlier in the conversation and that can be an incredible barrier, to say the least, in terms of taking in this information and really visualising what life might be like. I am horrified at how little men know about their very basic anatomy and how their body works. If you can understand how your body works, then you can understand a bit about how it goes wrong. If you can understand how it goes wrong, you can understand treatments that might be offered to you. And I think even more important than that is, you can understand why treatment may not be suitable for you when it's very suitable for the bloke sitting next to you. I mean, you know, it takes the idea of personalised medicine to a new dimension, doesn't it? Clare Delmar So we touched earlier when you were talking about multi-parametric MRI and now that is yeah, literally, you use the word revolutionised and I quite agree with you. Again I'm interested in your perspective as a former NHS doctor for many, many years, you've experienced firsthand how new procedures, new techniques, new technologies are adopted and implemented. How quickly do you anticipate some of the advancements we're seeing now in prostate cancer diagnosis and treatment being adopted? And I'd like to specifically talk a little bit about how you see, for example, screening being done through imaging techniques that are developing. Stephen Allan To be honest, it's always been a bit of a mystery to me how change can sometimes come about. Drug therapy has got a fairly standard process it goes through, and then it has to go through NICE and all that sort of thing. Surgical techniques, diagnostic procedures seem to be very different, and there seems to be a sort of very often the holdups in progress are not because people don't think that the procedure is bad, good or whatever, but it's very often because of financial implications and a good example of that is robotic surgery, incredibly expensive outlay on equipment and wasn't initially taken up very widely because of the cost, but now is the standard technique. Before I ask you to just expand on that, I just want to pick you up on the robotic comment you made a minute ago and show how that took a while to become implemented, but then it became, as you say, a standard of care. Now there are some people who would feel that because it took so long and because it was so capital intensive that that's now "blocking", using that word, sort of in inverted commas, other treatments being used because and maybe this picks up on your financial consideration comment, that hospitals want to fully depreciate their robots essentially and are doing at the expense of other treatments. I know that's a very big statement, and I'm just interested if you think there's any truth to that? Stephen Allan I think it's a difficult question to answer, because what you've got to have at the very front end of all this is people that want these new procedures, and it only comes with newer people coming into the specialties. A lot of hospitals well, not recently, but in the very early days when people were fundraising, suddenly found that, yes, some big charitable donation bought them a really lovely, expensive bit of equipment. But suddenly they've got the bill for maintenance, they've got the bill for servicing and that sort of thing. It may well be cheaper to do something in a way, but if then two years later it's producing lots of side effects, which then need treatment, those somehow should have been included in your cost assessment... Clare Delmar And they're not and it's frustrating, which actually leads me to another point, which is quite topical coming out of the pandemic, and that's around something people term health inequalities. So various

behaviours, various decisions, various procedures are going to emanate from that. But you know, what's interesting about that is that we know that there have been inequalities amongst men diagnosed with prostate cancer, and some of these are along racial lines. But I guess what I just want to focus on because I know we could talk about this forever, is what are your thoughts on how you think, like the variability of some practises that you've even talked about, for example, radiology reporting or treatment options? We all know that you need manpower to run the equipment, to look at interpretation of results, and we know that there are shortages. I think in the future, artificial intelligence may be one way of making things slightly easier. You can train computers to look at, and it's probably easier to train a computer to look for the normal rather than the abnormal. So then you can free up time of your specialist, if you like, to look at the more abnormal ones, the ones, but you need confidence in doing. And that's already being done to an extent in certain things in radiology, but not as far as I am aware, greatly with prostate cancer at the moment. Clare Delmar We know people who are looking into this, but again, it comes back to your point about how long things take to become fully implemented. Clare Delmar So I guess a final question is to really kind of bring this back full circle and to ask you, as a doctor, becoming patient advocate and one that's been incredibly supportive to men through these various support group are involved with, what are the most common concerns within these support groups? By default, we've tended to talk about men with prostate problems, but prostate cancer affects everyone, particularly wives, partners, so certainly, as far as Tackle is concerned, we want to be there for everybody who's affected by the disease and you scratch the surface and so many more factors come to light. Yeah, we talk about incontinence, sexual dysfunction, but the side effects of hormone therapy, the psychological and mental health issues, generalised fatigue, strain on relationships, not being able to work, financial difficulties. But our job should be to realise that we can't do that and then to direct people to those specialists who can help them. The disease of prostate cancer that was around, if you like, when I was diagnosed 13 years ago, is entirely different to the way we diagnose and manage today. And I confidently predict if we have this conversation again, if I'm still alive in 13 years time, and will we be saying the same thing? Do you think by that time some of the things we've touched on in this conversation will have been implemented? Yeah, I think in 13 years time, yes, we will have a better way of diagnosing not only prostate cancer, but the aggressiveness of it. It is a good indicator of prostate health, but it is not an indicator necessarily that you've got prostate cancer and the aggressiveness of it. Clare Delmar And hopefully these other sort of non clinical issues around the sexual health and urinary health will become a little bit more holistically integrated into.... Stephen Allan Well let's hope. Some of the socio-economic issues that we know are people with lower social economic status do much worse in prostate cancer. Stephen Allan And similarly with ethnic communities, you can't change the traditions of hundreds of years in just another 13, but it will need a very sensitive approach. Clare Delmar It's been really, really valuable and I'm already coming up with a number of other sub specialty areas that I'd like to speak with you again about, so I hope our listeners will look for to the next time, but really we covered quite a bit and your insights are both personal and professional and that's incredibly valuable. Clare Delmar Further information on diagnostics and treatment for prostate cancer is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. The Power of Words Being told you have cancer can render you mute, and viscerally disconnected between head and heart. The fear, complexity and taboos associated with prostate cancer in particular mean that finding a comfortable and effective language to express yourself can be challenging. Yet learning and using this language is crucial to achieving good outcomes for you and everyone around you. A shared expressive and honest use of language is what will enable you to:

- Understand what's happening to you
- Communicate with healthcare professionals
- Communicate with partners, family and friends
- Make informed choices about your care
- Support your mental health

As many of us know the power of communication doesn't come just from words themselves – who delivers them is equally if not more important in giving us the confidence to receive, accept and share their meaning. In our mission to support men in understanding their prostate cancer and making the right choices in their treatment, we've engaged a wide range of men who've used words to expressively and impactfully share their stories about living with prostate cancer. Raymond Poole and Gogs Gagnon have written books which we think many men and their partners will find helpful in providing a language and approach to support their own experience. Following his prostate cancer diagnosis and subsequent treatment, Raymond Poole has used words to express his emotions and communicate his experience with honesty and humour, inspiring others to develop their voice and make better choices about their

prostate cancer support and treatment. He's Irish, so that may not come as a surprise. In his two books *Nothing's So Bad That it Couldn't be Worse* and *Taking the Piss out of Cancer*, Raymond is unflinchingly open and honest about the side effects of prostate surgery and his personal struggles with erectile dysfunction and incontinence. "Burnout is a term we have all heard about but we make the assumption we have all the bases covered so that will never happen to us as that sort of thing only happens to others. Those were my very thoughts in relation to prostate cancer, sure that only happens to old men, I will be in my late 70s before I even have to think about that and even if I do contract it, it's not that serious an illness. The only thing I've discovered about having cancer is that it's not just your body that's affected but your mind, your mental health, your partner, your family and most definitely your business. This then creates a loop whereby it impacts your stress levels that, in turn, impact on mental health and wellbeing." He uses poetry and dialogue to express his feelings, and will shortly be publishing a book of poetry with proceeds supporting Unicef – keep an eye on his website for updates. I live to love and love to live in tandem we will fall." Gogs Gagnon was diagnosed with prostate cancer at age 57, and after his surgery and recovery, he decided to share his story to inspire others to advocate for their health and learn from his experiences. Prostate cancer hits at the very core of manhood, he says, and in a deeply personal account of his experience from diagnosis to recovery he reveals intimate details that every person impacted by the disease — man or woman — needs to know. In "Prostate Cancer Strikes: Navigating the Storm" Gogs writes with honesty and humility, reflecting constructively on his decisions along the way and encouraging his readers to keep an open mind about their situation: "above all, give yourself at least enough time to recover from the initial shock of your diagnosis before making a decision. Research your options based on the best available evidence from scientific research, reputable studies and facts. Some may even be limited by their own modality, so that a radiation oncologist may endorse radiation while a surgeon may prescribe surgery." He strongly advocates for second opinions: "If possible being someone with you to all your appointments and have them take notes while you ask questions from a list you prepared ahead of time. Don't be afraid to ask for more than one opinion – this relates not only to treatment options but also to confirming if your diagnosis is correct. We'd love to hear from you Living Life to the Fullest – Nigel Harris' story of rapid recovery after HIFU Focal Therapy Treatment. Joining OnFocus in this episode is Nigel Harris, a medical sales professional from Winchester who recently underwent HIFU treatment with Tim Dudderidge. He leads a very active sporting life, particularly on the ice where he both plays and coaches ice hockey – and following his prostate cancer diagnosis was intent on finding a treatment that wouldn't compromise his lifestyle. Clare Delmar Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK with this sombre fact because a multitude of challenges and opportunities. Joining me today is Nigel Harris, a medical sales professional from Winchester who recently underwent HIFU treatment with Tim Dudderidge. He both plays and coaches ice hockey and following his prostate cancer diagnosis, he was intent on finding a treatment that wouldn't compromise his lifestyle. Welcome. Nigel Harris Thank you very much for having me on. Clare Delmar I'm very motivated by the wonderful photo you sent to me of you in full hockey gear on the ice, which I'm going to share with our listeners. First of all, congratulations and wonderful success on your treatment and on your big ice hockey success as well. And tell us a little bit about your experience with that. Nigel Harris It was a bit of a surprise. And you're probably going to be the only person you ever hear saying thank goodness for kidney stones because I was under treatment for kidney stones and after the last wash out I had, the consultant came back to me afterwards and said, I really would like to have you go through a full screen with some dye. I started as an operating theatre technician these days called ODPs, so I had a little bit of background and understanding and thought this does sound a little bit suspicious. Clare Delmar Yeah. Nigel Harris So the first thing I did was say "absolutely no problem at all." After that, there was a couple of weeks and I was phoned up by Rob Keen, the Macmillan nurse who himself has gone through prostate cancer, and he let me know that I had prostate cancer. Although I'm 68, I'm still working and enjoy the hockey, enjoy skiing and enjoy the diving and haven't planned on giving up and clocking out yet. So he basically told me what was available from the full gland therapy, which didn't sound too good. Then it was going onto all brachytherapy, radiotherapy and all the others and all of them appeared to have significant drawbacks. And if you're fit, you're healthy and you're looking to carry on pretty much as you did, you've got to consider things like HIFU. Although my maths isn't wonderful, I went through it and it seemed to me to give very much similar outcomes to full gland therapy, but without all of the issues that can potentially go with it. But let's be honest, there are potential

procedures whenever you break the skin, which is why when I went back to see the consultant, my first thought was, well, if it is as they said it was, a Gleason three plus three. And the previous consultant had already suggested that it might be best for me if we just do active surveillance. However, Mr Dudderidge said, after I'd had the biopsy, which I forgot to mention, there were quite a significant lump on one side, although fortunately it was still contained, and a very small lesion on the other side. He said well and went through all of the options again, so I said, well, do you want time to think about it? Because the other thing he said, which is also quite important and people really do need to consider is that it's not a one off treatment. Why would you have brachytherapy unless it was absolutely necessary when you can't go and cuddle grandchildren for three months? Clare Delmar Indeed Nigel Harris Although this year has been slightly different, let's be honest. Clare Delmar How long did it take between your initial decision and consultation with Tim to actually undergo the procedure? Nigel Harris Well, I'm guessing I was very lucky because I learnt of the procedure, it was I think about the 1st of May and had the procedure on the 1st of June. Clare Delmar OK, so that was relatively fast. Nigel Harris Yeah, it was very fast. What I didn't tell him, of course, was, was that I planned on playing ice hockey 12 days afterwards. Clare Delmar And did you? Nigel Harris Yes. What was funny about being a coach, I coached medical students from Southampton University along with other students, and one of the medical students just happened to be on Tim Dudderidge's team. Clare Delmar Oh wow, that's funny. Nigel Harris And she was chatting to me about it because she knew who I was, but she grassed me out. Clare Delmar Wow. Bad boy out on the ice. Nigel Harris Fortunately he said, well, if he feels fit enough that's OK by me. And it's not like it's an open procedure. Clare Delmar Yeah. Nigel Harris If it had been an open procedure or anything else, it would have been absolutely no chance of me playing. Clare Delmar Yeah, no. I think that leads to be to sort of another question about your own experience and expertise in medical technology that gives you, I guess, sort of a specialist knowledge and perspective on both the risks and the benefits of new technologies in health care. So I'm wondering how that informed your decision and how you would describe these to men considering HIFU treatment. What are the risks and benefits that you based on your own personal experience and your professional experience, understand well and would like to share. Nigel Harris Obviously, technology is improving all the time. I mean, when I left the health service in nineteen eighty three, it was just to give you an idea, cataracts. Now they walk in and out. Clare Delmar Yeah. Nigel Harris So significant strides have been made with all forms of technology. And the fact that you can now do.... Well, using ultrasound to ablate tissue is incredibly well thought out because you're not going to be damaging the patient per say. And clearly, when you see the advantage of all types of ultrasound now, I mean, when my first son was born, you could barely make out a skeleton with the ultrasound. So if it is, if it's something that you feel that is appropriate for you and I can say it for me, it is appropriate, but it may not be for other people. They don't want to look at the advantages or they've got other issues that they want to consider. But, you know, just using heat from outside the body, not entering the body itself, it's got to be the way forward. If you're a younger person and let's be honest, 60 these days isn't old and the working age is now being put up to 67 for most people. And I'm fairly certain that even in ten years time, this procedure will be significantly advanced from where it is now. Clare Delmar I mean, one of the things you mentioned earlier in informing your decision were the side effects or the lack thereof that this treatment would afford you. One of the things that I find with our patients is that the very fact that they're having this conversation or this discussion with the doctor about HIFU usually means that they address the so-called taboos of prostate cancer like sexual dysfunction and urinary dysfunction. And I'm wondering how that played out in your discussions with Tim and with family members. Did it make it easier to talk about the whole situation you were in with your prostate cancer diagnosis and why this treatment was preferable? Nigel Harris Well, as I said before, I'm still working. I've been out today down to a hospital in Wales to look at some opportunities down there and came back. I understand that, you know, you can use leg bags if you have a degree of incontinence, but it's something that's going to play on your mind and there's no question about it. And that's where for me, I like to dive, I like to ski, I like to muck around on the ice with my students and try and coach them some ice hockey. All of these things would be much less easy if you have the incontinence and however good the surgeon is, there is still far more of a chance that you will get some of these side effects because it's a very innovative area. You know, and I'm not saying any surgeon is going to turn round to you and say, no, I can do this without or... There is a there's a fairly high chance if you're going for full gland therapy, that you will end up with one or maybe more of the side effects. Clare Delmar Yeah Nigel Harris and I think with full gland therapy, I didn't actually go around and look at the statistics. But if you do want anything of a sex life, then you are very likely not to be able to maintain an erection. Clare Delmar Yeah Nigel Harris I'm not

sure whether you could manage it with Pfizer's miracle drug or not. Clare Delmar Yeah Nigel Harris but you have to consider it. I mean with three plus three or even a three plus four Gleason, you've got far more options to consider than maybe you know, when I was in theatre, you know, they were probably very few options and maybe caesium seeds, radiotherapy and full gland therapy. He was diagnosed in 2007 and he actually had to stop his hormone therapy because, as he said, it's turning him into a very ugly woman... Didn't really... I had a colleague that went through bowel cancer and he was great to talk with, to be honest with you. My children, I got three boys, I'll say three boys. Clare Delmar Three young men. Nigel Harris Yeah, well yeah. The important thing for me to them was to let them know that they're now they, they have to be more vigilant, with someone in the family, it's something that they need to be aware of. So it seems to be quite a number of people I've heard of now that are willing to say they've had it or we know they've had it. As you rightly say it's a very, very prolific cancer and that clearly needs to be discussed more. Which is also good to know that people are wearing those so you can talk with them. Clare Delmar Yeah, I mean, one of the things that I found interesting in talking to you earlier was how well you understand the costs and the benefits of HIFU treatment to individuals. And you've discussed quite openly about the side effects and the options that men would have, especially if they have early stage like you did. But I'm also wondering, again, sort of wearing your professional hat, if you can comment on how you see some of those costs and benefits playing out in the health care system. I mean, do you see this as a long term economic advantage for the NHS or other health providers, given that...? Nigel Harris There has to be. With cataracts, 30, 40 years ago, you were lying on your back for six days. Clare Delmar Yeah. Nigel Harris And now you walk in and out. And if you have to go into an intensive care unit bed, it is magnified by a factor of 10 to 20. Clare Delmar Yeah. Nigel Harris So every day that you're in hospital is a massive drain on the NHS, so day procedures or overnight at most has to be the way forward. If you can do something without going through the skin, you are not breaching the main body's defences to infection and anything like that. However, you know, when we start looking at open procedures, even keyhole procedures, there's always a potential for something to go wrong. And you've got to be in a position to then look at if you're going to go for an open procedure, which is fine, if that's what you want to do and it has without question, it's the highest benefit that you can go for. So if you're working person and let's be honest, you don't have to be that old to have a prostate cancer, it can get younger people. So if you want to be working, your working life will be extended significantly if you go for the radiotherapy or brachytherapy, the keyhole surgery, whereas HIFU apart from a day or so to recover. I did have a week off work, in all fairness, that the boss insisted, but I could really have gone back a couple of days afterwards. Clare Delmar Yeah. Nigel Harris It was not something that you need to consider, that's going to be an issue. There's a massive, massive reduction in cost to everyone, not just the health service, but yourself, your family, of course, family. Clare Delmar Now, I definitely think that's a big advantage. And, you know, as a sort of a final point, what advice would you give to men who are newly diagnosed with prostate cancer and on how they might explore their treatment options? Nigel Harris Right. I had a fair idea of what was going through for me, but if I'd not had that background, obviously the first thing you're going to do is start thinking I've got cancer. And obviously I've got some background in looking into research, but, you know, talk to the Macmillan nurses, talk to your doctors, your family doctors, use the research, read the papers they offer you. So if you're very risk averse and you're very concerned about everything, you might well say, OK, I want the whole gland out. If you are prepared to have a slightly less risk, a slightly more risk, rather, and I say it's only very slightly, then HIFU is the way forward, will have to be the way forward. Some of the things you said I think will be extremely helpful to men and to their families. And thanks again very much and congratulations on your success. Nigel Harris Thank you very much. As my last point I was going to make, I don't know whether it will help anyone, but yes, you can play in an ice hockey match twelve days post procedure with HIFU. I'm not promising you'll be able to skate... Clare Delmar Your photos living proof of that, so look forward to people's comments on that. Thanks very much again. Nigel Harris My pleasure. Clare Delmar Further information on HIFU treatment is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk, and follow us on Twitter and Facebook at The Focal Therapy Clinic. Data Really Can Save Lives There has been much confusion and divisive opinion over the NHS campaign #datasaveslives, aimed at building support amongst NHS patients and the general public to give consent for sharing their personal medical data for research purposes. NHSx, the NHS group driving the campaign, explains why data sharing is important: "Information collected by health and care organisations helps to improve individual care, speed up diagnosis, plan local services and research new treatments. It also saves everybody time and NHS and care services money that can

be put back into patient care”What’s not clear to most people are the many types of patient data, much of which is shared already with patient consent.The latest initiative to share patient GP data, however, has met with considerable opposition.Many people have actively opted out of what they see as a “data grab”, and the initiative has been extended to later this year.Over the last year, we have witnessed first-hand how patient data can be used in research and even in place of clinical trials to interrogate the safety and efficacy of new diagnostic methods and treatments for prostate cancer.Biobank, The HEAT Registry, Prostate Pioneer and Health Data Research are each contributing to advancing knowledge on prostate cancer through patient health data.While the use of personal health data has catapulted into public awareness over the last year, it is not a new activity and indeed has underpinned significant advances in healthcare for many years.Some may be familiar with BioBank, which has been in existence since 2007, and has provided vital datasets to support a multitude of impactful projects, including many focused on prostate cancer.Biobank is holding an event this month which we encourage you to attend if you are keen to better understand the use of patient GP data.It’s called “How GP Data helps UK BioBank improve Human Health, and you can register hereThe Focal Therapy Clinic is involved with two data organisations which we’ve discussed in previous blogs here and here, both of which have had and continue to have a significant impact on advancement in prostate cancer diagnostic and treatment.Prostate Pioneer is a European Network for Big Data in Prostate Cancer, consisting of 32 partners across 9 countries.Established in 2018, its goal is to assemble, standardise and analyse high-quality datasets from diverse populations of prostate cancer patients across different stages of the disease to provide evidence-based data for clinicians and scientists in academia, industry and government.It aims to achieve this by 2023, by working through a detailed set of programmes and work packages.The HEAT Registry is a database of patients who have had focal therapy, containing information on their diagnosis, treatment and recovery.It has supported studies over the last 18 months that are crucial to building the evidence base for focal therapy – no small feat with Covid19 restrictions and precedents based on randomised control trials.An evaluation of functional outcomes for men having HIFU treatment for the second time is published here and a comparison of men who underwent focal therapy with men having had prostatectomy after eight years is here.Linking these Multiple data sources and making them accessible to everyone is the aim of Health Data Research UK.it has built one of the largest repository of prostate cancer data in the world at the University of Oxford.This collection of over 140,000 unique prostate cancer patients’ data and insights on the disease and its progression will be used to aid earlier diagnosis and more effective treatments.The Focal Therapy Clinic is a strong advocate of patient choice, and we strive to provide our patients with information that is evidenced and considered so that they can make these choices responsibly and confidently.We believe in the value and importance of patient data, and seek to help our patients understand the provenance of datasets used in past and current research and the potential of their own personal data in future applications.When used responsibly, data really can save lives.Are you concerned about the use of your personal medical data?Prostate Focal Therapy , The new standard of care Joining me today is Alan Doherty, Clinical Director at the Birmingham Prostate Clinic, and recently voted one of the UK’s top ten prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail.Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer, and joined The Focal Therapy Clinic last year to develop his expertise in delivering focal therapy.He’s here today to talk with me about what he’s learned in the last year and how he sees the fire of focal therapy from both a provider and patient point of view.Clare Delmar Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored.Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities.Joining me today is Alan Doherty, clinical director at the Birmingham Prostate Clinic and recently voted one of the UK’s top 10 prostate cancer specialists in a national poll of consultant urologists published in The Daily Mail.Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer, and he joined The Focal Therapy Clinic last year to develop his expertise in delivering focal therapy.Clare DelmarLet’s jump right in because I think it might sound a little bit ominous to listeners that you’ve only recently taken up focal therapy, but I think the whole idea is that you’ve been leading precision treatments for a long time.So I’m really interested in hearing what you have to say about what made you take up focal therapy with the dedication and fervour that you plainly exhibited in the last year.Alan DohertyThe question could be what are the influences which are out there which make people not look at this?And I suppose when I worked in the NHS as a consulting urologist at one of the

biggest trusts in the country, the focus was very much always to go for more established treatments like radical prostatectomy or radical radiotherapy. And these are the sort of treatments that developed over a long period of time and really probably started when cancers were picked up much more advanced than they are now, because PSA wasn't being used 20, 25, 30 years ago, and so people would present with very advanced cases in at least more advanced than they are now and the treatments had to be more advanced. I think that you get a mind set, the NHS and the teaching that we had was all that, you know, if there's a cancer there, you either left it alone, which is sort of a bit illogical because why did you find it in the first place if you're not going to treat it? All you have to have is a discussion with a patient before you biopsy them and say, what would you do if I found a cancer? But to the other extreme, where you say, well, if I find one and then we must treat it aggressively and achieve as high a curative percentage as we possibly can. It's sort of illogical, it doesn't really make sense because, not now anyway, because now that we're picking a lot of cancers much earlier than before, these cancers are often cancers that don't grow very quickly. And I think what's been a huge eye opener to me is that the mindset that comes with whole gland therapies is that it doesn't really matter where the cancer is. And I have found it absolutely incredible talking to colleagues who have been doing this for a long time, how much more information they're getting and they need to be able to advocate. And a lovely expression is with an MRI scan is can you rule things in or can you rule things out? And for that you need a high quality scan, so the machinery and the sequencing has to be good. And then you have to have a high quality radiologist who actually knows what they're looking at. Clare Delmar Well, it's interesting because we've talked before about variability and a whole range of the steps along the pathway. And I guess I'm wondering if you've seen that variability, you know, on the increase, as it were, during the pandemic. And I guess my question was, you know, building this expertise in focal therapy during the pandemic must have had its challenges. Is that one of them or are there others that you've seen that's impacted your practise and your patients? Alan Doherty Even though I practise in Birmingham, the radiologist that I really trust works in London with The Focal Therapy Clinic. And, you know, I've been amazed that patients are prepared to travel all the way from Birmingham on my recommendation to have the best MRI scan around. So there is an appetite to be managed properly, even if it's to the point of travelling 80 miles to get the best scan. So I do think covid has necessarily impacted on my perception of how patients want to be treated and, you know, in some ways would allow me to do because we were a little bit quieter, is spend more time digesting the treatments and thinking about it and doing the treatments because. All this takes quite a long time to set up hospitals in the Midlands that they can operate, that takes a lot of effort. Clare Delmar Do you find as well that the patient experience has shifted in that patients are more vocal about the side effects, for example, their sexual, urinary mental health? What do you think we can learn from them that will help us improve prostate cancer management for all men? Alan Doherty They have to ask themselves, the question is how important is sexual function to them? Because if it's very important to them, focal therapy is probably the only treatment that reliably preserves sexual function. And although it could be argued that removing the prostate is a better curative treatment, some people are prepared to offset that slightly better outcome to maintain their quality of life. And that's the discussion I like to have with people, because I don't know exactly what the trade-off is, but I know that that trade-off exists and people are prepared to take it. And so understanding different people's personalities is part of the management of this condition. Giving someone the right treatment for them and informing them so that they're properly counselled as to what's going on is the enjoyable part of my job. Clare Delmar In those conversations that you're describing with patients, are you seeing sort of a trend line of patients more interested in having that conversation and willing and able to process that information and make the right decision for them? And it's very sad when someone is not eligible for focal therapy because they read about the benefits of focal therapy and they're so disappointed when they're not able to have them. And that saddens me in a way, because, well, had your PSA measured earlier and had you had this diagnosed earlier, you would have been eligible for this. Clare Delmar I suppose the only upside if it, as it were, is that you point them a) in the right direction of treatment. But b) if they've had that conversation about the side effects, they can take that with them and be a bit more informed when they go into the appropriate treatment for them. And it is always difficult to disappoint someone when they've set their... Clare Delmar Of course, but what is interesting is we often hear from men who will say, you know, no one ever told me but before that decision, erm so I guess in this case at least, having that counsel is informative. It's you know, honesty, transparency is what people want and that's hopefully what we can give them in The Focal Therapy Clinic. So just because they contact us doesn't mean that they are necessarily going to be offered it, but at least they know they can have a very thorough

consultation. Clare Delmar Exactly, we're definitely seeing, that, in fact, you know, one of the questions I wanted to explore with you was just based on the observation that we're at such an interesting time where patients are getting more informed. I mean, you've just described that a bit with your own patients and we've certainly seen that. And equally, the technologies both diagnostically and treatment wise, are improving so much. Alan Doherty I think we're going to get more and more consultants who have been set in their mindset, starting to open their minds to say, well, I get it now, because if we pick up an early prostate cancer, for example, instead of just monitoring it, why don't we just treat it? Because that's got to be better than just waiting for it to become a more dangerous cancer. So the consultants who are seeing them in the NHS will get to hear about the treatments they've chosen and that will make them sort of interested in it. In fact, I've heard of people looking at research into focal therapies with radiation, for example. I mean, the percentage of people having focal therapy for an early prostate cancer in London is something like 30 percent or something like that. And whether you call it Dr Google or whatever, I think there's, we're certainly seeing that because, of course, people find us by going online. Alan Doherty It's a bit sad that the patients have to do all this research themselves when they're actually talking to not only urologists, but also their GPs. And I think what I can see it changing is I can see it being more doctor driven, in say, five years. Clare Delmar What's interesting about being sort of provider driven, as it were, is that these different trends that are driving that you've mentioned a few patients coming from a second opinion and informing doctors, particularly regionally. But also you wonder from an economic point of view, patients who are treated with focal therapy and how that actually systemically impacts providers. But I've never actually seen any fully costed study from a health system point of view on focal therapy. Maybe that's what puts the NHS off going that way, because what you have to remember with the focal therapy is that patients need monitoring and that requires regular MRI scans and good quality MRI scans as well. So, you know, it's not the cheapest of treatments, but in a way that shouldn't really come into it because it should be what's best for the patient. Clare Delmar Of course. But I mean, overall, you're very bullish about the future of this treatment, both from a provider point of view and from the patient point of view? And I think it's not going to be just treatments like HIFU that do, you know, there are new technologies because essentially what you're doing is trying to kill tissue where the cancer is. The good thing about HIFU is, of course, is that it is just heat, you know, it's not long term effects from radiation and it's very controlled and it's safe. I mean, there are other technologies using electrical energy, nanoknife and all this sort of stuff and cryotherapy. But, you know, the HIFU is probably going to remain the main line focal therapy modality I suspect. Clare Delmar Alan it's been really fascinating hearing your comments, and I'm sure our patients will find this even more interesting, spoken from someone who's kind of climbed a very steep learning curve, but with incredible dedication and very clear engagement with their patients. Clare Delmar Further information on Alan and his clinical practise is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Man Alive: A GP's View on Prostate Cancer Screening An Interview with GP and Author Dr Jeff Foster Joining OnFocus in this episode to discuss prostate cancer screening, NHS data sharing and maintaining wellness is GP and Men's Health specialist Dr Jeff Foster. Dr Jeff is the author of Man Alive in which he examines the most commonly misunderstood aspects of men's health. His expertise on testosterone deficiency, erectile dysfunction, prostate health, cardiovascular disease and nutrition & wellness has been shared widely through media and applied in his clinical practice. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870

How Best to Support Men Monitor their Prostate Health Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and even ignored. Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is GP and men's health specialist Dr. Jeff Foster, author of Man Alive, in which he examines the most commonly misunderstood aspects of men's health. His expertise on testosterone deficiency, erectile dysfunction, prostate health, cardiovascular disease and nutrition and wellness has been shared widely through media and applied in his clinical practise. Dr. Foster, thank you so much for coming today and welcome to OnFocus. Jeff Foster Thanks very much for having me. Clare Delmar One of the things that introduced me to you was obviously your book, which we can talk a little bit about later. But you recently had a piece in The Times which got a lot of attention where you talked about screening for prostate health, screening for prostate cancer specifically. And I wanted to just sort of start off on that and ask

what your observations have been over the last 18 months during the pandemic on screening for prostate cancer. What's changed and what do you think men can anticipate going forward? Jeff Foster Yeah, sure. So at the initial start of the pandemic, the uptake in all forms of screening and almost all primary health care just stopped almost dead to the point where it would probably be the first time since I qualified that we had clinics and you would have space and there was time and no one actually came in asking a question. And then, of course, there's a degree of acceptance and understanding about what was happening. And it's the rebound effect because in a lot of these scenarios, the end result in terms of patient user demand works out the same, except we've got a big gap where nothing happened so suddenly we're now trying to cram all that stuff back into the same amount of working day, which means obviously it's a big challenge to do. Clare Delmar And how does that play out with screening for prostate cancer and specifically around PSA testing? Jeff Foster The big thing for PSA testing, from my perspective, is that it's how you use the PSA that's important. And we regularly, I would say our practice has just short of sixteen thousand patients in the NHS practice, we would have maybe one or two patients a week who would just request to have a PSA test. They wouldn't necessarily want to see a doctor to discuss that, but would just send an e-consult or a medication request and on that would say, can I just book for a PSA test? Clare Delmar OK Jeff Foster These are not the same guys that have symptoms and these are not the same guys that are already under urology or may have other urological problems. But just that understanding that some people know about PSA, they've heard of it and they think I just want it tested. The problem that we have is that obviously you then say to your patient, well the PSA is not a widely accepted national screening tool for all forms of prostate cancer. But on the other hand, you also say, but on the other hand, it's the best we've got for now. You have to really counsel every patient to say, what is your risk, your age group, what is your expected level of PSA? And then you can start to give them a bit of informed choice about what they want to do with that test and whether it's going to be useful, and even if they do have it. What do you do with that result in maybe six months a year, five years time. Clare Delmar But you made a comment a minute ago about what your expected PSA. I mean, do you see a point where every man should have a baseline PSA and then they maybe eventually begin to self track? Jeff Foster A single PSA by itself I would consider to be useless. And obviously, as part of the book we spoke to several urologists about this and there is so much discussion around when and at what point we should start looking at people's PSAs. I think a PSA is very useful if it's initially screened properly and then it's used cumulatively. And the whole thing about medicine now, it's moving away from subjective feelings and symptoms of disease. And if you can say I've got a guy's PSA every six months for five years, then that's useful data. And you can do something with that. Clare Delmar Yeah, but I guess that's what I meant when I suggested self-monitoring or self tracking. I mean, do you foresee a point where you have your initial baseline done through a GP like yourself, but then you are able to monitor regularly whatever period that regularity is, Do you see, that is something in the future? Jeff Foster Probably not, to be honest, purely because again, there are too many variables around the local labs and what their PSA might be. Who's responsible for that test if it comes back abnormal, if you didn't order it? Clare Delmar Indeed. Jeff Foster Is there anything better than a PSA you could use that more to fill that gap. Clare Delmar Well, I'm going to come on to that, that you raised a really interesting point and I am going to come on to that. But again, you use the word variability, and that's something that we've been looking at a lot because we hear about it so much from our patients who, again, you talk about data, you know, we can track patients who have had such variable experiences across the NHS, whether it's from different parts of the country. And I guess that's something that I wanted to explore a little bit with you, that this variability in both the screening and in the diagnostic pathway that follows. How do you think this can be addressed in the sort of medium term and ultimately in the longer term? Because it can't stay that way, if one person gets tested one way and has a different type of biopsy or a different type of imaging or different type of treatment. How do you see that playing out? Jeff Foster The inherent problem with the pathway is the PSA itself. So if you are to compare, for example, with breast screening, a patient has a mammogram, based on that result, it then goes to a specialist who will then review patients. And the operating procedures are so well established, you can apply them to a national accepted screening process. If you have a test like PSA, which no one really agrees what use it really is, then you can't apply a very well-regulated process to go with it. There's rough processes and NICE guidance and two week criteria still fits and if you've got some enormous PSA you can just refer your patient. I mean not everyone get referred and some hospitals will run the results of those PSA differently to others. Clare Delmar So now, I do want to come back to your point you made earlier about the PSA being that the best we have, I think, is how you expressed it. You know, amid this kind of controversy, we've actually

begun to see a new approach in imaging that's emerging that it could be used for screening. Do you see a role for this in primary care in future? Jeff Foster If you could devise a screening test that was cheap, reliable and minimally invasive and you could get men to engage with that, then it would easily surpass the PSA. And if you could have a national screening program service or something similar comparable to cervical screening or breast screening, and it allowed men to be walking in for a quick image which was non-invasive, had a very good pick up rate and was relatively cheap to do, then we could get rid of PSA as a screening tool in primary care completely. Clare Delmar Are you familiar with the program? In its current form it's still being trialled. Jeff Foster Yeah, and the problems with it at the minute would be the cost is too prohibitive. You couldn't use that as a GP referral source because everything we have to do has to be justifiable in primary care. It's a very odd scenario, whereas if you're a hospital doc and you work in the hospital, for the majority, 99 percent of stuff, you can just test for it if you need it, there's no look at the budget. There's been a lot of discussion around how the NHS is using patient data and particularly GP records. What are your views on this and how do you see the NHS data being used to support and advance men's health? Jeff Foster It's all about what you feel you want your data to be used for and what understanding you have in terms of what your data offers. So to clarify, what I mean is, a lot of people are very fearful of giving their NHS data out, as if in some way this is going to impact on their ability to function in life, as if in some way this is personalised stuff that we don't want Big Brother to know, that sort of thing is very hidden. Whereas actually what we're finding also as we move to the electronic system of prescribing and hospital sharing of notes, is that actually data in the NHS is not particularly well protected anyway, and it is shared amongst various groups within the NHS quite freely. If you then say you want to sell it on to third parties, well of course that has to be with the explicit consent of the patient because you're crossing that that boundary from what is NHS agreed. Well, actually, I might have BUPA, Virgin, Nuffield, any secondary company might decide, actually, they've got your data and they might be able to advertise something to you. Now, if this is the way that the NHS could fund its shortfall, then perhaps people might agree. On the other hand, people are also very protective of the NHS and the NHS data, and they feel that their health records are very personal to them. But I think the way it's been done almost surreptitiously and with a lot of behind closed doors sort of feel behind it has meant that for many patients it has not been a very positive experience into the data sharing. Clare Delmar Which is such a shame. If we could square the circle, because, as you said, it potentially plugs a financial shortfall. But also, as we've seen during the pandemic, when clinical trials themselves are being compromised, data has become the way we actually do our studies and look at how we actually will advance various problems in health care. I mean, so you've got this resource, but somehow it's kind of stuck. Jeff Foster Yes, I totally agree. So, for example, patients always imagine that the hospital guys can see what we write in our electronic notes, which they can't. And the hospital also imagine that the district nurses can see what I write in the notes, but they can't. And this kind of separated piles of data, the amount of information out there is just unbelievable. And if it was more readily available, the difficulty behind research would be surmounted so much more easily. Clare Delmar Well, again, this is something that's going to, I think, plough on and on. So just to close out, pull this back down to the patient level, so to speak, and that Times article that I referenced earlier was quite popular. And I'm really interested to hear what you have to say about how you would advise men, you know, at certain benchmarks, 40, 50, 60, and what the top thing is they could do in managing their prostate health. Jeff Foster I think the best thing you can do is don't just focus on your prostate and to focus on any gland, any organ, any specific item in your body is the route to failure. Because if you are truly interested in men's health and you're interested in your own body and you're interested in getting better quality of life, then you want to focus on your entire self, this holistic idea. So you would always say to every patient, when you're 40, 50 and 60, you want to get a full blown health check and you want to look for everything that you can try and look for in terms of disease risk profiling. The reason that's important in terms of looking at prostate health is because it has ramifications. So if, for example, you pick up one form of disease that may have implications on your overall prostate disease or prostate cancer risk, for example, there's tenuous evidence, or slightly better evidence suggests that vitamin D supplementation could reduce your risk of prostate cancer. People don't make that connection, especially if they are thinking, crikey I need to look after my urine flow or to get a PSA test. But if you look at it as a wider picture, there's lots of stuff you can do to improve your overall prostate health. So MOTs in the first place, get a health check every decade or even more frequently if you are able to. And I think after you've done the screening, the other thing to look for, what are those elements of my life that I could improve, that would decrease my overall prostate disease risk. And if you think of prostate cancer, I mean, yes, it is incredibly common for men, but it's just another cancer. Well, there is very

good evidence that for prostate cancer and others, if you're just more overweight, that's going to increase your prostate cancer risk. Interestingly, large amounts of calcium, which seems to be more an isolated risk to prostate cancer than most others, but we're talking pretty excessive amounts – necking pints of milk every day. Eating healthy diet is the most banal and what usually is unhelpful phrase, but you should eat a healthy diet, because you can make TV programmes out of it. If you can effectively keep your overall body healthy by not being overweight, by exercising and eating a healthy diet. Those are the best things you can do to remove prostate cancer risk. Clare Delmar Well, good advice. Dr. Jeff. Jeff Foster Thank you. Clare Delmar Links to Dr. Jeff's book, website and media pieces are available on the programme notes. Further information on prostate cancer diagnosis and treatment is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Thanks for listening, and from me, Clare Delmar, see you next time. Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and even ignored. Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is GP and men's health specialist Dr. Jeff Foster, author of Man Alive, in which he examines the most commonly misunderstood aspects of men's health. His expertise on testosterone deficiency, erectile dysfunction, prostate health, cardiovascular disease and nutrition and wellness has been shared widely through media and applied in his clinical practise. Dr. Jeff, thank you so much for coming today and welcome to On Focus. Jeff Foster Thanks very much for having me. Clare Delmar One of the things that introduced me to you was obviously your book, which we can talk a little bit about later. But you recently had a piece in The Times which got a lot of attention where you talked about screening for prostate health, screening for prostate cancer specifically. And I wanted to just sort of start off on that and ask what your observations have been over the last 18 months during the pandemic on screening for prostate cancer. What's changed and what do you think men can anticipate going forward? Jeff Foster Yeah, sure. So at the initial start of the pandemic, the uptake in all forms of screening and almost all primary health care just stopped almost dead to the point where it would probably be the first time since I qualified that we had clinics and you would have space and there was time and no one actually came in asking a question. And then, of course, there's a degree of acceptance and understanding about what was happening. And it's the rebound effect because in a lot of these scenarios, the end result in terms of patient user demand works out the same, except we've got a big gap where nothing happened so suddenly we're now trying to cram all that stuff back into the same amount of working day, which means obviously it's a big challenge to do. Clare Delmar And how does that play out with screening for prostate cancer and specifically around PSA testing? Jeff Foster The big thing for PSA testing, from my perspective, is that it's how you use the PSA that's important. And we regularly, I would say our practise has just short of sixteen thousand patients in the NHS practise, we would have maybe one or two patients a week who would just request to have a PSA test. They wouldn't necessarily want to see a doctor to discuss that, but would just send an e-consult or a medication request and on that would say, can I just book for a PSA test? Clare Delmar OK Jeff Foster These are not the same guys that have symptoms and these are not the same guys that are already under urology or may have other urological problems. But just that understanding that some people know about PSA, they've heard of it and they think I just want it tested. The problem that we have is that obviously you then say to your patient, well the PSA is not a widely accepted national screening tool for all forms of prostate cancer. But on the other hand, you also say, but on the other hand, it's the best we've got for now. You have to really counsel every patient to say, what is your risk, your age group, what is your expected level of PSA? And then you can start to give them a bit of informed choice about what they want to do with that test and whether it's going to be useful, and even if they do have it. What do you do with that result in maybe six months a year, five years time. Clare Delmar But you made a comment a minute ago about what your expected PSA. I mean, do you see a point where every man should have a baseline PSA and then they maybe eventually begin to self track? Jeff Foster A single PSA by itself I would consider to be useless. And obviously, as part of the book we spoke to several urologists about this and there is so much discussion around when and at what point we should start looking at people's PSAs. I think a PSA is very useful if it's initially screened properly and then it's used cumulatively. And the whole thing about medicine now, it's moving away from subjective feelings and symptoms of disease. And if you can say I've got a guy's PSA every six months for five years, then that's useful data. And you can do something with that. Clare Delmar Yeah, but I guess that's what I meant when I suggested

self-monitoring or self tracking. I mean, do you foresee a point where you have your initial baseline done through a GP like yourself, but then you are able to monitor regularly whatever period that regularity is, Do you see, that is something in the future? Jeff Foster Probably not, to be honest, purely because again, there are too many variables around the local labs and what their PSA might be. Who's responsible for that test if it comes back abnormal, if you didn't order it? Clare Delmar Indeed. Jeff Foster Is there anything better than a PSA you could use that more to fill that gap. Clare Delmar Well, I'm going to come on to that, that you raised a really interesting point and I am going to come on to that. But but again, you use the word variability, and that's something that we've been looking at a lot because we hear about it so much from our patients who, again, you talk about data, you know, we can track patients who have had such variable experiences across the NHS, whether it's from different parts of the country. And I guess that's something that I wanted to explore a little bit with you, that this variability in both the screening and in the diagnostic pathway that follows. How do you think this can be addressed in the sort of medium term and ultimately in the longer term? Because it can't stay that way, if one person gets tested one way and has a different type of biopsy or a different type of imaging or different type of treatment. How do you see that playing out? Jeff Foster The inherent problem with the pathway is the PSA itself. So if you are to compare, for example, with breast screening, a patient has a mammogram, based on that result, it then goes to a specialist who will then review patients. And the operating procedures are so well established, you can apply them to a national accepted screening process. If you have a test like PSA, which no one really agrees what use it really is, then you can't apply a very well regulated process to go with it. There's rough processes and NICE guidance and two week criteria still fits and if you've got some enormous PSA you can just refer your patient. I mean not everyone get referred and some hospitals will run the results of those PSA differently to others. Clare Delmar So now, I do want to come back to your point you made earlier about the PSA being that the best we have, I think, is how you expressed it. You know, amid this kind of controversy, we've actually begun to see a new approach in imaging that's emerging that it could be used for screening. Do you see a role for this in primary care in future? Jeff Foster If you could devise a screening test that was cheap, reliable and minimally invasive and you could get men to engage with that, then it would easily surpass the PSA. And if you could have a national screening prostaogram service or something similar comparable to cervical screening or breast screening, and it allowed men to be walking in for a quick image which was non-invasive, had a very good pick up rate and was relatively cheap to do, then we could get rid of PSA as a screening tool in primary care completely. Clare Delmar Are you familiar with the prostaogram? In its current form it's still being trialled. Jeff Foster Yeah, and the problems with it at the minute would be the cost is too prohibitive. You couldn't use that as a GP referral source because everything we have to do has to be justifiable in primary care. It's a very odd scenario, whereas if you're a hospital doc and you work in the hospital, for the majority, 99 percent of stuff, you can just test for it if you need it, there's no look at the budget. There's been a lot of discussion around how the NHS is using patient data and particularly GP records. What are your views on this and how do you see the NHS data being used to support and advance men's health? Jeff Foster It's all about what you feel you want your data to be used for and what understanding you have in terms of what your data offers. So to clarify, what I mean is, a lot of people are very fearful of giving their NHS data out, as if in some way this is going to impact on their ability to function in life, as if in some way this is personalised stuff that we don't want Big Brother to know, that sort of thing is very hidden. Whereas actually what we're finding also as we move to the electronic system of prescribing and hospital sharing of notes, is that actually data in the NHS is not particularly well protected anyway, and it is shared amongst various groups within the NHS quite freely. If you then say you want to sell it on to third parties, well of course that has to be with the explicit consent of the patient because you're crossing that that boundary from what is NHS agreed. Well, actually, I might have BUPA, Virgin, Nuffield, any secondary company might decide, actually, they've got your data and they might be able to advertise something to you. Now, if this is the way that the NHS could fund it's shortfall, then perhaps people might agree. On the other hand, people are also very protective of the NHS and the NHS data, and they feel that their health records are very personal to them. But I think the way it's been done almost surreptitiously and with a lot of behind closed doors sort of feel behind it has meant that for many patients it has not been a very positive experience into the data sharing. Clare Delmar Which is such a shame. If we could square the circle, because, as you said, it potentially plugs a financial shortfall. But also, as we've seen during the pandemic, when clinical trials themselves are being compromised, data has become the way we actually do our studies and look at how we actually will advance various problems in health care. I mean, so you've got this resource, but somehow it's kind of stuck. Jeff Foster Yes, I totally agree. So, for example, patients always

imagine that the hospital guys can see what we write in our electronic notes, which they can't. And the hospital also imagine that the district nurses can see what I write in the notes, but they can't. And this kind of separated piles of data, the amount of information out there is just unbelievable. And if it was more readily available, the difficulty behind research would be surmounted so much more easily. Clare DelmarWell, again, this is something that's going to, I think, plough on and on. So just to close out, pull this back down to the patient level, so to speak, and that Times article that I referenced earlier was quite popular. And I'm really interested to hear what you have to say about how you would advise men, you know, at certain benchmarks, 40, 50, 60, and what the top thing is they could do in managing their prostate health. Jeff FosterI think the best thing you can do is don't just focus on your prostate and to focus on any gland, any organ, any specific item in your body is the route to failure. Because if you are truly interested in men's health and you're interested in your own body and you're interested in getting better quality of life, then you want to focus on your entire self, this holistic idea. So you would always say to every patient, when you're 40, 50 and 60, you want to get a full blown health check and you want to look for everything that you can try and look for in terms of disease risk profiling. The reason that's important in terms of looking at prostate health is because it has ramifications. So if, for example, you pick up one form of disease that may have implications on your overall prostate disease or prostate cancer risk, for example, there's tenuous evidence, or slightly better evidence suggests that vitamin D supplementation could reduce your risk of prostate cancer. People don't make that connexion, especially if they are thinking, crickey I need to look after my urine flow or to get a PSA test. But if you look at it as a wider picture, there's lots of stuff you can do to improve your overall prostate health. So MOTs in the first place, get a health check every decade or even more frequently if you are able to. And I think after you've done the screening, the other thing to look for, what are those elements of my life that I could improve, that would decrease my overall prostate disease risk. And if you think of prostate cancer, I mean, yes, it is incredibly common for men, but it's just another cancer. Well, there is very good evidence that for prostate cancer and others, if you're just more overweight, that's going to increase your prostate cancer risk. Interestingly, large amounts of calcium, which seems to be more an isolated risk to prostate cancer than most others, but we're talking pretty excessive amounts - necking pints of milk every day. Eating healthy diet is the most banal and what usually is unhelpful phrase, but you should eat a healthy diet, because you can make TV programmes out of it. If you can effectively keep your overall body healthy by not being overweight, by exercising and eating a healthy diet. Those are the best things you can do to remove prostate cancer risk. Clare DelmarWell, good advice. Dr. Jeff. Jeff FosterThank you. Clare DelmarLinks to Dr. Jeff's book, website and media pieces are available on the programme notes. Further information on prostate cancer diagnosis and treatment is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. GP Surgeries need to support, not discourage Prostate Cancer Screening The substantial drop in GP referrals for prostate cancer diagnostics over the last year has led to concern over a mounting cancer backlog, mainly focused on hospitals. But it also merits a look at patient's experience in primary care and how this might be improved. We've explored this a lot over recent months by talking with patients, primary care and men's health specialists. Delroy Wright is a former patient from south London whose primary care experience appears to be shared by several black men we spoke with. I said, well, you know, I said, well, nah, you can't really do that, because being a black guy, you know, we don't really have anybody just go up into your passage just like that. So I asked him if there's a lady doctor on site that can do it, and he said, yeah, and he laughed because he knew, you know, because I've got an Indian doctor, he said he knew how black guys were regarding just going up the passage. Six months later, I had another PSA test and this time they wanted me to do a MRI." Marcus McKenzie, also from south London, felt he had to challenge his GP for a PSA test, even though as a mixed-race man he knew he was at higher risk for prostate cancer. "Well, being a man of mixed race in terms of Asian and black, I was aware of my heightened risk. There are some obstacles I have encountered at the doctor's surgery level whereby one particular doctor sort of suggested that I ought not to have a PSA test because it wasn't particularly reliable, knowing full well that that's the only barometer or gauge one has. So I had to challenge that particular doctor and I insisted that I have the test by virtue of the fact that I was 50 percent more likely to develop prostate cancer because of my ethnicity." Del and Marcus struggled to get screened for prostate cancer despite being both higher risk and proactive in managing their health. We discussed this with Dr Sam Merriel, a practicing GP in Somerset and a clinical research fellow at the University of Exeter, where he is investigating ways of improving the early diagnosis of cancer in primary care. He feels that despite the drop in referrals during

the pandemic, some encouraging signs emerged that are most likely here to stay and can be improved further. Video and telephone consultations is an example where he has seen men who might have been more reticent about going to a GP surgery and discussing prostate-related issues are more likely to engage. He also believes that PSA testing can be better guided by the Prostate Cancer Risk Management Programme which is aimed at helping GPs to engage with patients more substantively, and that GPs should have conversations with men who are symptomless about their prostate cancer risk. In terms of improvement, Dr Merriel feels that GPs could do better on their knowledge of the prostate cancer diagnostic pathway. While this is the domain of hospital specialists, GPs do support patients later as they undergo treatments such as Active Surveillance and hormone therapy. He hopes that emerging Primary Care networks can connect these dots and integrate more diagnostics locally. Another approach comes from Prof Gordon Wishart is a professor of cancer surgery at Anglia Ruskin School of Medicine and the Chief Medical Officer and CEO of Check4Cancer, a leading cancer detection and cancer prevention organisation. He's been a leading voice in lobbying the government and NHS to address the backlog in cancer diagnoses incurred by the pandemic, and spoke to us recently about how certain aspects could be addressed through primary care. One aspect is risk stratification – we know that age, ethnicity and family history (including BRCA gene) increase the risk of prostate cancer, and this information could be more systematically used to bring men into their local GP surgery for screening. In terms of screening itself, Prof Wishart would like to see more use of at-home PSA testing, which he believes to be both accessible and effective, allowing more men to regularly measure and track their PSA levels. Another leading voice in primary care focused specifically on men's health is Dr Jeff Foster is well-known GP and men's health specialist who is frequently featured in the media. He notes a clear difference between men and women in their GP attendance: "For many men, the thought of going to the doctors' fills them with deep dread, and they may only attend primary health care at the insistence of a partner or significant other who has booked the ap Women are much more likely to seek medical help than men, and there are several potential factors for this phenomenon. Firstly, the fear of receiving bad news can cause this reticence, especially if doctor google has been employed prior to the visit. The feeling that they are wasting the doctor's time has also been found to be a cause, as well as not wanting to lose time off work for health issues. Another important factor is that not all GP's have specialist knowledge specific to men's health and some men feel embarrassed by discussing issues that relate to sexual or reproductive health." He emphasises the importance of finding a GP that understands men's health: "It's long overdue that we think about men's health issues separately rather than combining it into a generic one-size-fits-all screening that is currently available. For instance, as women produce oestrogen up until their menopause they experience greater physiological protection from diseases affecting the heart than men. In fact, many men start to experience heart issues during their thirties but these are not picked up until much later in life, by which time it is too late to correct and can only be managed at best." He advises all men to do their homework. "Too few men visit a doctor let alone place enough importance on their health to shop for a decent one. So, look for a doctor who will treat you comprehensively as an individual and who you feel comfortable enough to talk openly with" As a wish list, we'd like to see GP practices supporting men in the following ways: More accessible screening In future, possibly to include emerging imaging approaches such as Prostagram Campaigns to encourage black and mixed-race men to get screened for prostate cancer Information hubs, signposting links to and providing information on prostate cancer, diagnostics, treatments, side effects and support groups. Pre- and Post-treatment care for sexual, mental and urinary health Communication on why consenting to share GP Data is so important to improving research, diagnostics, treatment and services for men with prostate cancer -- For two reasons: Training for healthcare professionals and tools for data-driven healthcare are growing continually and can be channelled into men's health At a time when the NHS needs funds, its data is a resource of unparalleled scale and scope Accessible and effective approaches to health promotion, ideally encompassing the 4Ps – healthcare that is predictive, preventative, personalised and participatory What has your experience been with your GP? Tim Dudderidge – Prostate Cancer UK Clinical Champion In April 2021, 22 Health Care Professionals from across the UK became inaugural Clinical Champions for Prostate Cancer UK. The programme was established to create projects that aim to transform care for people living with or affected by prostate cancer over the next eighteen months. Twenty-two Clinical Champions were selected, and we're delighted that Tim Dudderidge from the Focal Therapy Clinic and Southampton University NHS Trust is one of them. Describing the project work he will undertake through Prostate Cancer UK, Tim says he wants to: Reduce the harm in treating prostate cancer, through offering active surveillance or focal therapy for suitable men. Offer early testing

with imaging rather than PSA tests, which may give a new momentum for screening for prostate cancer. Tim's vision for prostate cancer includes the reduction of harm in treating cancer, through offering active surveillance or focal therapy for suitable men. This allows them a choice between that and 'radical' therapies which have more side effects but possibly no oncological advantage for many men treated. Early testing with imaging rather than PSA tests may give a new momentum for screening for prostate cancer and when coupled with less risky treatments may bring the benefits without the same harms. This exciting possibility is behind his current project to deliver patient-initiated testing for men in Wessex. Several of Tim's fellow Champions are pursuing projects that aim to address issues our patients care about deeply. Edward Calleja from East Sussex Healthcare NHS is implementing a survivorship programme to address the unmet needs of prostate cancer patients through: Transforming the erectile dysfunction clinic into a more holistic sexual wellbeing clinic Setting up a dedicated active surveillance programme Launching a fitness assessment clinic as part of the preoperative optimisation programme supporting patients physically and mentally prior to their surgery. We've discussed sexual health and prehab programmes in recent blogs and will keep an active eye on Ed's progress. Nick Burns-Cox from Taunton & Somerset FT NHS Trust aims to improve the quality of data and the use of a dashboard in the Southwest of England which will be used to highlight improvements needed along the prostate cancer pathway. Nick hopes to transform this into a national tool to ensure national quality of prostate cancer services and support operational management and planning. This is an exciting project as we enter a new era of data-driven research and data-informed practice. Mark Robinson from Aneurin Bevan University Health Board focusing on reducing the variability in diagnostics across the NHS, particularly in imaging. His project aims to Develop a dedicated primary care referral form allowing patients to go straight to test Audit mpMRI quality, to include each MRI scanner used in each Health Board Standardise mpMRI reporting with support for those professionals reporting Standardise biopsy techniques in each Health Board and ensure access to transperineal biopsy. Maintaining high standards and uniformity in prostate imaging and reporting is essential to effective focal therapy and something the Focal Therapy Clinic itself has pioneered through its reporting process and MDT. William Cross from Leeds Teaching Hospitals NHS Trust is planning to develop an IT system which will assist and guide healthcare teams to provide the latest therapies, and record real-world clinical outcomes which will inform future services improvements. This is focused on providing the patient with a personalised treatment pathway with access to the latest information, support and guidance. This approach to personalised treatment pathways is something we all aspire to and we look forward to hearing more about William's project as it develops. Prostate Cancer Hormone Therapy – What Every Man Should Know Joining this episode of OnFocus is patient advocate & educator Andrew Gabriel, who through his own experience with prostate cancer and his advocacy work has become a well-known leader of patient support groups and a recognised source of knowledge on hormone therapy. His hugely popular talk 'Surviving Hormone Therapy' has been attended by hundreds of patients and clinicians who value its honesty and candour. Andrew is part of Prostate Cancer UK's Patients as Educators Programme, which support clinicians in their patient engagement. Links to Andrew's videos:

<https://www.youtube.com/watch?v=soAzPAmhG50> https://www.youtube.com/watch?v=zAtYQZ_IT3s

Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870 An interview with patient advocate Andrew Gabriel Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is patient advocate and educator, Andrew Gabriel, who, through his own experience with prostate cancer and his advocacy work, has become a well known leader of patient support groups and a recognised source of knowledge on hormone therapy. His hugely popular talk called 'Surviving Hormone Therapy' has been attended by hundreds of patients and clinicians who value its honesty and its candour. Andrew is part of Prostate Cancer UK Patients as Educators programme, which supports clinicians in their patient engagement. Clare Delmar Yeah, well, hopefully the first of many and you have so much to say about hormone therapy. And one of the things that we've talked about before is about the use of hormone therapy during the pandemic. And do you think that the challenges that men face under the hormone treatment has actually been exacerbated during this period? I perhaps ought to sort of explain for listeners who are not familiar with what hormone therapy does, you know, why it's used. So the prostate gland in men is required for fathering children and it produces some components of semen. Contrary to what many men sort of heading into prostate cancer treatment might imagine, it's not required for erections and it's not required for orgasm, although the erection nerves run around the outside of it, so

some of the treatments, you have to be really careful and there is a risk to that mechanism. The prostate is activated by testosterone, which causes it to produce the semen contributions that it normally generates and causes it to grow. So you can kind of switch off prostate cancer, at least temporarily, by switching off testosterone. So it basically switches off the testosterone temporarily while you're on the hormone therapy. In order to sort of think has the use of hormone therapy grown during this period of covid? So there is probably about four different reasons that it would be used in prostate cancer. If you're going to have a whole gland treatment, for example, external beam radiotherapy or brachytherapy, it's useful if the prostate is not too big. Now you can use a narrow beam so it's less of the other organs or you can use fewer seeds in the brachytherapy. For incurable prostate cancer, it increases longevity, unfortunately, doesn't work forever, but it does give many men many years. Clare Delmar OK Andrew Gabriel So often it's not been possible to continue with diagnosis or to perform some treatments that were decided upon immediately because some facilities were not available, some staff were not available, operating theatres got turned into ICU, anaesthetists got taken off to be intubating covid patients. So what do you do with a man who's got prostate cancer and you're halfway through diagnosing, but you can't now do a biopsy or diagnose and he's chosen that he's going to have prostatectomy, but he can't have it because no operating theatre is available. Andrew Gabriel Well, you can put him on hormone therapy because the hormone therapy pauses the cancer at that point and it will pause it for long enough that you can, generally speaking, get through these temporary covid disruption. Now, there's probably one other effect, which I saw happen quite a bit, and that is some men who chose prostatectomy actually then discovered it wasn't available because going back to this problem, no operating theatres, no anaesthetists, because they're being used for other purposes and then switched choices and they might have switched then to external beam radiotherapy and that would normally come with hormone therapy. Some men had longer periods on hormone therapy before they started their radiotherapy than normal. That I don't think is an issue because actually getting your PSA down really low, which is what hormone therapy will do, for radiotherapy, has some advantages. But I suspect that there is a higher use of hormone therapy during this period, in terms of proportion. Now, of course, one sad fact here is that an awful lot of men have not gone to their GPs and got tested during this period. And there are tens of thousands of men who haven't been referred who would normally have been referred. And that does translate to rather a lot of men who are walking around probably with high risk prostate cancer, who don't know, and are not diagnosed, who would normally have been diagnosed in the absence of covid. Clare Delmar So, I mean, the first group when you mentioned about the possible increase in hormone therapy, and you mentioned two groups. You mentioned that the second group, which was those that might have elongated periods on hormone therapy while they were waiting for treatment or intervention not treatment, and then mentioned another group, which might be those that are put on hormone therapy, simply to pause during the period of their diagnosis and before treatment could become available. Plenty of patients in our support groups have experienced that, who were diagnosed during this period of covid. Because, you know, I mean, something else that you talk a lot about is what the effects are, of course, of this therapy on the healthy mind and the healthy body. Andrew Gabriel I think they were counselled to the extent that... I mean it wasn't compulsory, it was, would you like to do this? But no, as you've heard me say before, men are not really counselled when they start on hormone therapy. But I want to pick up on something else you said a minute ago, and that was again talking about the covid era and the delays or actually the deluge of patients who haven't actually presented with symptoms or without, but haven't been tested. And one of the things that I hear and I'm curious about your experiences is how random PSA testing is. And I'm just wondering how you see that amongst the people you engage with and how you might think this could be fixed. If you consider, for example, the guy working in a high end job in an office, possibly with private annual medical checks, those will always include PSA tests. I mean he's got prostate cancer because he will have been having annual PSA tests and a trend or rise that's excessive will be very quickly picked up. Those who are aware might go to their GP and ask for a test and some GPs will give them a test. And it's another one of these factors where people lower down the scale have poorer health outcomes. And when you move down those levels, those patients are predominantly not going to be aware and they're not going to go to a GP until they've got symptoms. And of course, you actually want to pick prostate cancer up before you have symptoms, because you have a much better chance of a cure with fewer side effects. Andrew Gabriel Then you come down to the actual ethnic minority communities who engage less with health care anyway Clare Delmar and are at a higher risk as well. They get prostate cancer generally much, much earlier and tend to get more aggressive prostate cancers. And those people just don't get picked up, you know, often not until they've got quite serious

symptoms. But there's also stratification, according to your you know, your social status, like, I'm afraid there are in many aspects of health care. But something else I want to pick up on about sort of about the hormone treatment, because I know that's something you know a lot about. But we've talked a little bit about informed consent and what it means for a patient to seed it or to consent to the recommendation. Do people feel that they had informed consent, that they feel that there might be some initial steps to possibly improve that process? I mean, the words informed consent are not necessarily used because it's not a term patients necessarily are familiar with. But, yes, when you consent to a treatment, you need to be informed, which means that you're given all the information about the treatment, including benefits and risks and what alternatives there might be and what will happen if you don't have the treatment, whatever options you've got. Generally, you get put on to hormone therapy the moment you're diagnosed with prostate cancer, possibly after a bit of decision making about treatments. But it depends if you've got any choice of treatment: you may not have depending on the stage for your cancer. It is a bit more complicated because usually a couple of weeks later, you start some injections as well. I'd actually sort of read about it a bit because I was expecting that this would happen to me. But when the urologist said to me, oh, you're starting hormone treatment, he didn't say anything about it. Andrew Gabriel Yes, because of course, you talk with men who've actually been on hormone therapy a while. Clare Delmar Of course Andrew Gabriel And they say, well, nobody told me this was going to happen and many of these men are going for radiotherapy. And when you go in for the radiotherapy, you get a multi-page document that lists all the things that might happen to you and you have to sign it. But if you look at the men that went for the hormone therapy and radiotherapy and talked to them some time after the treatment, they will typically say the radiotherapy was a non-issue. It was a few weeks of loose bowels and having difficulty retaining a bladder full of water. Clare Delmar Yes Andrew Gabriel Nobody went through the process of describing that to them. There's a whole load of things that you really need to do to look after your health while you're on hormone therapy, things like making sure that your blood pressures monitored and that your cholesterol is monitored, your blood glucose levels are monitored because all these are things that hormone therapy can push up. But actually, if you don't take some active measures to protect yourself at the end of the hormone therapy, you'll find it's become permanently damaged because your sex organs don't work if you leave them for like two or three years not using them. Clare Delmar Yeah, so that's interesting because that brings us into the sort of domain of prehab, which is gaining a lot of momentum for... Andrew Gabriel Yes. Is it something that you've seen successfully applied for men before, specifically for hormone treatment? Andrew Gabriel No, I mean, usually men don't get any warning they're going to hormone therapy. But in order to preserve function, there's a whole set of things you need to do and nobody offers those to you. So you can't go for two or three years without an erection and expect the erections will still work because they won't. You know, it's crazy because it's a totally avoidable but major issue with prostate cancer and it just needs some education. I mean, it's because not many people talk about this level of detail or this level of openness. I want to ask you something else that we've talked about, which is sort of equal access to treatment, because you've actually said to me before that across the health system, you know, depending on where you are and people use the phrase postcode lottery, but depending where you are, you may or may not even be offered a particular treatment. But yeah, I'm interested in other treatments and how you see systemically that possibly improving. Andrew Gabriel Well, when the guy gets referred for potential prostate cancer diagnosis, you usually get referred to your local district hospital. A lot of men don't realise that they can actually be referred to... In England you can be referred to any hospital in England. Clare Delmar Yes, indeed Andrew Gabriel so you could ask your GP to refer you to one of the main cancer centres or you might start at your local district hospital, but you go through a lot of options. There's this multidisciplinary team, MDT, which is a team of all the urologists and oncologists and radiologists and a number of other people you never see. Clare Delmar Yes Andrew Gabriel and they'll be working out which treatments would be a good idea for you. Clare Delmar Yes Andrew Gabriel so, you know, if your hospital offers radiotherapy and prostatectomy, either locally or via a tertiary service, so you get sent to a specialist, you'll get offered those. If, you mentioned focal therapies, if you would have been an ideal candidate for a focal therapy, but there's nobody in the MDT that's involved in focal therapy treatment, because your hospital doesn't do it and they don't bring anyone in, you're not going to get offered that treatment. I see a lot of patients actually who get interested in HIFU because it does get mentioned quite a bit in the press and will actually say, well, how do I get HIFU? It doesn't just happen with the treatment side, I see the same thing happening with diagnostic procedures. Andrew Gabriel If you're in a hospital that's got, for example, a PSMA PET scanner, they may think nothing.... If you had a prostatectomy and your PSA

started rising and you've hit the magic nought point two, which is about the limit that some of the better PSMA PET scans can pick up where your cancer is, they'll think nothing of just saying right, just go and get a PSMA PET scan. If you're in a hospital doesn't have a PSMA PET scanner, it'll be, well we better stick you on hormone therapy and we'll wait a bit or we wait till your PSA gets to eight or ten and then we might send you off somewhere else to get a PET scan so you can see a difference there that. That delay may take you past the point where a curative treatment that would have been available to you earlier on, is now no longer an option because the cancer has grown. Andrew Gabriel ...necessarily grown to get your PSA high to meet the higher criteria for a scan. So, Andrew, you have so much knowledge and so much accumulated know-how and experience from your own experience, as I said, and from dealing with all these other men who've gone through similar journeys. I mean, what would you say are your top challenges that these men face and when they're diagnosed with prostate cancer, and do you often find that there's often a sort of a 20/20 hindsight? And I'm just wondering, what do you think are those challenges and how men might deal them with foresight as opposed to hindsight? Andrew Gabriel It's an interesting question, because when you're diagnosed with prostate cancer, it's almost always out of the blue. So it's really anxiety generating because your future has suddenly been thrown off course and you're suddenly not in control of it anymore. Andrew Gabriel And there's a lot that we do in support groups to try and educate patients, to teach them what's happening, make them understand their diagnosis, make them understand disease. And actually, as you start to understand things, you gradually feel that you're more in control. It may not be where you wanted it to be set, but it may not be as bad as you imagined from your naive position at the outset. And this really lowers level of anxiety, because you now bring yourself more into control and you can predict the future a bit better. So what we do here a lot is for patients who actually never found the support groups at that stage of their treatment. Sometimes patients come along two or three years later and say, nobody told me there was a support group. I've been having treatment for three years at this hospital and I've just discovered we've got a support group. And that's crazy because they're missing out on so much that they could have gained from it. And the reduction in anxiety, talking to other patients who've had just about every possible treatment, you know, to gain their experiences and understanding issues. This has got a lot worse during covid, and we don't fully understand why, but all the support groups are getting far fewer men referred to them by the hospital urology and oncology departments. And I think it probably relates to a change in the way that patients are interfacing to clinicians. So if you have a telephone call with a clinician, which has obviously become much more common, that tends to be quite a short call, concentrating absolutely on the issue and telling you your results and asking what treatment you want. I mean, the hospitals tell us they're telling patients and patients are finding us via some of the route, like Google. Obviously, the day that you're told you've got cancer, you're probably told several of the things that go in one ear and out the other, to be honest. But in terms of sort of discussing, if you do get hooked up with a support group, then you can talk about things like treatment options. Maybe you didn't have as much information as you have now, but I think decision regret is something that I really try and steer patients away from. But, Andrew, sorry to say that your insights are incredibly valuable and a lot of the comments you're making, I actually haven't heard. And I hope it's the first of several of these because clearly I've only scratched the surface. Further information on prostate cancer treatment and how patients are determined suitable for them is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook

@TheFocalTherapyClinic. Links to Andrew's videos:

<https://www.youtube.com/watch?v=soAzPAmhG50> https://www.youtube.com/watch?v=zAtYQZ_IT3s
Hormone Treatment – What Every Man Needs to Know We have a continual stream of patients who come to the Focal Therapy Clinic having undergone hormone therapy, or having had it recommended to them and exploring alternatives. Those who wish to exit tell us they weren't counselled on its side effects and those exploring alternatives know all too well about the side effects but haven't been counselled about alternatives. There are really two things going on here: men with localised prostate cancer are on hormone therapy, and men being advised to go on it are not being informed of either side effects or alternative treatments. TFTC and Royal Surrey Consultant Urologist and Andrologist Raj Nigam tells us that "men with early-stage prostate cancer diagnoses have been prescribed hormone therapy as other treatments within the NHS are unavailable -- it is an unfortunate negative outcome of the Coronavirus era, if you like, that traditional treatments have all had to be halted for at least three or four months, in particular radical prostatectomy and radiotherapy, and as a result of this, men have inadvertently been advised to go onto hormonal therapy without, I hate to say, proper and adequate

discussion.” Raj points out that this is not the fault of any individual surgeon or doctor. “It’s just the position that they have been placed in in terms of trying to control the condition — with limited time and often in telephone consultation they will say we’re having to put you on hormones until and unless normal services are up and running again.” He emphasises that for some men, hormone therapy is effective and appropriate. disease that has spread to the bones or to the lymph nodes and beyond, and they will have to have hormone therapy to try and control the disease. There are some men who they know that they are definitely going to have radiotherapy and it has been shown that those men will do better with at least a three month period of antigen deprivation therapy prior to having radiotherapy.” He then adds “But those two groups aside, there are a lot of other men that have been put on hormonal therapy, which under normal circumstances would not have been.” This is a significant problem, in Raj’s view, because hormone therapy does not come without side effects. “In my recent experience, some men who have not been advised which side effects to experience are now complaining about it and wondering why they getting these side effects”, he says. Not necessarily because men have had hormonal treatment, but they are what we call hypogonadal in the sense that they have low testosterone levels. Because the hormonal therapy is designed to reduce the testosterone levels in men.” There a number of serious side effects that hormonal therapy can have. “We all know about sexual side effects that decrease testosterone level can have in particular loss of libido, erectile difficulties, ejaculatory difficulties and so on.” “We also know about its effect on muscle mass and bone density, particularly with longer term treatment. And this can lead to increasing and early fatigue, a desire of not wanting to do exercise, a constant feeling of weakness. So those are physical, real physical issues that men are experiencing whilst on hormonal therapy.” Asked about the effect of hormone therapy on mental health, Raj worries that men are not aware of this potential side effect. “I think that the effects of testosterone on the brain are under recognised and underplayed. Men who come to my Andrology clinics often do complain of a loss of cognition or loss in the speed of thought. They may still be at work and they’re finding that they got sort of brain fog type symptoms. We know that you can also experience mood changes and depression with low levels of testosterone”. And of course once men go on hormones and experience impact on their sexual and mental health, they rarely have the counselling available to them that could help them through. Enter Andrew Gabriel, who is the go-to expert on hormone therapy from the patient’s point of view. He has become a specialist in demystifying everything about hormone therapy and runs several support groups for men undergoing it. “Patients are not taught any of the things they need to know about being on hormone therapy, which is why I started doing the Surviving Hormone Therapy sessions. It’s a half-day session when run in the hospital, so you can see why no one can cover it in a 15 minute appointment” Andrew works with Prostate Cancer UK as a patient educator. Speaking with him recently, he discussed hormone therapy in the context of informed consent. I mean, the words informed consent are not necessarily used because it’s not a term patients necessarily are familiar with. But, yes, when you consent to a treatment, you need to be informed, which means that you’re given all the information about the treatment, including benefits and risks and what alternatives there might be and what will happen if you don’t have the treatment, whatever options you’ve got. Generally, you get put on to hormone therapy the moment you’re diagnosed with prostate cancer, possibly after a bit of decision making about treatments. But it depends if you’ve got any choice of treatment you may not have depending on the stage for your cancer. It is a bit more complicated because usually a couple of weeks later, you start some injections as well. I’d actually sort of read about it a bit because I was expecting that this would happen to me. But when the urologist said to me, oh, you’re starting hormone treatment, he didn’t say anything about it. That was it.” Asked about how the many men he counsels feel about this, Andrew comments “they say, well, nobody told me this was going to happen and many of these men are going for radiotherapy. And when you go in for the radiotherapy, you get a multi-page document that lists all the things that might happen to you and you have to sign it. But if you look at the men that went for the hormone therapy and radiotherapy and talked to them some time after the treatment, they will typically say the radiotherapy was a non-issue. It was a few weeks of loose bowels and having difficulty retaining a bladder full of water. The hormone therapy, however, was a major effect on their lives.” And continues “Nobody went through the process of describing that to them. There’s a whole load of things that you really need to do to look after your health while you’re on hormone therapy, things like making sure that your blood pressure’s monitored and that your cholesterol is monitored, your blood glucose levels are monitored because all these are things that hormone therapy can push up. But actually, if you don’t take some active measures to protect yourself at the end of the hormone therapy, you’ll find it’s become permanently damaged because your sex organs don’t work if you leave them for like two or three years

not using them.” Are you worried or confused about hormone therapy?

Prehab & Rehab: Support for Prostate Cancer Treatment and Recovery

Recent studies have shown that prehab/rehab can deliver big benefits to prostate cancer patients. A recent Australian study demonstrated the importance of prostate cancer prehabilitation, concluding that these interventions demonstrably helped to optimise physical and psychological recovery, and “played a key part in enhancing person-centred care.” Research in the UK has shown that by combining exercise with nutritional and psychological interventions, a prostate cancer patient can be “set up to significantly improve preoperative physical and mental fitness in preparation for surgery and beyond.” This in turn leads to improvements in recovery time, with lower risk of complications and reduced length of stay in hospital. And these implemented changes also promote healthier lifestyle choices at a time when men are fully engaged with their bodies and its limitations, which leads to enhanced and sustained physical & mental health and wellbeing habits and behaviours.

Macmillan have produced information and guidance for professionals on prehabilitation and rehabilitation for cancer patients. We spoke with Prehab4Cancer, an initiative for cancer patients in Greater Manchester, about the benefits gained from interventions in exercise, nutrition and emotional wellbeing when one is diagnosed with cancer.

Kirsty Rowlinson-Groves spoke passionately about the benefits this programme brings to patients and the outcomes she has witnessed over the many years she has been involved: “We all know that exercise releases happy hormones, so people get a buzz from that and feel better because of that sort of reaction that exercise can do in rehab. Men seem to talk more openly when they’re doing something active, and while exercising together they talk, they compare notes on their treatments and their side effects and just get a bit of peer support that way.” She points out how building confidence in their bodies through the programme leads to other benefits. When you are set a challenge, an exercise challenge and then you notice that your body can do it, it really improves somebody’s wellbeing to achieve goals that way. And then we also look from the exercise perspective on how we can help with side effects of treatment. So we know deep core control and pelvic floor exercises can help with some sexual health and some urinary incontinence issues. The point here is that many men wouldn’t acknowledge or discuss the sexual, urinary and mental health impact their prostate cancer is having on them, but the confidence and support gained through the prehab programmes allows them to do this. It’s critical to support men with prostate cancer by making them fully aware of the “big three” side effects of prostate cancer treatment. Counselling and support for each of these is hard to find but is available, and we can help you to access these.

Pelvic floor support

For most men, a prostate cancer diagnosis will be the event that reveals the essential elements of their pelvic health and elevate its status to high priority. Hearing the term “incontinence” in relation to their own health is anxiety-inducing and often quite scary for most men, who struggle at the prospect of losing control of one of their most basic of bodily functions and the social and lifestyle consequences that go with it. And because no one likes to talk about it, many men make decisions about prostate treatment without fully understanding what the impact on their pelvic health will mean for them.

Sexual health support

From our conversations with almost 1,000 men who have approached the Focal Therapy Clinic about prostate cancer treatment, we know that many, if not most of them consider the preservation of their sexual function, sexual identity and sexual relationships second only to the preservation of life itself in considering their treatment options. They also tell us that, despite its importance to them, the impact of prostate cancer and treatment on their sex life is usually discussed from a purely functional perspective – and sometimes not at all. Most welcome a conversation about what to expect in terms of all aspects of their sex life, so that they can understand, share with their partner, and make a treatment decision they won’t regret.

Mental health support

More and more people have experienced periods of poor mental health during Covid, manifested as anxiety and depression arising from a continuing sense of uncertainty, fear and for many, an unbearable waiting for things to get better. This will sound very familiar to many men with prostate cancer, with uncertainty and fear all too common, and the unbearable waiting has only been exacerbated by Covid as appointments, tests and procedures are delayed and cancelled. This, and the increase in both Active Surveillance and Hormone Therapy offered as treatments, has been a double whammy for the mental health of prostate cancer patients over the last year. By using exercise as a gateway prehab/rehab programmes can give men with prostate cancer a channel for coping with and questioning their care. Addressing both their physical and mental health often leads to confidence in making the right decision about treatment, and supports more positive engagement with partners, families and workplaces. Ultimately, it can help men who take part to feel more in control of their circumstances and situation.

Innovations in Prostate Cancer Treatment and Care – Tim Dudderidge

Urologist Urological Consultant Tim Dudderidge speaks to OnFocus about the innovations shaping the

future of Prostate Cancer management TFTC Urological Consultant Tim Dudderidge, based at University Hospital Southampton, joins OnFocus to discuss some of the new technologies that are coming through that we can expect to see impacting the experience and outcomes for men with prostate cancer. Tim is an innovator in focal therapy and has co-investigated most of the clinical trials and studies that have built the evidence base for focal therapy and advanced its adoption and practice. He has recently been appointed as Clinical Champion for Prostate Cancer UK, which will give him even more impact on innovative clinical practice across the NHS. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870 Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is urology consultant Tim Dudderidge, who works with The Focal Therapy Clinic and is based at University Hospital in Southampton. Tim is an innovator in focal therapy and has co-investigated most of the clinical trials and studies that have built the evidence base for focal therapy and advanced its adoption and practice. He's recently been appointed as clinical champion for Prostate Cancer UK, which will give him even more impact on innovative clinical practices across the NHS. He's here today to talk with me about some of the new technologies that are coming through that we can expect to see impacting the experience and outcomes for men with prostate cancer. The Prostate Cancer UK project is really exciting because I get to work with some real leaders from all over the UK, not just urologists, but a whole range of health professionals. And we're all going through this process together where we're sort of spurring each other on, supporting each other so that all of our new projects can be successful. So I'm really looking forward to the next 18 months where we'll see our projects come to life. Clare Delmar Well, we'll keep in touch with those and we'll look forward to hearing you report on in here, on the podcast, so look forward to hearing more. So let's just jump right in on this whole area around technology, because we hear so much bad news. And I thought this is an opportunity to be a little bit more sort of forward thinking, as it were. And so one of the things I'm interested in getting your views on what you see as the areas in prostate cancer management that are really becoming transformational or you would expect to become so over the next few years. And just to give you some touch points, I mean, would these be around ablation or imaging or pathology informatics, there's so many areas that that the prostate cancer pathway touches on and they're all undergoing change. Tim Dudderidge Well, I think this is an incredibly broad question, because one of the things that attracted me to urology is the way that technology was having a real impact in changing how we did things. But of course, as I focused in on prostate cancer, I look back over the past 20 years, you know, the first prostate biopsy I did was in 1998. And this was a finger guided Tru Cut biopsy using this metal gadget to drive the needle into the prostate and I just think how things have changed. If you think about what technologies we could be referring to, yes, you mentioned imaging with MRI, but it's functional imaging with PET-CT. We've got robotics, ablation modalities, like HIFU, cryotherapy, IRE, laser ablation, there's improvements in image guided radiotherapy, the use of rectal spacers to reduce rectal toxicity, and using computers to help guide the prostate biopsies where previously the job was done with my finger. And simply because everything else that we're doing now with prostate cancer flows from having really accurate information about the location, the extent and even the biology of the tumour. And so instead of having to rely on really random bits of information like we had with even just with transrectal ultrasound guided prostate biopsy, we now have quite precise information about the location and the nature of the tumour. And I think without that, really, all of the other technologies don't have anything to work with. Clare Delmar OK, so do you see that a massive change in performance in terms of accuracy coming ahead, or is....? Tim Dudderidge I think the biggest challenge, because I think we do now have very good scanners, good protocols, but I think we're not seeing a consistent level of performance across the health economy of different countries, but also within the UK. So I think the next process really is to standardise and have minimum standards for the performance of MRI. So that's the acquisition of the images, which device, which protocol, which sequences we're using. If we're going to move to having no contrast as the sort of standard opening format of the MRI, then I think we need to make protocols so that very quickly, the patients who may benefit from contrast get that. I'm thinking particularly of those where focal therapy questions are being asked or even for active surveillance. I think having the best quality imaging is most helpful in those cases, but also the reporting format. We've got to get some standardisation so that we can have images in the report, demonstration of the lesion, so that urologists can understand and help make treatment decisions. And we may find that actually a lot of this is supported by machine learning and artificial intelligence types of software that supports the

radiologist in their reports and may also be the backbone of having these image based reports so that some of those key images are picked out and can show the area of interest. Clare Delmar It's interesting around when you mention machine learning and AI because, of course, that relies on lots of data to actually develop those tools. And I know we've talked in the past about how data is enabling the drive to get more evidence on focal therapy, for example, you are involved in a study earlier this year that used a database that we're involved in building that was the HEAT Registry, right? So, I mean, it's a topical issue to discuss right, like even this week, because the NHS has recently announced plans to use patient data to share with third parties. So I'm wondering how you think we can best use patient data going forward so that they improve the diagnostics and treatments for prostate cancer? Tim Dudderidge Well, I think the first thing to say is that we really have to have patients on board. And I think one of the problems with the recent thing is that patients feel like something's being stolen from them. And I think that we need to make sure that people have real confidence that whatever data is being taken, it doesn't in any way undermine their confidentiality, the security that they have that no one else is going to know about their medical situation other than their doctor. So I think the government need to work on communicating how this data is going to be used, for what purpose? But I think one of the things that you communicate is how valuable this sort of data can be in understanding shifts in the epidemiology of diseases. And it may even be helpful for spotting the benefits of certain types of treatments in big populations, which is maybe a slightly different approach than is used in randomised control trials, but can be good for hypothesis generation. Thinking particularly about prostate cancer, you know that the HEAT Registry is not that sort of data acquisition. And generally patients know within the NHS that if they're not going into a clinical trial, that they are by force of guidelines required to be in registries. I think we could have more support for gathering data in these innovative areas of medicine so that a bit like in a research trial, there is a resource there for the nursing staff and the research staff to actually gather this data and input it. That is harder when you're dealing with a non-research setting innovative treatment kind of investigation. If they have enough granular detail in them, then actually we can use those registries really well. And we can start to expand on those kind of studies as we get more and more data collected. Tim Dudderidge Yeah, and I think also at the moment, that's mostly about prostatectomy, but I think maybe it can be expanded to include other treatments and I think focal therapy being incorporated into something like that, it would almost make the HEAT Registry redundant in the same way we saw the BAUS prostatectomy registry sort of downgraded because we're starting to get this collection of data in a more routine fashion. And I think if we're going to push to have focal therapy as a standard treatment, then like the other standard treatments in prostate cancer, I think the data collection should be incorporated into these big registries so that it can be collected in an easier fashion for all the centres involved. I mean, it's one thing to have data and technology, as we've been discussing, and another to actually implement these through clinical practice. I mean, can you describe some of the challenges you faced in implementing new technologies into practice? I mean, I think as surgeons, we're naturally inclined towards learning new technical skills and that's what we're good at. Whenever you're doing something new as the pioneer, you feel, I guess, individually convinced of the merits of doing this new thing and you feel that there's an advantage. But there's so many other people that you interact with who sort of need to be similarly inclined. And I think the first phase of introducing this new technology is to kind of go through that process and learn to deal with the conflict and manage it. Certainly with prostate cancer, it's full of uncertainties and learning how to explain the risk of different competing issues. And I think when you're introducing something new, which perhaps is a useful challenge to some of the difficulties of existing treatments, you need to explain, yes, this is a new and untested treatment. And so that process of explaining that, so that patients are making a decision to enter a trial or try a new treatment, that they're doing that fully informed of the pros and cons, and that again, takes a lot of time. But the other challenges I'm not so good at is trying to fit these new technology solutions into the NHS economy. Can the hospital financially kind of come out neutral with something new because of the cost of these things is not always clear. So I think this is a big challenge, which you really need to have good connections with the finance people in hospitals to be successful in introducing new technologies. I mean, actually something else to pursue down the road, because it's only going to be getting more so, I guess, as there's all these uncertainties about what the harms are, but what the benefits are, as you say. So, I mean, I guess final question for you is in terms of prospective patients listening, what emerging technologies do you think that men really should be aware of if and when they are diagnosed with prostate cancer? Tim Dudderidge I think the most important is to know whether their MRI scan was up to scratch. And I think always the best time to ask that question is before you've had it, because it is a difficult question to ask at your local hospital. But

the main thing to be aware of is that once you've had a biopsy, you've sort of lost your chance to repeat the imaging if it wasn't really good. So I think if people read about focal therapy and they are worried about prostate cancer, they go and have a PSA test and it looks like they need an MRI scan, it's really worth trying to get an MRI scan done in a centre where it's done really well. I think personally, I like MRI scans done with contrast, but I can understand why centres are doing them without. And I guess if you've got an MRI scan, which only shows sort of subtle or minimal signs and it's uncertain what the nature of things is, that's particularly, I guess, the most useful time, when contrast could be helpful. If you've got a prostate absolutely packed full of prostate cancer, it probably doesn't make any difference at all. The next thing is whatever treatment you're heading in the direction of, be aware of the experience of the surgeon and what technique they're doing. I don't think it has to be robotic prostatectomy, if your surgeon does the other form, either laparoscopic or open, really, really well. With radiotherapy, I think it's really important that they've got the latest sort of image guided radiotherapy techniques and the use of the rectal spacer, I think that's really helpful. In terms of other ablation techniques, being in a place where you can access a conversation about focal therapy, I think that's really, really important. I think we need to start to recognise that there is sufficient data to say this is an option. We don't know that it's absolutely the same as surgery and radiotherapy in the long run, but we do know there are fewer side effects. There are other needle based treatments that are perhaps not as well disseminated like IRE electroporation of the prostate and laser ablation is something that may well come in in this country, it's already quite commonly seen in America. So there are other radiotherapy techniques which get a bit of attention and the proton beam is the kind of classic one. My understanding is that this doesn't offer much of an advantage over conventional image guided radiotherapy. But nevertheless, the marketing of that type of approach is quite pronounced on the internet, so a lot of men ask me about that. And there's bound to be other novel things which come through, and I think when it comes to those, it's really important to recognise that there are some existing ablation type techniques which have got a lot of data to show that they're successful. And I think before considering one of the newer ones, I would make sure that you have spoken to your local focal therapist, because they can give you a bit of perspective about that whole field and patients who rush off to Germany to have things done, I think they sometimes find that they are so disconnected with the rest of their medical team that they don't really get a good experience. They might have sought out some new technique overseas, but actually then they're isolated and they don't have good communication about what's going on with their case. So I'd just be cautious about travelling to get some novel technique that hasn't been proven. This has been a kind of a whistle stop tour of some really important emerging issues that you've actually spoken to them, I think, in a really helpful way.

Clare Delmar And best of luck with the Prostate Cancer UK assignment, really look forward to hearing what comes out of that. Further information on emerging technologies for focal therapy is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

Prehab4Cancer: Exercise helps men to recover faster from Prostate Cancer Treatments

An Interview with Exercise Specialist Kirsty Rowlinson- Groves

Kirsty Rowlinson-Groves, an exercise specialist who supports men with prostate cancer in preparing for and recovering from treatment, joins OnFocus to how men can benefit from programmes like the one she runs in Manchester called Prehab4Cancer. This is an exercise, nutrition and wellbeing scheme run through the NHS in Greater Manchester, and has won numerous awards for its dedication, commitment and innovative approach to cancer patients across the region. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870

Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Kirsty Rowlinson-Groves, an exercise specialist who supports men with prostate cancer in preparing for and recovering from treatment. She's a programme manager at Prehab4Cancer, an exercise, nutrition and wellbeing scheme run through the NHS in Greater Manchester. She's here to speak with me today about the impact programmes like hers have on men living with prostate cancer.

Clare Delmar I'm really excited to learn more about what you do, because I can see from the website that Prehab4Cancer has won all kinds of awards and just seems to be a really fantastic programme that a lot of clients that go through it are just really excited about. And I'm really interested if you can tell us specifically what is the difference between prehab and rehab. So we work with newly diagnosed cancer

patients in Greater Manchester, just on three tumour groups at the moment but we are looking to expand. And the prehab is basically the preparation for the physiological but also the psychological challenges of cancer treatments and/or surgeries that people face when they are diagnosed. So the prehab is sort of like preparation and we always use the analogy of you wouldn't run a marathon without any training and we think of the impact of cancer treatments and surgeries, the physiological impacts on a body can be akin to something as big as a marathon sort of thing. So making sure that blood pressure and iron levels are correct, there's pharmacological optimisation and there's also like smoking and alcohol cessation and support for that sort of optimisation. So it's getting people back to their pre diagnosis fitness or even higher than that, and getting people back to work, getting people back to just coping with their everyday life, which sometimes can be a bit of a challenge, especially in active treatment and directly straight after surgery. And as we've spoken about before, prostate cancer presents particular challenges around sexual health or urinary incontinence and mental health, which I know you mentioned a few minutes ago.

Kirsty Rowlinson-Groves In one of my previous roles in a rehab programme the particular challenge of urinary continence and mental health came up a lot with the gentleman that came through our prostate referral pathway. For the exercise point of view, obviously we all know that exercise, like the exercise high, so it releases those happy hormones. So people getting a buzz from that and feeling better because of that sort of reaction that exercise can do in rehab, but also from the wellbeing. They could talk, they could chat, they could compare notes on their treatments and their side effects and just get a bit of peer support that way and just talk to other men going through the same thing and talk about how they were feeling. When you are set a challenge, an exercise challenge and then you notice that your body can do it, it really improves somebody's wellbeing to achieve goals that way. And then we also look from the exercise perspective on how we can help with side effects of treatment. So we know deep core control and pelvic floor exercises can help with some sexual health and some urinary incontinence issues. So we look at the side effects and we try and pick the exercises that we know are going to try to help with those side effects. But also, I think just openly discussing on that prostate pathway from the rehab programme. And we can try to help by putting in certain things like, say, the deep core control or the pelvic floor exercises, the breathing exercises.

Clare Delmar No, it sounds fantastic and I completely take your point about just even vocalising these things. And if that's done through a medium like exercise or core strengthening programmes, that's absolutely fantastic.

Kirsty Rowlinson-Groves In the current programme and in the past, every patient gets a full make up, so a full make up of assessments, and from that we then design the best tailored exercise programme for the individual.

Clare Delmar OK Kirsty Rowlinson-Groves At the moment in remote delivery like we are at the moment due to covid restrictions, we design a tailored home exercise programme every patient gets and then patients can also be categorised into levels, so level one, level two level three, and then they're directed to the exercise classes that most suit that level. So they can still get that peer support because they're going onto online exercise classes. They all still get a tailored home exercise pack, which looks at functional capacity, their aerobics fitness, as well as the strength and their core.

Clare Delmar OK, and something else that I always find interesting with programmes that help men open up about how they're feeling. And as you say, their wellbeing, is exactly the role of their partners, because we often find that it's the partners of our patients that play a critical role in their other halves' health and care. I've also been the partner of a cancer patient, so I have really good knowledge of how that partner becomes the care navigator, the administrator. If we can get the partner involved and get them motivating the patient and encouraging the patient, we know that the patient is more likely going to enjoy it because we sometimes get partners involved as in they do the exercise as well. If we bring them into the gym, they get the free gym membership just as the person affected with cancer does. And also it gives that little bit of wellbeing to the carer as well, because I think sometimes they're overlooked. So it also gives it gives the carer or partner that role of, oh, it's something I can do as well for me.

Kirsty Rowlinson-Groves Kirsty Rowlinson-Groves Yes, yes, we see that a lot, especially in the gym. If they were side by side on a bike or a treadmill or rowing machine there is definitely some competition there. We have come up against the other side of that coin, though, where the partners or carers are a bit overprotective and want to wrap their significant other up in cotton wool a little bit. And the thought of exercise, especially if somebody is going through active treatment, can be very, very scary for a partner or a carer. They're the ones that see behind closed door how much that treatment is affecting that person. And so sometimes we have to do a lot of education with the partners and carers about the benefits and why it's so important.

Clare Delmar OK, and which leads me to another question, which is about personal control, particularly in a man with prostate cancer, because diagnosis often brings with it a loss of control. So I'm wondering how your programmes bring back that sense of

personal control through exercise and through the wellbeing and nutrition workshops? You're getting called for appointment after appointment and everybody wants blood and everybody wants to take a scan. And it's a bit like being on a conveyor belt and everybody's prodding and poking and getting their own bit of that person. As an exercise specialist, whenever I've met any cancer patient, it's always I feel my job to put a stop on all that and ask them, do they understand why exercise has been suggested for one. In that whirlwind of information that gets given out, they get sent everywhere so they might not even remember the exercise was offered. And it's usually things really simple, like they just want to be able to climb up the stairs a bit easier or they don't want to get out of breath when they're running down the stairs or something like that. They're the ones that have to wake up in the morning and think, right, when am I going to fit my exercise in? So I think that's how they take control as well, because there's nobody else who can do this type of intervention apart from them. So given your experience working with men living with prostate cancer, are there any obvious gaps in their care that you've seen or you currently see? Kirsty Rowlinson-Groves So I think the obvious gap in the care, I think, is the mental wellbeing side. And just because of the way the services are stretched and I think with the prostate cancer pathways I've worked in in the past, I think because men tend to not be openly asking for it, it can take a while to get that referral through. And then I'd also say that the conversations around sexual health as well don't happen as easily or as quickly as they possibly should. Again, I think it's down to the patient or the carer because it usually falls on the carer and partner's shoulders to go and educate themselves about that side of the side effects of the treatments and ask for more information rather than it being readily available. Kirsty Rowlinson-Groves Kirsty Rowlinson-Groves Yes, when we had the prostate referral pathway in my rehab programme, we were set up really closely with the local hospital. So if a partner or a carer or even the gentleman themselves said anything, then we could refer on to the correct services. A talking therapies group, who we used to signpost a lot of men to, who didn't openly discuss things, but seeing that they wanted to but didn't feel safe in the setting that we were in. So we were able to signpost them into the correct services, or into the more gentle community based stuff like talking groups and walking groups for men. I mean, it's so inspiring to talk to you about such a positive signposting and positive messages and positive programmes for these cancer patients. It's very refreshing and I wish you all the best in continuing to give men and their partners the benefits of your expertise and your enthusiasm. Further information on support programmes like Kirsty's and like Prehab4Cancer is available on our website, along with a transcript of this interview and additional information and interviews, stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic.

New Technologies Driving Focal Therapy Forward

We discussed in a recent blog how Focal Therapy is emerging from the pandemic in terms of what's driving awareness and demand among prospective patients. What we didn't comment on is how the provision of focal therapy is advancing, as new approaches and technologies are investigated, developed and adopted along the diagnostic and treatment pathway. Focal Therapy is all about accuracy – accuracy in hitting the target to treat prostate cancer, and accuracy in avoiding healthy tissue and incurring unwanted side effects. Four things enable Focal Therapy to do this: A diagnosis of localised prostate cancer - making early screening & detection paramount the availability of precise imaging of the prostate followed by accurate contouring and reporting safe & accurate biopsy methods- sampling and histology a powerful & controlled energy source applied to ablate and destroy targeted cancerous tissue Each of these areas is advancing through innovation and new technology which over time we believe will make focal therapy more available, effective and accessible. Below we offer some highlights and indicate the directions of travel for you to monitor going forward. Screening GP-based PSA testing continues to be variable, despite active campaigns to build public awareness about this. We continue to hear patients tell us about their requests for PSA testing being challenged and even denied. We will continue to support these campaign and in the meantime can point to two advancement in screening for prostate cancer. review commented "This test says it can detect abnormal levels of prostate-specific antigen (PSA) in the blood, but this is an unreliable marker of prostate health and the test doesn't address the complications with this type of testing, nor the consequences of taking a PSA test. Our experts were concerned that the cut-off level for 'normal' PSA used in this test is higher than NHS guidelines for men between 50 and 69, so there's a danger that men who would be urgently referred on the NHS would be told by this test that they have a 'normal' result. It also says that men are recommended to get their PSA checked every year, which is not true. The NHS says there's currently no national screening programme for prostate cancer in the UK because the PSA test is not always accurate." So it's not the test itself that is being challenged, but its compliance with current NHS guidelines. We will continue campaigning for access to

GP-based PSA tests, and in the meantime draw your attention to advances in imaging for prostate cancer screening. This year saw the publication of an initial cohort study for Prostagram, which demonstrated that a short, noncontrast MRI may have favourable performance characteristics as a community-based screening test, potentially leading to a world where men undergo Prostagram screening for prostate cancer as regularly and routinely as women undergo mammogram screening for breast cancer. Results from the study showed that Prostagram picked up twice as many prostate cancers compared to the standard PSA test. The investigating team said "The Prostagram study opens up a new chapter in the screening, diagnostic and treatment pathway for prostate cancer. Precision screening will improve the detection process increasing diagnosis of clinically significant disease and reducing unnecessary detection of insignificant disease. It's likely that focal therapy will emerge as a preferred alternative to surgery and radiotherapy for many men with localised prostate cancer. The other exciting consequence of an image-based screening programme could be the acceleration of AI supported reporting systems for both MRI and pathology. This will provide the framework and free time for radiologists and pathologists to provide image-based reports to help guide treatment planning." Diagnostic Imaging and reporting mpMRI for the prostate is advancing all the time, through both clinical research and clinical practice. As Prof Hashim Ahmed of Imperial College and a world leader in this research commented recently, "mpMRI misses very few cancers and of questionable clinical significance when it does." Recent studies confirm this and give more confidence to clinicians in the adoption of mpMRI and its enhancement with contrast agents. Further attempts to standardise mpMRI practice across health centres based on these levels of performance means that in future all more men will have access to the highest quality of imaging. Advancements in imaging at both screening and diagnostic level is leading to more research and innovation in artificial intelligence and machine learning which will support the inevitable increase in scale across the population. Technologies under development at Lucida Medical, Qantib, and Siemens Healthineers look promising. Biopsies and Histology As imaging advances through new technology, so does the accuracy of biopsies under the MRI/US fusion method, which accurately links biopsy samples to targeted regions of interest. As discussed in a recent blog, histology is also improving through new approaches and technology, leading to improvements in consistency and accuracy. New focal ablation technologies emerging Three new approaches to focal therapy are emerging: Avenda This US-based company has developed technology that uses a laser to ablate cancerous tissue in the prostate. According to its founder Shyam Natarajan, "Avenda Health was founded, with support from a National Cancer Institute grant, to usher in the future of prostate cancer treatment. The company's technology and device system, which are being developed to treat only the tumor in the prostate – a similar approach to a lumpectomy for breast cancer – uses imaging, artificial intelligence (AI) and laser ablation. Using a large database of cancer imaging and pathology, in conjunction with a patient's own clinical information, a cancer probability map and treatment plan is created to calculate precisely where treatment should be applied, preserving the nerves around the prostate and the urethra". The technology has recently been given clearance from the FDA, the American regulator, which has designated it a 'breakthrough device for the ablation of prostate tissue in patients with localized, favourable intermediate-risk prostate cancer. Its founder says that "Unlike other similar options in development, this approach will offer patients a personalized treatment plan through the use of the AI-based software and allow treatment to be performed in-office using local anesthesia. This minimally invasive and local treatment will not impact the possibility for additional future treatment options, if needed, for particular patients. The TULSA Procedure is a minimally invasive procedure that uses directional ultrasound to produce very high temperatures to ablate targeted prostate tissue. The procedure is performed in a Magnetic Resonance Imaging (MRI) suite and uses the TULSA PRO system to ablate prostate tissue. The procedure combines real-time MRI with robotically-driven directional thermal ultrasound to deliver predictable, physician-prescribed ablation of whole-gland or partial prostate tissue. IRE – Irreversible Electroporation Irreversible electroporation is a newly developed non-thermal tissue ablation technique in which short duration electrical fields are used to form permanent nanoscale defects in the cell membrane which leads to cell apoptosis. Thus, IRE is a non-thermal technique, which means that changes associated with tissue freezing or heating are not relevant. Following irreversible electroporation (IRE) treatment of prostate cancer, no residual cancer was found in 23 of 28 (82%) of study participants at 6 months after targeted prostate biopsy. Prostate-specific antigen levels decreased from 8.65 ng/mL to 2.35 ng/mL at 12 months ($P < .001$) following IRE of the prostate. IRE of the prostate was associated with a leak-free and pad-free continence rate of 96.3% and stable urogenital function at 12 months. All of the technology developments discussed here are very exciting and are driving focal therapy forward so that more men

can benefit from it. What we haven't talked about here is timeframes for development and barriers to adoption, all very critical to when, where, which and how patients benefit from these emerging technologies. We are fortunate that TFTC clinicians are involved in the investigation of several of these developments through research and clinical trials, so we are keeping on top of advances and will continue to update our patient community. Advocating for Men with Prostate Cancer Ten Years On

Prostate cancer survivor and cancer rehab specialist, Simon Lord, reflects on the changes in the 10 years since his diagnosis. Simon Lord is a personal trainer and cancer rehab specialist, he is also a prostate cancer survivor having had successful robotic surgery in 2010. He joins OnFocus to discuss the changes and developments he's observed in diagnostics and treatments for men with prostate cancer and how this impacts the experience of men he works with. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870

Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer amongst men in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Simon Lord, personal trainer and cancer rehab specialist who is also a prostate cancer survivor, having had successful robotic surgery in 2010. He joins On Focus to discuss the changes and developments he's observed in diagnostics and treatments for men with prostate cancer and how this impacts the experience of men he works with. Well, one of the things that sort of brought me to want to chat with you is, aside from all the great work you do with men both pre and post prostate cancer treatment, is that you've seen some incredible changes. And I'm really interested in hearing how you've seen these changes work for the benefit or maybe you've seen some challenges that need to be addressed. So during this period, what would you say is the good news and what is the bad news in terms of progress?

Simon Lord I think the good news for many but not yet all men is that the pathway for prostate cancer diagnosis has definitely been speeded up and within that pathway there is more use of better technology than certainly was the case when I was diagnosed. If you go back 11 years, every man was diagnosed with prostate cancer following a transrectal biopsy. So device put up the rectums, a needle shot out through the rectal passage into the prostate. Now, some men still have that biopsy process, but it's a shrinking number and the majority of men are now diagnosed following a biopsy taken directly through the perineum with the aid in many cases of an MRI scan. So I think what we should be seeing is fewer men needing more biopsies, but more biopsies giving greater, more accurate information to the surgeon or to the oncologist to allow them to really prescribe the right treatment.

Clare Delmar OK, does that manifest in the men you work with that in that they feel confident that they've been diagnosed accurately and effectively and that the treatment is a good thing? They just coming in and now we're starting to see some real evidence that they work and that MRI guided biopsies work. And so I think within the next five years we will probably see the majority of men being diagnosed with that.

Clare Delmar Yeah, I mean, it's interesting because you say that it's becoming more prevalent, but yet we also talked in previous conversations about how there's still variability across the NHS and this can impact men going through diagnostics and treatment. Best practice, we should allow this to happen, but best practice isn't yet universal practice. But there are some other more niggling issues, I think, around best practice, we still see one or two, more than one or two sadly, a significant number of men, being put off having PSA tests by primary care, by GPs because those GPs don't think it's relevant. And clearly some men will therefore receive a late diagnosis of prostate cancer and have their treatment options limited and their life limited as a result. Do you see this having improved in the time since your treatment, both in terms of quality and quantity, for example?

I would say even now it's very poor and I would think very few men and their partners are properly counselled in terms of treatment options, they might be given them, but whether they're counselled over them is another matter, because counselling is not just a question of, well, here's a piece of paper with the information on it, what do you want to choose? Fully to counsel someone about that is not something that you can do with a 15 minute session or even one or even a couple of 15 minute sessions. So I don't think that we are anywhere close to the level of availability and the quality of counselling that I would want to see for men in that respect. I mean, do you think that the need for counselling is greater now than when you were going through your treatment?

Not really, I mean, I guess the issue is that we're probably seeing an increasing number of men being diagnosed younger and in that respect, do they deserve more counselling? Well, on one level, yes, but overall not really, because it's still the same impact, whether you're forty three, fifty three, sixty three or seventy three. So I don't really hold with the idea that just because they're younger, they should get counselling because

that's rather writing off the older man who for all we know might be just as healthy and vigorous as someone twenty five years younger. When we see this all the time and I guess we're referring here to counselling around side effects and particularly around sexual health. Simon Lord The side effects are massive in some cases, but I don't see that at the age of the patient should have a bearing on that. Well, I guess my question really about the side effects was, given that there are more options in theory available, that there's more information and more potential impact around side effects. Maybe the NHS hasn't really caught up with the technology because I think the NHS is still sort of based on the idea that this has to be done one to one in a hospital setting. And the reality is that actually the vast majority of this could now be done, maybe still one to one, but certainly remotely. There's no reason why this couldn't be done at a regional or national level with men having access to the type of counselling they want to have, not the one size fits all that the NHS wants to put at them. So that there would be an opportunity to have counselling done, still very effectively, but remotely, rather than someone having to travel to a hospital to have that take place. Clare Delmar And in a previous conversation we had, you talked about how funding and awareness for prostate cancer is actually very small compared, for example, to that for breast cancer. Simon Lord It's always difficult in a situation like mine to not to be seen to be complaining about another tumour's funding. I don't want to complain of that and say, well, breast cancer gets ten times the amount of prostate cancer. You've got to remember that breast cancer has got a lot of history, breast cancer obviously has got a lot of high profile patients and advocates going back across years. Breast cancer has got a remarkable profile really because if you believe the publicity, you would believe that most women are diagnosed with breast cancer in their 30s or 40s, relatively speaking, in their prime, but the truth of the matter is it's just like all cancers is actually a disease of getting older and that most people diagnosed with breast cancer are over 50, in the same way that most men diagnosed with prostate cancer are over 65. But the breast cancer campaigners have been very effective at what I would call, and what you would understand as, linking breast cancer to apple pie and motherhood. And making it or the support of it, obviously not the disease itself, but making it glamorous to support breast cancer. Simon Lord And we don't hear about men in their late 40s and 50s being diagnosed with prostate cancer. Very, very recently, a smaller number of what the media would call celebrities have come out with the fact that they're being treated for it. Clare Delmar Are you referring to like Stephen Fry and Bill Turnbull is that kind of what you're thinking? Simon Lord Well, Stephen Fry is an interesting example, but I would say well, actually, I think but the flip side of their being open about it is that it does bring more awareness to the topic. And so they have a big audience, but if say they've been able to get more men in to be checked for the possibility of prostate cancer, then that's clearly a good thing. The flip side of it, however, is that what it's actually also shown is that there's been a reduction in my 10, 11 years of advocacy of the press wanting to talk to Joe Average about prostate cancer because we've now got celebrities who are happy to talk about it. What, of course, you don't hear about celebrities is that clearly they've already got a significant income. My family were worried about my income and my future health and the impact on the family as a result of that, because I'm the only earner in my family, whereas in the case of the celebrity prostate cancer survivors, none of that is an issue. Simon Lord And so I think there's been a bit of a skew away from the man in the street talking about his prostate cancer towards the celebrities, which ultimately I think is disappointing because it makes it sound that actually prostate cancer probably isn't too bad because you can throw money at the problem. Now, obviously, in the case of Bill Turnbull, we know actually his prostate cancer is advanced. But he still has significant advantages over a man with a manual job and no big savings behind him. So drawing this to a close, I guess I'd be really interested in your views on what you would say to newly diagnosed men and men going through treatment, who I guess you engage with pretty regularly in both your advocacy and your rehab. And if that means having a second or even a third opinion on your situation and the treatments available and the likely outcomes, then do it. They will be your greatest supporters and will comfort you in ways you didn't believe possible, despite the fact that they might have been strangers 10 minutes or more ago, you know? There is a huge and very positive energy out there for men going through what you're going through, find that energy and draw from it because it will carry you through. Clare Delmar OK. Simon Lord And the third piece of advice, which I rather would say wouldn't I, is if you're not already fit, get fit. Because the fitter you are, as you go through both diagnosis, treatment and recovery, the better your future life will be. Clare Delmar Simon, I want to thank you very much for speaking with me today, it's been an absolute pleasure. Clare Delmar Further information on standards of care and diagnostic procedures and treatment for prostate cancer is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on

Twitter and Facebook at The Focal Therapy Clinic. Consistency Drives Best Practice Across Prostate Cancer Pathway

Despite national guidelines, we see considerable variation across the country in key elements of the diagnostic pathway for prostate cancer, exacerbated over the last year by the constraints on diagnostic services incurred by the Covid19 pandemic. We hear this continually from our patients, who come to us with imaging, biopsies and histology that often need to be undertaken again in order to accurately assess these patients for their suitability for focal therapy. If a patient is suitable, this upgraded quality of diagnostic information is required for focal therapy to be effective in removing targeted cancerous tissue whilst preserving healthy tissue within and around the prostate. Focal Therapy is literally defined and guided by the highest standard of precision and accuracy in determining the location, size and severity of cancerous lesions within the prostate. Our patients' stories paint a picture of variability and inconsistency across the health service, so it's important for prospective patients to know what the standards are in prostate cancer diagnostics that will give them accurate information and optimal choice in their treatment.

Imaging A pre-pandemic report on availability and variation in prostate mpMRI by the Royal College of Radiologists revealed that about 87% of cancer centres provided the service, but that there was considerable variation in implementation across centres. A recent study on prostate Cancer diagnostics during the Covid19 pandemic investigated 148 cancer centres in the UK, all of which offered mpMRI pre-pandemic. While, 39 (37%) continued to offer MRI for the same indications as prior to the pandemic and 48 (46%) offered prostate MRI to selected high-risk patient groups only. As evidenced in a recent study led by TFTC uro-radiologist Clare Allen, overcoming this variability through standardisation of practice delivers real benefits. Her study explored prostate mpMRI protocols across 14 London hospitals to determine whether standardisation improves diagnostic quality. It concluded that targeted intervention at a regional level can improve the diagnostic quality of prostate mpMRI protocols, leading to improvements in prostate cancer detection rates and targeted biopsies. We uphold the highest standards for imaging as it drives the consistency and accuracy required to assess suitability and undertake focal therapy on our patients. It underpins both biopsy and treatment planning as it reveals the exact location, size and severity of prostate cancer. More information on what every man should expect from his mpMRI and its reporting is provided [here](#).

Biopsy According to the most recent National Prostate Cancer Audit, 70% of prostate biopsies in England were TRUS, and only 21% were transperineal (TP) despite national guidelines to adopt the latter approach. Interestingly, The BMJ study of prostate cancer diagnostics during Covid shows that while the overall level of biopsies dropped across centres, of those that performed prostate biopsies there was a shift away from TRUS. "Most centres that continued biopsy during the COVID-19 pandemic did so only on selected higher-risk patients. Of all centres that responded to the survey LATP (local anaesthetic transperineal) was offered for higher-risk patients in 43 (41%), GATP (general anaesthetic transperineal) in 23 (22%), and LATRUS (local anaesthetic TRUS) in 22 (21%) centres. However, some centres continued to offer biopsies using the same method as prior to the pandemic; LATP 13 (12%), GATP nine (9%), and LATRUS 12 (11%) centres." Our biopsy standard at TFTC is MRI/US fusion transperineal biopsy, undertaken with a detailed report on the patient's mpMRI and a targeted biopsy plan prepared by an expert uro-radiologist.

Histology The final piece of information in the diagnostic pathway is generated under the pathologist's microscope when s/he grades and scores the cancerous cells observed from the biopsy samples according to a system known as Gleason scoring. Studies have shown that there is known "inter-observer variability" in histological detection and grading from biopsy samples, and it's the one area where machine learning is emerging to aid in accuracy and consistency. Automated deep learning systems have delivered promising results from histopathological images to accurate grading of prostate cancer, and studies have shown that deep learning strategies can achieve better outcomes than simpler systems that make use of pathology samples. Men should be aware of the variability that exists in Gleason scoring and ask about the pathology lab undertaking their biopsy results and its record.

MDT This is perhaps one element of the pathway with the greatest variation in availability, constitution and quality. At TFTC each patient is reviewed by an MDT made up of a uro-radiologist, several urological surgeons, an oncologist and medical technicians that have been involved in patient procedures. Since the pandemic these have been undertaken digitally which has in fact improved frequency, attendance, quality of discussion and patient outcomes. Ultimately the diagnostic pathway comprised of these elements leads to treatment recommendations, which again will vary across hospitals depending on a number of factors in addition to the diagnostic information. Similarly, support services for non-clinical aspects of prostate cancer and its treatment also vary considerably – this includes counselling for the impact on sexual, urinary and mental health that a prostate cancer diagnosis brings. The variation here is stark - from nothing at all, to

the recommendation of a service provider, to active counselling. All men need to know about the side effects of any treatment they are recommended, and to have access to counselling on these. In summary, it's a challenging time to manage a prostate cancer diagnosis, and we want to encourage and support men in building awareness of best practices, so that they can discuss diagnostics and treatment recommendations meaningfully with their care teams and feel confident to challenge them when necessary.

When Active Surveillance Lets You Down Marcus McKenzie discusses his prostate cancer experience. Marcus McKenzie, a teacher from South London who recently underwent prostatectomy surgery after two years spent on Active Surveillance, joins OnFocus to discuss the heightened risk of prostate cancer that Black and mixed race men face, how this impacted his experience and what all Black and mixed race men need to know about managing their prostate health. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and sometimes ignored. Joining me today is Marcus McKenzie, a teacher from South London who recently underwent prostate surgery after two years spent on active surveillance. Marcus is mixed race and was aware of his heightened risk of prostate cancer at the time of his diagnosis. Can you tell us how you came to be diagnosed with prostate cancer and subsequently placed on active surveillance?

Marcus McKenzie: Well, being a man of mixed race in terms of Asian and black, I was aware of my heightened risk. There are some obstacles I have encountered at the doctor's surgery level whereby one particular doctor sort of suggested that I ought not to have a PSA test because it wasn't particularly reliable, knowing full well that that's the only barometer or gauge one has. So I had to challenge that particular doctor and I insisted that I have the test by virtue of the fact that I was 50 percent more likely to develop prostate cancer because of my ethnicity.

Clare Delmar: Indeed Marcus McKenzie. She acquiesced and I had the test and then unfortunately, the rest is history.

Clare Delmar: OK, so you on your own initiative were regularly attending your GP to get the PSA test and then you had this one roadblock with the person you just described?

Marcus McKenzie: Which wasn't insurmountable, but it then indicated that my PSA level had doubled. Marcus McKenzie. Within one year, so it was an obvious sort of next step in terms of investigating as to why it had sort of doubled. And I was advised that the MRI facility that they had was inferior to that of King's College. I did a bit of research and the MRI is really important if you have to take your sort of investigation further, because it sort of more or less pinpoints where any sort of abnormalities are.

Marcus McKenzie: I spoke to my doctor and they had no problem whatsoever referring me to King's College...

Clare Delmar: OK Marcus McKenzie and then I had an appointment at Beckenham Beacon, it's a hospital in Beckenham, basically, and I was put under the care of one of the consultants.

Marcus McKenzie: Well, this is where my journey started because I spoke to a very confident, very affable consultant who gave me what was an ultrasound. He said, the size of my prostate and my PSA reading was probably commensurate with my age and ethnicity. And I think a few weeks later I had an MRI and that's when I had the MRI, I was really concerned about taking it any further because when you do a little bit of research or a little bit of knowledge is dangerous. And I remember sat down with my wife and we were talking to the surgeon and they were going around in circles and he said, lo and behold, you've got cancer, you've got prostate cancer. And if I was going to have cancer, this is a cancer that would I would want because your Gleason score is very, very low. And so it really took me by surprise and then prior to that, those comforting words from the consultant saying no no no, I doubt it very much whether you have prostate cancer. So what we want to do is put you on active surveillance and we will monitor you every three months. On occasions it had actually sort of went below four point seven to maybe four point three.

Clare Delmar: OK Marcus McKenzie I'm going to jump back a bit because the biopsy is a nightmare. And when I woke up, there's lots of blood and the nurses were looking at me and they said, how are you? And I wasn't allowed to leave until I could pee, but there was lots of blood and it was an awful lot of discomfort thereafter for a period of time. So fast forward, I've been on active surveillance for coming up to two years and the doctor suggests now it's time to give you an MRI. And Marcus was the MRI, the second MRI that you were just describing was that at the same imaging centre than your first one?

Marcus McKenzie: You know, I can't remember, but I think it may have been actually at the hospital at London Bridge.

Clare Delmar: OK, OK. And that was your second imaging after two years on active surveillance? And then they told, well, unfortunately, we need to do another biopsy just to be absolutely sure. And they I think they put some sort of probe up my backside and then they proceeded to take the samples. At one point, my legs started to shake uncontrollably because you have no control after a while. I think it's normally a couple of weeks, but I

think it was literally days, maybe four, I can't remember exactly, but it's four to six days. And another consultant, because my original consultant had now retired, a new consultant got on the phone and said, I'm really sorry, it's bad news. It was something like six months of chemotherapy and then followed by another month or something of radiotherapy and my knowledge is that I know that really wrecks your body. So I spoke with him, I think maybe a week later or so, and he said to me, look, I'm not he just it was a matter of fact. So thereafter, I lobbied, I wrote to them and I basically said everything you have said to me thus far has been wrong, i.e., I'm not likely to have cancer because my initial readings were supposedly commensurate with my age and ethnicity – wrong. Active surveillance, it's not likely to spread a man of your age and fitness, it's not likely to get any worse – wrong. Marcus McKenzie So waiting for another three months, what was going to happen during that period? Marcus McKenzie And retrospectively, now that I've had the operation, the surgeon in question had said to me, you are very lucky because it was about to break out. They didn't respond to the letter that I wrote to come back to me and say, well, would you like would you consider going with somebody else, which is an absolute yes, I will. And I still ended up waiting for three months and heaven forbid, if covid had got really, really bad because it was October. Clare Delmar Yes Marcus McKenzie I might still have been waiting and it would have it would have broken out and that would have been a whole different story. Clare Delmar So you felt that was because you challenged them to actually move up your procedure? So I wanted to explore focal therapy because obviously having a prostate removed has major ramifications in terms of the urinary incontinence, erectile dysfunction, nothing that, you know, a young and active man wants to contemplate so I was exploring all other options. And alas, when they looked at my X-rays or my MRI, my biopsy readings, they said, no, we can't help you because you've got cancer on both sides of your prostate now. And I feel I have a colleague who was in a similar position to me myself his PSA reading was very, very similar, but his hadn't spread as much as mine, so he opted for focal therapy. And I just think on reflection, that should have been an option that should have been presented to me right at the outset and I wouldn't be here. Clare Delmar So couple of questions, the friend you mentioned who did go on to have focal therapy. And yeah, you do a little bit of research in terms of that living that one does can impact your cancer in terms of your diet, whether it's sugar, alcohol, there's all manner of things that can impact the progression of the cancer. And I have another friend who upon diagnosis many, many years ago, he opted to have brachytherapy where he had a radioactive pellet inserted, it solved his problem. Clare Delmar So you feel that you were very much let down by the active surveillance programme? I think one should be given the option to sort of have a look at the cancer there and then, here are your options. And every time I mentioned it, it wasn't, oh, well, it depends on the size of your prostate, whether you can go this particular route. Clare Delmar It's interesting because, you know, active surveillance really places considerable obligations and responsibilities on both parties, patient and doctor. Marcus McKenzie I think they were going down a particular path that is prescribed for them to some extent, because there are a lot of men in that surgery that are being sort of actively monitored. And I suppose if they offered everyone an early intervention, it would sort of, the budget would go up significantly. From my understanding, it's pretty successful early intervention in terms of focal therapy, brachytherapy. And so was the way you found out about it through the friend who you mentioned earlier who actually underwent focal therapy? It wasn't an option because post surgery, I'm living with the reality of what happens after you have your prostate out. But in looking back, do you feel that you were given this sort of counselling and support for those side effects? Marcus McKenzie It was there, and I haven't really joined the group as such because I think it's the reality that what's happening is how best you manage it and how best to sort of rehabilitate yourself. I mean, I've trained all of my life, so I'm disciplined in many respects, and my rehabilitation is going quite well. I mean Marcus, do you, do you feel that your race played a role in the whole procedure from your diagnosis to ultimately your surgery? Marcus McKenzie That's a very difficult question because I don't necessarily have the evidence to say that that it did. But what I would say is that we know black men are 50 percent more likely to get prostate cancer. Doctor's surgeries should be writing to men of a particular ethnicity and age to routinely screen them. And I've heard it said many, many times, I know many men that have encountered the pushback from a doctor. And I think there should be a national campaign where men of a particular age and ethnicity are targeted because it's a really avoidable cancer and men stand a much better chance if it's caught early. What advice would you give to other men and particularly black and mixed race men on getting screened and then managing a diagnosis if they ultimately get one? And sometimes it does necessitate a physical examination, which is having a finger in your rectum. You have no idea what comes next, because if you travel a path I mean, bearing in mind my diagnosis was early, but I still went through an horrendous time, it gets a lot worse if you do not check yourself

regularly and if you do, heaven forbid, develop prostate cancer. But it was a really, really bad experience and apparently my experience was quite good, but I still found it... I mean, that was the most I mean, post operation. That's the most traumatising period, frankly, when you come home with a catheter and there's lots of side effects that you experience, which no one tells you about, and it's very, very, very difficult. Would you have anything specific to say to other black or mixed race men who are who are given active surveillance as a programme to undergo? Marcus McKenzie Yes, I would I'd ask them to sort of find out about alternative treatments. Clare Delmar Do you think that you know, when you talked a little a few minutes ago about targeting screening programmes, particularly to black and mixed race men, do you think that that's something that's realistic, that there are communities, that this could be very realistic to benefit from that, I mean, would you have specific ideas? Marcus McKenzie I think it is realistic and at a doctor's surgery, there's your database, here's your age, you know all the people that are risk in terms as women have sort of regular screening for breast cancer or cervical cancer, men need screening for prostate cancer. It's known because my trajectory and sort of the costs associated with my treatment, I'm sure are far greater than it would have been if I was monitored regularly. So as men, certainly men of a particular ethnicity, chicken, cheap chicken, I'll call it, in terms of if it's not organic chicken, don't eat it. There are lots of studies that sort of link that to prostate cancer and many other things that you really have to examine your diet. If I can help to sort of raise the awareness and I haven't gone into the detail in terms of the trauma, post-operative trauma that I've suffered. And I you know, if a man can avoid that, go the regular check up route, change your diet, be active, stay fit, and you can avoid all of this. But most importantly, if you do have to engage with conversations about prostate cancer and understand what your options are and don't be fobbed off. Further information on active surveillance is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk and follow us on Twitter and Facebook at The Focal Therapy Clinic. Prostate HIFU Focal Therapy – Becoming the treatment of choice for men with localised Prostate Cancer Few treatments for prostate cancer have been unaffected by the pandemic, and focal therapy is no exception. But a combination of clinical, social and institutional factors are combining to increase its visibility and are driving more men to make it their preferred treatment of choice for localised prostate cancer. Imaging, reporting & MDTs With the widespread adoption of multiparametric MRI, we now have a robust and reliable imaging platform to support patient selection for focal therapy, and to provide posttherapy surveillance. While there is variability in quality across the NHS, there is a growing consensus on what constitutes a high standard of imaging and what is required to support focal therapy. Improvements in reporting both in terms of content and digitisation mean that MDTs, themselves made more accessible through digitisation over the course of the pandemic, can review and interrogate imaging in real time leading to robust diagnostic and treatment decisions. Recent trials and studies Several short- to medium-term outcomes have been reported on primary focal therapy, ranging from single-institution and multicentre studies to small clinical trials. From a functional point of view, most would agree that the results of focal therapy overall have been exceptional at preserving urinary function and continence. Potency outcomes have also been very competitive with, if not better than, traditional whole-gland therapies. A multicentre study published earlier this year produced robust outcomes for focal therapy when compared with men undergoing radical prostatectomy over eight years. Data availability for more research Partly due to the pandemic and partly to the challenges of undertaking randomised clinical trials on surgical and non-surgical procedures, recent studies demonstrating outcomes of focal therapy have been based on patient data. A key source for this is the HEAT Registry, a database of men who have undergone focal therapy which The Focal Therapy Clinic team helped to create ten years ago and is growing substantially. This is enabling and supporting further research and clinical studies on the effects and benefits of focal therapy. Data-driven research in prostate cancer generally is growing more widely and global organisations like Prostate Pioneer are pursuing research on a vast array of questions and topics using large datasets to better understand prostate cancer and to improve its management. Raised awareness on the side effects of radical treatments The side effects of sexual dysfunction, urinary incontinence and compromised mental health are becoming more talked about as we realise how devastating they are for many men. It's crucial for men to know about these and how they will be potentially impacted by them to make an informed choice of treatment. Counselling men on side effects has been woefully neglected across the NHS and within private healthcare too, and we, along with others, are committed to changing this. A campaign to tackle prostate cancer "taboos" has been developed by leading prostate cancer charities Prostate Cancer Research and Tackle Prostate Cancer At TFTC we've begun to advocate on these issues with

campaigners Elvin Box, Tony Collier and Chris Lewis. We've also joined with psychosexual specialist Lorraine Grover, oncological psychiatrist Asanga Fernando and pelvic health specialist Jane Simpson to inform and support prospective patients the impact of prostate cancer treatment on their sexual, mental and pelvic health. Ageing The pandemic has exposed other secondary, more systemic side effects in prostate cancer care and one of these is ageism. Most of our patients over 70 have felt "written off" by their care teams and many have undergone life-changing treatments such as hormone therapy for localised disease. Increasingly, however, we're seeing a changing narrative around ageing which is also driving men to seek curative treatments like focal therapy that preserve sexual, urinary and mental health in older men. Pandemic and compromised care As the pandemic led to more delays and cancellations of appointments, diagnostic procedures and treatment offerings, many men have developed expert and forensic research skills about the prostate cancer diagnostic pathway, and have questioned their care teams with far more information and determination than we've seen before. All of our patients come to the clinic well informed and determined to achieve optimal treatment through a second opinion, and question why focal therapy wasn't presented to them at their initial diagnosis. Focal Therapy is giving many men a viable option to avoid the side effects of invasive treatments while benefiting from effective control of localised prostate cancer, and as we emerge from the pandemic we expect to see more and more men investigating and ultimately choosing this option. Question Everything: The Advantage of a Prostate Cancer Second Opinion The Focal Therapy Clinic patient Ian Paul joins OnFocus to discuss how even the best care can go wrong and what he's learned from his experience seeking a second opinion on his prostate cancer diagnosis. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870 Ian's Story Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Ian Paul, a recent patient at The Focal Therapy Clinic who came to the clinic seeking a second opinion following what turned out to be an incorrect diagnosis. He works as a project manager in the energy sector, and he's played guitar in a band for over 18 years as well. OK, well, let's jump right in because you've got quite a story that I know many of our listeners will very much appreciate and value hearing about. And let's just start with one of the things that really struck me when we first met, which was, you know, your experience began in what I might call almost an ideal setting. And this is all, you know, as you said, through my sort of work based insurance health checks and my PSA was around about three and a half to four and it was relatively stable, but it was probably what could be considered to be slightly raised. But then the people I was talking to at the time, the consultant said it's pretty normal for someone of my age to have a raised PSA. And it wasn't until, I suppose about Feb/March time last year I had the regular six monthly test and it was fine, it was a four and then six months later, it suddenly jumped to seven. I'd heard about cycling on road bikes and stuff like that, especially how a hard saddle can aggravate the prostate and it can increase the PSA within the blood. I made an appointment to go see the urologist who I'd seen and I've been seeing, you know, I suppose I'd seen a couple of times over that three year period. I went to see him and he suggested that because it's such a sharp rise over such a short period of time that I have an mpMRI scan, which was the next course of action, I suppose. And then in January, when I got the results, I was told that there was an abnormality showing up on the scan. I was told not to concern myself about it because it was going to be nothing more than going to the dentist. Although I have to say that nothing could be further from the truth, to be honest with you. Ian Paul The local anaesthetic injections in that particular area of your body is really, really unpleasant. And then the actual needles going in to actually take the samples, even with the anaesthetic, was excruciatingly painful. And I'm surprised, actually, that the biopsies are actually done in that way and that particular method. And the one thing that I was very conscious of was the fact that, you know, I'm not sitting quietly and still because it was so painful. I knew I was shifting, you know, my position and I'm thinking to myself at the time that there couldn't be an awful lot of accuracy if I'm shifting around, you know, because of the squirming in my seat basically, because it was so painful. And consultant told me that of the ten samples that he took, one of them contained five percent cancer cells. And so, in effect, what he told me is it was low grade cancer, nothing really to worry about. He said, well, you know, we'll just go through regular six monthly PSA tests and we'll just monitor it that way. You know, I mean, he said, well, the other option potentially, he said I could have a prostatectomy, which basically would be the removal of the prostate. You know, that way there's a guarantee that, you know, you're not going to get prostate cancer again and it's going to be something that would, you know, remove the situation. Now, I said, well, I've obviously done my own research, and that to me isn't an

option because, you know, I'm only 58 years old. You know, I think that's, all the things that I'd heard about prostate removed would suggest erectile dysfunction and incontinence. You know, he said, well, you know, there's brachytherapy, but then there's hormone treatment, but that's not... I don't recommend that. And he said, I think, you know, given the grade of cancer, I said, I think you should be looking at the active surveillance route. I left his office and I was driving home, and the more I thought about it, the more kind of, not angry, but the more concerned I felt because the more I thought about it, the more I thought, well, this is a sentence hanging over my head over the next few months, next couple of years or whatever, my PSA could raise, you know, or double in the space of six months, which it had done. Who's to say that within the next six months after my PSA test, you know, during active surveillance, that, you know, that cancer wouldn't spread outside of the prostate and impact other parts of the body, then I'd be dealing with a situation where I'd probably have to have the prostate removed and I'd be dealing with secondary cancer. And just reading through, you know, every single page, every single interview, every single bit of information was there. It made me suddenly realise that, you know, that there's so many more options out there and not every treatment and not every solution is suitable for everybody. Let me let me just ask really quickly, just before we go on to the second opinion that you eventually sought. Was the covid situation a concern to you, given that you'd have to be continuously monitored? And it seemed to have involved some very different approaches to both the diagnostics and the treatment options. Ian Paul Having found The Focal Therapy Clinic online, the first thing I did was basically go on and complete their online questionnaire, which basically asked for a whole bunch of details about me, the diagnosis I had received and any details associated with that diagnosis, plus sort of providing some notes as to why I was contacting them specifically. And then literally the following day, I received a response from Suki Cooper, who is one of the patient advocates. Just having someone tell me about the different options that could be available to me, it was really eye opening. So, you know, one of the things I talked to her about was the fact that having read pretty much everything I could about the high intensity focal ultrasound therapy, that would be an ideal treatment for me if I was a suitable candidate, because it could potentially be what I would call the silver bullet, the thing that would actually get rid of cancer without any long term treatment plan after that. She basically put me in touch with one of the consultants' secretaries, after I looked over the locations where the various consultants were located, and I decided on Marc Laniado because he was very much local to where I live. Clare Delmar OK, and then you know what happened with actually your diagnostic results even before we get to assessing your suitability for focal therapy? Ian Paul Marc Laniado in the first meeting, said that his sort of view on the MRI scan and also on the pathology results weren't clear. And he said it's going to be difficult for him to provide a very precise diagnosis because of that. And so he said, look, you know, the one thing that we really need to do is make sure that we get the diagnosis 100 percent accurate. And, of course, this worried me, you know, it worried me because of what I went through for the first time. And I think just judging by his reaction, I think he was surprised that I thought it was going to be done under a local anaesthetic, which then got me thinking about well should I have had the original one done under local? So I went into the hospital as a day case and underwent a general anaesthetic and had the second biopsy. And of course when I got the results of that, Mr Laniado basically said, you know, it's actually probably worse than perhaps you thought it was going to be and certainly worse than your original consultant said, in that the Gleason score came back as a three plus four, as opposed to a three plus three. But what he did tell me was that the tumour was very much sort of centred in one specific location, and it wasn't something that was spread around the prostate. So, you know, in his opinion, I would be a candidate for the HIFU therapy, but he had to basically take that through to the multidisciplinary committee that he chaired, where cases like mine get discussed and they go through all of the results and they go through the pathology and the MRI scans, et cetera, and basically come up with a kind of, if you like, a like a committee decision based on the evidence that's being presented. And fortunately for me, it meant that I was going to be a suitable candidate for this therapy. Clare Delmar The MDT is a very powerful approach because you... I'm sure it gave you a lot of confidence to know that the treatment was actually something that was going to be appropriate and was thought to be something that would be curative? Ian Paul Having had that conversation and knowing that there are other people that were actually assessing my case. Ian Paul Inspired me with exactly the kind of confidence that I needed to know that I was in the right hands. Initially, you hadn't even really been briefed about the different elements of the diagnosis, whether it was the PSA test, which you clearly knew about, but then the imaging, the role of the quality of the imaging, the type of biopsy, the quality of the biopsy, the pathology, I mean, you clearly learnt a lot in this whole process. Clare Delmar So given that and the fact that you had a good outcome,

because just to conclude your story, you then did undergo HIFU treatment with Marc, and that was when Ian? And the results came back as a positive in that there was no evidence of any further cancer cells. Ian Paul Took me about two or three weeks to get to a position where I actually felt comfortable again. Ian Paul But, and it does take a while before, you know, some of the side effects start to wear away and disappear. But I think equally, we spoke about the fact that it made you wonder about what happened before you sought the second opinion. And I want to talk a little bit about the outcome of your attempts to challenge the original consultant urologist who initially diagnosed you. Ian Paul Yeah, I mean, one of the things I found was that, you know, we all tend to look at consultants as the font of all knowledge. You know, they're the people that we go to because they know what's good for us and what's right for us. At least that's the impression that we will always have because of the position they hold within the medical profession. But when I was presented with my first diagnosis with the original consultant and the fact that he said active surveillance is the thing, you know, I'm recommending, you know, I went back to him and I did email him and say, look, I'm not convinced about this, because in the letter that you sent to my doctor, you said that you've taken me through all of the suitable treatments and that I'm recommending active surveillance. And I said, but the point is, you didn't take me through all of the options because there are so many out there. And the more research I did, the more I realised that there were lots of different options. You know, some might be suitable, some might not be, but to have the information presented to me, would at least made me feel like I was, you know, kind of getting the right level of data so that I can make a decision about what's right for me. Ian Paul Absolutely, you know, and as a result of that, I mean, I said, look, I'm keen to find out more about this thing called HIFU therapy because, you know, to me, that sounds like a really good treatment. I know it's under trial within the NHS, and I know that it's available through private medicine as well, because my insurance company have said that they would support it financially. So they would support it and the fact that it's under trial and has been for about eight to 10 years says to me that it's you know, it's a good option. And now the consultant who I spoke to came back to me and said I wouldn't recommend HIFU therapy to my relatives, let alone to you. And I said, well, how on earth are these treatments ever going to make it into mainstream unless there's data to support it? If I had been in a situation where I was being told you could have this thing called HIFU therapy, but it's only available on the NHS and it's only available as a trial, I would have looked at the numbers. I would have looked at the success rate, and I would have still made the same decision to say it's got to be better than sitting around doing nothing and waiting for something worse to happen. We're being presented by information by some consultants that doesn't always provide the full picture, to me is not right. And perhaps he's not prepared to embrace new technology and new treatments or even to recommend new treatments because he's not necessarily up with what's going on. I think the important thing for me was that I made the decision to go for a second opinion because the moment I did when I was in control of it. Ian Paul Question everything, and if you're not happy with what you're hearing, say, look, you know, I appreciate your opinion, but I'd like to get a second opinion. But also I'd recommend to anybody in my situation to just have a look on Internet, because you've only got to do a single search and you'll find so many different organisations. Clare Delmar I mean, you were lucky because you were also privately insured and you obviously had the initiative and the knowledge to do this, but I think the more we hear stories like yours that even the best care can have flaws and it's important for you to self advocate and question everything. I mean, yesterday I got a call from a colleague of mine and his neighbour has just told him two days ago, he's had a diagnosis of prostate cancer and he wants to know who I went to see, what the name of the clinic was, what the treatment was. And so I basically sent this guy links to The Focal Therapy Clinic, to a number of different other websites that talk about the different options that you could have available to you. And I'm delighted that you've had such a good outcome and that you've been so generous in sharing your time and your personal experience with us. Clare Delmar For further information on standards of diagnostic procedures and how these underpin optimal treatments is available on our website, along with the transcript of this interview and additional interviews and stories about men living with prostate cancer. Don't settle for the anxiety of Active Surveillance, take control and explore your treatment options. There's been lots of that around over the last year, and few men with suspected or diagnosed prostate cancer have escaped it as the pandemic constrained diagnostic and treatment services. We speak with so many men who are confronting and managing FUD throughout their experience with prostate cancer, and we've been inspired by those who refuse to let it cripple them and have created opportunities to gain more information about their diagnosis and ultimately get a better outcome. Two of our patients have shared their recent experiences with diagnoses and treatment recommendations, and described how they overcame FUD by equipping

themselves with knowledge and using this to challenge what was being offered to them. Michael Clay is 76, and as an NHS patient in Torbay he was put on Active Surveillance following an initial diagnosis of low-grade prostate cancer. This did not go well, due in large part to increasingly levels of FUD stemming from poor communication with his hospital team. He wrote several detailed letters to his local hospital; this is one of them (edited):

BRIEF HISTORY Following a prostate MRI on the 30th June 2020, XXX conducted a DRE and stated my prostate felt normal which was backed up by the recent MRI. However, as the MRI was unclear on the right-hand side of my prostate, masked by a metal resurfaced right hip. Post biopsy, early September, YYY phoned me to confirm “everything was OK” apart from a few very low-grade cancer cells detected in one of the biopsy samples on the left of my prostate.

MOVING FORWARD I note that while the MRI did not indicate any concerns with the left side of my prostate, low grade adenocarcinoma Gleason 3+3 was detected in the left-hand side biopsy sample which does concern me. Following on from this I have conducted some research of my own and have a number of questions, detailed below, that I would like answered so I can fully understand my condition and move forward with my life.

QUESTIONS How many biopsies were taken and was it considered to be a “standard mapping” biopsy or something less, where other cancer areas could have been missed? I just want to ascertain if there could be a significant area of the prostate that was not sampled. I understand my cancer score is Gleason 6 (3+3) but did these cancer cells extend to, or beyond, 6mm or more in any of the sample cores? Is it suspected that the prostate cancer is just a few low-grade cells or is it contained within a larger tumour within the prostate? I understand my prostate is around 40 cc in volume, which is larger than normal, and wonder if this could be a contributory factor to my recent UTIs? I regret that I have had to ask for this information by writing to you as due to Covid issues it has not been possible to have a face to face consultation to discuss my worries. Thank you in anticipation of your reply with answers to my 6 questions.

Michael never received a reply to this or three additional letters that he wrote. The process of researching and producing them, however, definitively helped him overcome FUD about his treatment and he sought help elsewhere, ultimately receiving a different diagnosis and undergoing a different pathway that has worked well for him.

Another patient, Ian Paul is 58 and was a fully insured private patient in SE England, undergoing regular health checks through his employer which included PSA testing. When he was told his PSA had become elevated, he underwent mpMRI imaging and a biopsy, and was told he had early-stage prostate cancer and recommended Active Surveillance. Initially he queried AS as he was uncomfortable with “letting cancer grow inside me” and was advised that his only alternative would be radical prostatectomy. Ian built an extensive knowledge of the entire prostate pathway – from early diagnosis to treatment and recovery. This included PSA testing, imaging, imaging reporting, biopsy approaches, histology and ultimately treatment options. Much of his learned knowledge did not square with what he was hearing from his consultants, which was worrying. Ultimately he sought a second opinion which led to new diagnostic procedures, done very differently than had been done initially, which led to a different diagnosis, treatment recommendation and a very different recovery.

Key themes emerging from our patients’ experiences is recognising both the variation that occurs in each element of the pathway across hospitals and health centres, and the value in understanding what the highest standards are for each of those elements, whether it’s imaging, biopsy procedures, histology and most of all, treatment. In all cases, overcoming FUD by building knowledge is what brought them to the Focal Therapy Clinic.

What has your experience been in managing the FUD associated with a prostate cancer diagnosis?

Active Surveillance: A Double-Edged Sword

Michael Clay came to the Focal Therapy Clinic after having been placed on Active Surveillance at Torbay Hospital in South Devon. Michael’s a 76-year-old retired banker who leads a very active life with his wife and family which, despite his early-stage cancer diagnosis, was being severely compromised by his treatment. He encountered several issues which he feels are very important for all men to hear and understand before they make decisions about treatment for prostate cancer, and he’s joined OnFocus to discuss these. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870

Michael’s Story

Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Michael Clay, a recent patient at The Focal Therapy Clinic who came to the clinic after having been placed on active surveillance at Torbay Hospital in South Devon. Michael’s a 76 year old retired banker who leads a very active life with his wife and family, which, despite his early stage cancer diagnosis, was being severely compromised by his treatment. He encountered several issues which he feels are really important for men to hear and understand before they make decisions about their own treatment for prostate

cancer. Welcome and thanks so much for joining me today. Michael Clay Hello Clare, and thank you for inviting me. Clare Delmar Wonderful. I mean, if you can be kind of brief, but just kind of highlight your experience from when you were initially diagnosed to when you ultimately got treated with focal therapy? Michael Clay Through my life, I have always had my PSA taken and it was always in the mid-range. And so my GP referred me to our local hospital who did a digital rectal examination that didn't prove anything and an MRI scan, the results of which were no cancer in the left, but we couldn't see the right due to your metal on metal sports hip. So biopsies were taken and amazingly, the results came back saying they'd found cancer in the left. It was a low grade Gleason score six and I was to be put on active surveillance without any further discussion. But I do accept that we were in the middle of a covid pandemic and maybe that was the reason. My concern was why was my MRI on the left clear and yet the biopsy showed cancer on the left? I started thinking, could I have missed something or could they have missed something? Clare Delmar So can I just interrupt really quickly? Back when I was 60, I had some arthritis in I got hit on rather than having a hip replacement, I had what's called a metal on metal hip resurfacing. Clare Delmar So that impacted the imaging. Michael Clay That impacted the MRI scan. And so the biopsy was taken to really check the right hand side to make sure that was clear. So because there was not the opportunity to have a discussion, I carried out my own Internet search. At that point, I saw HIFU from the focal therapy group and I thought that looked really promising. I watched some of the videos and I then emailed The Focal Therapy Clinic for further information. He explained the entire role of your group and also what could be achieved, not necessarily what could be achieved for me personally, but what generally can be achieved. I spoke with Tim Dudderidge, who is the urologist at Southampton, who listened to my story and agreed to take on my case. And so Tim decided he would get the hospital scan results and the biopsy notes from Torbay Hospital. Well it would have been a couple of weeks later, that Tim phoned to say that the MRI really isn't of sufficient quality for me to use. And so I agreed with him that he would organise a new MRI scan in Southampton and he used a contrasting dye. The results of that a few weeks later were a twenty two millimetre lesion in the left of my prostate. So I popped up to Southampton again and he took biopsies, which then showed a rather different story than just pure low grade. It was Gleason seven with significant pattern four cells, which again, I said is quite different from the hospital's diagnosis to. Tim said, I really favour treatment over active surveillance and wrote a letter to me confirming that and to my doctor. Now ironically at that stage, we were then more than three months on from the original hospital diagnosis. My PSA had then risen to 9.2, but still my local hospital find that quite acceptable, not to worry at all, which I was quite surprised at. So Tim and I discussed treatment and due to some calcifications within the prostate, which Tim said was pretty, not normal, but it was it was not unheard of, many men have this. And so we opted for ... Clare Delmar Cryotherapy Michael Clay Cryotherapy, and I readily agreed to that. And I'm so grateful to Tim because he moved heaven and earth and that took place on the 21st of December 2020 at the Spire in Southampton, which was, as you can imagine, the pandemic was just starting to really kick off quite badly. I was really ecstatic at that result, very grateful to Tim and his team, for his excellent treatment. And at this point, I must thank his PA, Kirsten, who is really wonderful at organising all that. Clare Delmar And that's really, really, really good to hear. I mean, your experience with active surveillance then is pretty significant because twice now you were at Torbay you were actually sort of officially treated that way. I mean, based on your experience, what would you say to men being offered active surveillance and how can they get a better experience that you had? And of course, we passed the first of March when my PSA was taken at not nin point anything but 0.85. So that's really my focal therapy experience, which I have to say to this day I find absolutely exceptional and excellent. Clare Delmar Good. I would say, of course it's up to each individual whether they're happy with active surveillance or not. Most men, I think, just leave it in the hands of the urologist as to what treatment is considered appropriate. I understand that some early interventions or treatments have been proved to be unnecessary in the early stages. But in my case, my diagnosis was never discussed with me and no treatment other than active surveillance was ever offered, despite numerous emails requesting a consultation to the hospital. It was therefore left up to me to seek a second opinion, and I looked for an alternative treatment to active surveillance, which was supported by my local doctor. I investigated many of these treatments radiotherapy, brachytherapy and even complete prostate removal, and realised that they're not always appropriate, particularly in low grade cancer cases. But it seems to be rarely offered, and I do believe that so few people are, in fact, aware of it. I think my answer would be look at all the options, including focal therapy, HIFU and Cryo. And the beauty I understand of the latter is that they can be repeated at a later date if needed. It was quite interesting and I think it's a point that all men should consider, I eventually discovered that my tumour was at the front, the anterior, of my

prostate. So it was difficult, if not impossible, to detect any abnormality through a digital rectal examination so I think my best advice would be analyse what you're told, but always seek a second opinion. Clare Delmar Indeed. And in fact, I want to come back to that question about some of the diagnostic procedures, but I want to pick up on something that we had talked about previously and what you said just a few minutes ago about being offered a full range of treatments, because at one point you had told me that hormone therapy was something that was offered to many men. I think in one of your support groups, you said this was the case and you had some pretty strong views on that. And why do you think this is happening and what would you say to other men? Michael Clay I suppose I have to say at this point that I don't have a medical background, however. I believe it's a question probably of reduced availability for all of the alternatives in many areas. And on our Zoom calls, I've spoken with several members who are a little bit older than me and who have been on active surveillance for several years. Sadly, they've told me that as their PSA has risen, indicating that prostate could have grown possibly outside the prostate. It seems that the main treatment option at that stage is hormone therapy with its horrible side effects. And I believe that this is possibly because it's just too late for other treatments, especially if it is metastasised outside of the prostate, for those treatments to be effective. And of course, as I said, no other treatment was offered to them, especially for the focal therapies on first diagnosis. It seems to me in many areas of the country, active surveillance is the standard for low grade prostate cancer as focal treatments are not widely available. So while active surveillance may be effective for those who have a life limiting health issues, are they likely to die maybe from a known cancer related condition, for those men that are reasonably fit and have an otherwise long life expectancy, active surveillance for the patient was an organ containing cancer, followed by hormone therapy once that cancer spread, to me, doesn't seem to have the best outcome. Why would any man with a low grade organ containing cancer run the risk of it spreading while on active surveillance when it could be effectively ablated with focal therapy? Clare Delmar Exactly. Michael Clay For me, it was just it was just an absolute no brainer. Clare Delmar So coming back to focal therapy. You found that the imaging required to plan and undertake your treatment was considered of poor quality and had to be repeated. So I guess I'm interested in exploring to what extent do you think men are aware of, I guess, a) of how important the imaging quality and reporting is in their diagnostic and treatment pathway? And I guess, b), how variable do you think it is across the health system? Michael Clay Right. I personally doubt whether any patient, unless in the medical profession, would know anything about the equipment or the quality or the reporting of MRI images. I certainly wasn't aware that there was any difference between MRI scanners or even the quality of staff reading the scans. However, once I'd spoken with Tim, I realised how shortcomings in my original hospital MRI scan could have affected my diagnosis and the treatment and why it was so important for Tim to repeat my MRI. I confirm that the quality of the Southampton MRI scan and the expertise of the related staff was absolutely pivotal in my final prostate cancer diagnosis and of course, my eventual focal therapy treatment. Well, we hear that the NHS is a bit of a postcode lottery when it comes to treatment and certainly in the south west, I think generally in the UK, there, to me anyway, appear to be too few specialist centres with first class equipment and most importantly, experienced staff and consultants who can offer some treatments including focal therapy. So the NHS has gone through a terrible time recently and we must all thank the NHS for their amazing work during covid. But just looking to the future, this is probably something that's got to be a governmental thing, but I believe the goal has to be to build more first class hospitals equipped with high quality equipment and staff with experience, urologists, similar to Tim. Clare Delmar I mean, I'm sure other people would share that view. Several aspects of your experience suggest that your age might have been a somewhat limiting factor in discussions around treatment options. And do you think that there is any form of age discrimination in parts of the health service that men should be aware of? Michael Clay That is a very difficult question to answer with any certainty. As I've said, I do understand the constraints that covid has placed on the NHS, which may also be a factor because I was a pretty fit and healthy 75 year old man. I was only offered active surveillance and despite repeated written requests over seven months asking for a meeting to discuss all other options, I've still not received a reply. Clare Delmar Really, really? Michael Clay Yeah, yeah. But maybe the section that states access to treatment is based only on clinical need could be taken to imply there's less clinical need to give certain cancer treatments to, say, an 80 plus year old man with other life threatening health issues, as opposed to an otherwise healthy and fit 70 year old who only has a contained low grade prostate cancer. It's very clear the NHS is totally underfunded and now the constraints of covid and obviously the vaccine programme are probably a factor in patients not being given information about the full range of treatment options. But the reason I

really felt my age was against me was when I was advised of my biopsy results, a conversation about it went like this, the consultant rang with a results of the biopsy and said, oh, good news Mr Clay, no concerns; however, we have found just a couple of low grade cancer cells, but nothing to worry about. We believe half the men over 75 had these low grade prostate cancers, never knew anything about it and never die from it. So, we'll pop you on active surveillance because it's unlikely to die from prostate cancer, you'd be more likely to die from something else at your age; goodbye. Well, you can imagine I was pretty shocked at that. Clare Delmar Yeah. Michael Clay I did not like having a ticking time bomb inside me. And that makes future planning, if you want to go on holidays and do things with the children or grandchildren, it makes life very difficult. Clare Delmar Of course. Michael Clay I do think that my generation probably has a life expectancy now, well past 80. We expect the best treatments to enrich the remaining years of our lives, which is why I believe withholding information about the different options, is a form of age discrimination, although probably not intended. And I believe that focal therapy like HIFU and cryotherapy should be available and an option for all because of their minimal invasiveness and I understand they can be repeated should be an absolute need for everyone to know about. Clare Delmar Well, Michael, I really appreciate your comments, I think our listeners will find them extremely helpful as well. And I want to thank you so much for speaking so openly and so honest with me, today, it's been a real pleasure. Michael Clay It's a pleasure to have been able to have told you what's happened to me. But I think the work that the focal therapy group and all the staff and the consultants have done is absolutely amazing. And I just hope that that will now grow and become the gold standard rather than active surveillance. Clare Delmar Well good luck to you to and enjoy the summer with your family after all of this. Michael Clay Thank you, indeed. Clare Delmar Further information on alternatives to active surveillance is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer. Please visit www.thefocaltherapyclinic.co.uk. Thanks for listening and from me, Clare Delmar, see you next time.

Navigating Prostate Care Through a Cancer Backlog Despite active campaigns to address the NHS cancer backlog, many men are feeling the impact of delays and restrictions in cancer diagnostics and treatment incurred by the pandemic. A recent report from the Southeast London Cancer Alliance on cancer diagnoses over the last year of lockdowns showed a 51.4% drop in prostate cancer diagnoses in 2020 compared with 2019 – the highest drop of all cancers. It concluded: “The experiences in cancer are a salient warning that pandemic control measures and policy need to balance all health and welfare. Alternative strategies need to be adopted during further waves of the current and any future pandemic to ensure that patients with cancer are prioritised for diagnosis and treatment to prevent late-stage presentation and an increase in avoidable deaths” Navigating care following a prostate cancer diagnosis in these circumstances is challenging indeed, and we've spoken with cancer specialists, health policy experts and patients about this. Professor Gordon Wishart of Check4Cancer joined a recent OnFocus episode to share his views on the impact of the pandemic and successive lockdowns on prostate cancer diagnostics and treatment. While he acknowledges the severity of delays and waiting lists, he also describes some real opportunities to improve both screening and diagnostics that have been accelerated by the pandemic: “it's now possible to do a finger prick blood test for PSA at home now... we know that through some laboratory tests that the fingerprint test is just as relevant and accurate as the traditional blood draw. And so men aged 40 plus can now access a very simple test that they register online, a kit is sent to their home. And so you can let them know when they should next have a test.” He cites the future benefits of vaccines as well as new practices adopted in treatments: “some developments in cancer diagnosis and treatment have been accelerated during lockdown. The technology that's been developed for covid vaccine, some of that could be applied to cancer treatments and to cancer vaccines in the future. In breast cancer, traditionally radiotherapy has been for three weeks after surgery and the Fast Forward trial, was really pushed through quickly, because that showed that for a large number of patients, having one week of radiotherapy was the same as three weeks. So I think we're going to see really an avalanche of innovations coming through, which is great in cancer services in the next three to five years.” While this is encouraging for the future, what can men do now to ensure they are getting access to the best care possible? The constant advice we hear from our patients is “question everything” – that is, try to understand how your diagnosis and treatment pathway is being managed and unpick each element of that pathway: Imaging: what is the quality of images produced at the centre recommended to me? Reporting: who is the reporting radiologist of my MRI scan? If so ask for a trans-perineal, and ideally MRI/US fusion biopsy to ensure accuracy Histopathology: what is the lab analysing my biopsy samples? Who will be on that team? Treatment recommendations: what is the full range of treatment options available to me? Does

this include those that are considered experimental, and if so, are there clinical trials I can join? Two other things we'd like to share: Know your rights: Patient consent is enshrined in the Montgomery Ruling which upholds the right to informed consent on any medical treatment or procedure, and while patients do not have a legal right to a second opinion in the NHS, there are cases where this can be accommodated. Make your voice heard The All-Party Parliamentary Group on Cancer aims to be the voice in Parliament of cancer patients and their families, and campaigns on multiple issues, including early diagnosis, workforce, rarer cancers and patient experience. The Group brings together MPs and Peers from across the political spectrum to debate key issues and campaign together to improve cancer services. Chris's Cancer Community is an influential online community of people affected by cancer, led by campaigner Chris Lewis. Movember UK is a charity focused on men's health, and actively campaigns to support improvement and access in prostate cancer care. An Interview with Professor Gordon Wishart Professor Gordon Wishart joins OnFocus to discuss the backlog of cancer referrals, diagnoses and treatments in the NHS and offer some suggestions on ways forward. Professor Wishart is founder, Chief Medical Officer and CEO of Check4Cancer, a leading early cancer detection and cancer prevention organisation. As the former Director of the Cambridge Breast Unit from 2005-2010, and current Professor of Cancer Surgery at Anglia Ruskin School of Medicine since 2008, Professor Wishart has a strong track record in clinical research and modernisation of cancer diagnosis and treatment, with more than 100 peer-reviewed papers in scientific journals. In 2010 he led a team of clinicians and scientists that developed the PREDICT breast cancer treatment and survival model, now used worldwide. <https://www.check4cancer.com> Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Professor Gordon Wishart, founder, chief medical officer and CEO of Check4Cancer, a leading early cancer detection and prevention organisation. As the former director of the Cambridge Breast Unit from 2005 to 2010 and current professor of cancer surgery at Anglia Ruskin School of Medicine since 2008. Professor Wishart has a strong track record in clinical research and modernisation of cancer diagnosis and treatment, with more than one hundred peer reviewed papers in scientific journals. In 2010, he led a team of clinicians and scientists that developed the PREDICT breast cancer treatment and survival model, which is now used worldwide. He's a vocal critic of the government's handling of the current backlog of cancer patients in the NHS, and he's here today to chat with me about this. Gordon Wishart Well, it's probably one of the biggest challenges, certainly in my career as a cancer surgeon. But essentially the lockdown restrictions have had a devastating impact on cancer diagnosis, really throughout 2020 as a result of several things. I think, firstly, the stay at home government message, a lack of access to GPs and the reduction in access to non-covid NHS services. And as a result of that, there were approximately 350,000 less urgent cancer referrals in 2020 compared to 2019. And out of that, throughout the UK, we've seen almost 40,000 less cancers diagnosed in 2020 compared to the previous year, and out of that number, about 8000 were screen detected cancers. So because of the suspension of screening services, a large number of early stage cancers have not yet come to light. But before we do, what elements of variability are you seeing in these numbers that you reference so across region or against disease area in particular? With regard to actual cancer treatment continuing, then some parts of the country were better than others. But unfortunately, they were not all used by the NHS and many of them lay fallow throughout April to July. So, for instance, in Cambridge, I know one of the local independent hospitals has really done a large number of NHS procedures in the last 12 months. If we look at which particular cancers have been most affected, then sadly, because of delays in diagnosis, we see patients presenting with cancers at a later stage when there's less chance of cure and in general they require much more treatment. And in terms of prostate cancer, which I know you're very interested in, almost a four percent increase in patients presenting with stage four prostate cancer so the most advanced stage. And I'm happy to send you that paper that you want to share with any of the people that listen to the podcast. So four percent and again, it picks up on something else that I'm very interested in, which is some of the numbers that get a little bit masked because so for example, that men will get treated. So wouldn't be part of the numbers you cite in terms of not getting treated, but they might be treated inappropriately. Gordon Wishart I think whatever cancer we're talking about, the professional bodies that look after the cancer specialists that manage cancer really issued guidelines to try and help clinicians guide their way through the various lock down restrictions. And that has meant that some people might have had what would have been a traditional treatment pathway changed. So

there might have been less people having surgery and more people having non-invasive treatment like radiotherapy, for instance, and we know that a number of people had chemotherapy deferred, delayed or sometimes even cancelled. I've just seen a paper published on variations in breast cancer treatment throughout the last 12 months. And actually, although there were quite a number who had their treatment varied, it was fairly minor differences. But again, I think that will be cancer specific and some cancers will have been affected much more than others. In particular, those cancers that need intensive care treatment after surgery because those intensive care places were just not available because of so many people being unwell with covid. Gordon Wishart I think it's fair to say that we are probably back to pre-pandemic levels of activity in terms of cancer screening, cancer diagnosis and cancer treatment. But in my opinion, that's not really good enough because we know from a Cancer Research UK report in 2019 that the state of cancer services in the UK was really poor, with quite mediocre national survival rates compared to many other Western countries, and that was largely due to inadequate early cancer detection and lack of access to optimal treatment. So, yes, we've gone back to pre-pandemic levels of activity, but as I've just said, they were not great. So I think this has to be a time not just to be saying we need more money to employ more cancer specialists and get better access to imaging and treatment. But we should take this as an opportunity to really review all our cancer services and really try and improve things for the UK as a whole going forward. Clare Delmar Yeah, I mean, it's interesting when you talk about variability and levels of diagnosis and modernisation of diagnosis, because, of course, as we've spoken about before, this is very much the case in prostate cancer, that the diagnostic pathway has improved radically over the last 10 years. Two recent studies, PROMISE and PRECISION, have shown that if you add multi parametric MRI scanning to the pathway for someone with an elevated PSA, then it really improves that pathway. It reduces the number of unnecessary biopsies and detects more patients with a clinically relevant prostate cancer. We've known for a long time that PSA screening does actually reduce the number of deaths from prostate cancer. But it has had a lot of bad press because of the number of unnecessary biopsies and because of the complications from prostate biopsy. And I think the great challenge is to make sure that that expertise in reporting these very complicated MRI scans is now rolled out across all hospitals, apart from those that were involved in those two important studies. Do you think that the pandemic and the lockdowns and the things you've just been discussing have affected that? We have to... You know, there's going to be a big workforce issue, I think, in terms of delivering cancer services and radiology is one of those critical parts of that equation. There are the men who might be having some symptoms: needing to rush to the toilet to pass urine or feeling maybe that they're not emptying their bladder properly or getting up during the night. And I think my message, as in all cancers, is that if there are people sitting at home with new symptoms, you should come forward and get checked. On the other hand, we know that men have had real problems, men over 50, getting a check with their GP during lockdown and many GPs were only taking video conferences. So I think we know that there are certain people who have an increased risk of prostate cancer and family history is really important. So, you know, if men have a close family history, maybe their brother or their father or maybe even their son who's had prostate cancer, then they're at increased risk. And then also if men come from a family where there's a strong family history of breast cancer caused by one of the BRCA genes, then again, there's an increased risk of prostate cancer there. So I think if people are in those increased risk groups, I would encourage them to seek screening either through their GP or if that's not possible, then there are other ways to do that. Clare Delmar So can you talk about that a little bit, how men might access that and how they can be reassured that it is indeed effective? Gordon Wishart This is something that we've been doing it at Check4Cancer for a couple of years now. And we know that through some laboratory tests that the fingerprint test is just as relevant and accurate as the traditional blood draw. And so men aged 40 plus can now access a very simple test that they register online, a kit is sent to their home. Gordon Wishart Well, you could look online on the Check4Cancer website, but there are a number of different companies now offering similar tests. So I think if you just search for PSA fingerprint blood test and there will be several opportunities to do that. So if someone's got a PSA less than one at age 40, then their future risk is really very, very low. So I think that element of risk stratification is important for prostate cancer and I think will become important for the management of all cancers going forward. But while we're talking about sort of innovations like that, there has been a lot of talk about a whole range of innovations in health care that the pandemic has generated, not only around the covid vaccines themselves and the treatments for covid, but also in fundamental health care processes, for example, such as telemedicine and home testing, as we've just been discussing and monitoring, for example. So I guess my final question to you is, do you think men with suspected or diagnosed prostate cancer will

benefit from any of this? I think we have to be careful when applying tele medicine to cancer and video conferencing. But I think there are a number of follow up consultations and results consultations that can be done by video conference, and stop people going to hospital unnecessarily. So I think clinicians will need to have access both to the traditional face to face consultations with people with prostate symptoms and prostate cancer, but also supported by video conferencing when that can be done and just to make the whole cancer treatment pathway easier to manage as patients go through it. I'm very excited to hear about the pin prick test, and I will refer, as I said, on the programme notes our listeners to that. And I guess they can also learn a bit more about risk stratification as well, which, as you say, is really, really important to benefit from any of the innovations we're discussing.

Gordon Wishart You're absolutely right that some developments in cancer diagnosis and treatment have been accelerated during lockdown. The technology that's been developed for covid vaccine, some of that could be applied to cancer treatments and to cancer vaccines in the future. In breast cancer, traditionally radiotherapy has been for three weeks after surgery and the Fast Forward trial, was really pushed through quickly, because that showed that for a large number of patients, having one week of radiotherapy was the same as three weeks. So I think we're going to see really an avalanche of innovations coming through, which is great in cancer services in the next three to five years.

Clare Delmar Further information on Professor Gordon Wishart is available on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer.

The Four Ps and Your Prostate We've been thinking a lot in recent months about age and its impact on men's experience with prostate cancer. This is a continual and growing theme that we're trying to understand, and one question keeps popping up ---- why should all men aged 70 and over be treated the same, when there is such wide variability in their overall physical health, mental health and lifestyle? Men who come to the Focal Therapy Clinic are, by default, seeking a second opinion on treatments that have been recommended for them, and while they range in age they all share a desire to continue an active lifestyle both physically and mentally while they're being treated for prostate cancer, and after treatment is completed. And they like to tell us about their experiences, so we are learning from them all the time. And what we are learning deeply is that there are lots of men 70+ who are expecting a full 20+ years ahead of them, and don't want to be condemned to "elderly" status. Fortunately, and conveniently, the concept of and narrative around age is changing, and fast. We've looked at chronological age and biological age in previous blogs and increasingly this distinction is gaining more acceptance both in concept and measurement. A key challenge to integrating the changing narrative of ageing into patient advocacy and patient care is language; many, if not most people lack a vocabulary around ageing, which in turn limits them in engaging with and questioning medical professionals effectively. So for example, a conversation between a 75 year old man and his doctor around treatment options for prostate cancer may centre on his chronological age and treatments that are statistically well tolerated in men of that age. But if the same man had an evidence-based measure of his biological age, the conversation might change to include a focus on his activity levels and lifestyle, and a different range of treatments offered. Similarly a shift in language from "lifespan" to "healthspan", where the former focuses on life measured in time and the latter on life measured as time in good health, would also change the conversation around survivorship. We recently spoke about this with Dr Michael Sagner, current president of the European Society of Preventive Medicine and author of Lifestyle Medicine, who advocates for a "healthspan" approach to medical care based upon "4 Ps" Prediction – will my care predict the onset or recurrence of disease? Personalisation – is my care personalised to me and/or targeted to my experience with disease? Along with a team of researchers, he has developed an integrative approach to chronic disease, including cancer: "with slowly progressing and often 'silent' chronic diseases now being the main cause of illness, healthcare and medicine must evolve into a proactive system, moving away from a merely reactive approach to care. Minimal interactions among the specialists and limited information to the general practitioner and to the individual receiving care lead to a fragmented health approach, non-concerted prescriptions, a scattered follow-up and a suboptimal cost-effectiveness ratio." He believes this is best addressed through a new approach that is "predictive, preventive, personalized and participatory, which we label here as "P4", holds great promise to reduce the burden of chronic diseases by harnessing technology and an increasingly better understanding of environment-biology interactions, evidence-based interventions and the underlying mechanisms of chronic diseases." Why does this matter to men with prostate cancer? After diagnosis and treatment you're different – physically and mentally, hopefully for a temporary period, but an approach to care that is driven by 4 Ps gives structure and focus to getting well and staying healthy. It gives a language and structure to conversations with medical professionals that can overcome ageism

or other biases, allowing you to focus on 4 simple objective elements to your care. Looking at your medical care through this framework will make you think more carefully about what you are being offered by doctors and possibly leading you to seek better care. The 4P approach provides a useful backdrop to considering care alternatives and can help increase confidence in researching and interrogating diagnostic procedures and treatment options. Do you agree with this approach?

Integrating the 4Ps into Prostate Cancer Care

An interview with author and healthcare pioneer Dr Michael Sagner. Dr Michael Sagner, bestselling author of *Lifestyle Medicine* and a pioneer in preventative healthcare, joins OnFocus to discuss the changing narrative around ageing and outlines how a focus on prevention, personalisation, prediction and participation can impact men's experience with prostate cancer. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870 <https://www.amazon.co.uk/Lifestyle-Medicine-Environment-Preventive-Disease-ebook/dp/B06XSJ4ST9>

How Prevention, Personalisation, Prediction and Participation can impact patient experience

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Dr. Michael Sagner, author of the best selling book *Lifestyle Medicine*, and a pioneer in the development of preventative health care. Dr. Sagner has developed a large following around his four Ps approach to personal health, which is based on care that is predictive, personalised, preventative and participatory. He's joining me today to explore how these principles might integrate with the management of prostate cancer and how they can benefit with men with a prostate cancer diagnosis pre and post treatment. Thanks for having me.

Clare Delmar: So what you do is really fascinating, and you have indeed developed quite a following. So you're clearly having an impact on both the medical world and on a whole range of patients.

Michael Sagner: Yeah, I'm quite happy about this obviously, when we started looking into this, this connection between lifestyle factors and health, especially the maintenance of health, people thought that we are not practising medicine because medicine historically was always about fixing diseases, looking at symptoms and treating them with pharmacology. Yet since the very beginning of what we would call Western medicine and obviously also Asian medicine, the influence, the impact of lifestyle factors such as nutrition, diet, stress, sleep and physical activity and some others, on your health, disease progression and ageing are well known. We just for some reason forgot about them and medicine just stopped talking about them.

Clare Delmar: I mean, you mention ageing, and that's actually really where I wanted to kick off here, because, of course, prostate cancer is a disease of ageing. And yet we know that people age differently and increasingly there are ways to control the rate and extent of ageing. You know, fundamental to your engagement with patients is understanding something called chronological age versus biological age. So I wonder if you can describe what that means and how it impacts caring for patients?

Michael Sagner: Yes. So the difference between chronological age and biological age is basically the difference between what's written in your passport and what your cells look like. So for a very long time, we just assumed that after you peak in your mid 20s, early 30s, you just decline. And that decline, that rate of decline would be, we just assumed that it's the same for every person and men and women totally independent of your job, stress levels, and so and obviously that doesn't make sense. And we now understand that the number in your passport and the actual age of your cells can be very different. One of them is epigenetic tests that allow us to determine this biological age, and that is to realise that you want to look at a lot more important than the number, as I said, that, you know the day you were born.

Clare Delmar: So this epigenetic age, is this something that's measurable?

On cellular age?

Michael Sagner: Yes, obviously, it's quite difficult to determine biological age, you will have to take cells and you would have to do very complicated assays. Since the early 2000s Elizabeth Blackburn won the Nobel Prize in medicine and physiology for her discovery of what's called telomeres. And a very convenient way to measure biological age, and that's usually how laboratories do it nowadays is instead of, you know, taking apart the whole cell, you just look at these caps, these protective caps of your DNA, of your genetic information. And if they are worn off very short, then we would say that you have a rather, you have a reduced biological age, meaning you are older. And if these caps are longer, thereby protecting your DNA better, then you would be younger.

Clare Delmar: OK. Michael Sagner: That's how we measure it.

Clare Delmar: It seems to have quite an impact. I mean, one of the questions that I'm really keen to ask you, because it comes from patients consistently, if not increasingly, is. For example, we have a lot of men who are 70, 70 plus and are fit and active, have very positive cognitive, mental, emotional outlook, etc., etc. And when they're diagnosed with prostate cancer, they feel that they're

actually in almost the best stage of their life. You get men who are 70 who say they feel like they're 50 in terms of their physical and mental health, but then they say they're treated in what they perceive as an age discriminatory way. So I wonder if you can tell me how you think this might be best addressed in a world where we know that there's a difference between chronological age and biological age? Michael Sagner Yeah, as with so many new things in medicine, innovations, medicine, so the traditional healthcare systems, which are more or less, to be a bit cheeky, they're disease management systems, more than true health care systems. These health care systems globally, doesn't matter whether it's the NHS or any other system, they have been very slow when it comes to innovation, and that is both technological, scientific innovation, but also culture. And it is very important that this cultural change, which is both, as you just said, this ageism issue, but also that we look at prevention and the biological age of that patient and then choose the treatment accordingly. We know that it's slow, which is another reason that more and more patients are looking at getting treatments and interventions at private facilities where maybe these cultural changes are already taking place. Clare Delmar So what can men who have or have had a prostate cancer diagnosis do to optimise their health and wellbeing? Michael Sagner The interventions that we would recommend and the interventions that are evidence based are very similar to the interventions that we would recommend to prevent the cancer from occurring in the first place. Most of them are related to lifestyle, obviously nutrition, as I said, diet, stress management and sleep and so on. And then there are a few things, many of them experimental, that might help to support the treatment or might be a standalone treatment. There are some studies showing that very, very strict lifestyle interventions could be used in early stage prostate cancer. In any case, no matter what treatment the patient and the clinician decides to go for, the lifestyle intervention, the lifestyle support should be there, no matter whether it's surgery, radiation or something else. It's very important that this basic foundation of a healthy lifestyle is in place both to prevent cancer, not just prostate cancer, but many other cancers. And then to continue with this, let's just call it healthy lifestyle, while you're undergoing treatment and obviously after the treatment to prevent recurrence. Clare Delmar So that leads me to my next question was which was actually honing in on your four P approach and how you think that specifically might integrate with the prostate cancer diagnostic and treatment pathway that would improve patient care? I mean, I know you're suggesting that patients become a lot more attuned to their health, without doubt, once they have a disease diagnosis such as prostate cancer. But do you think that the four P approach could actually become something that is actually integrated into clinical pathways or certainly care pathways? Michael Sagner Yes, absolutely. The four P's are again, more of a cultural change, and these changes are absolutely necessary because if we continue treating our patients the way we've been treating them, then we are going to deny them a lot of the innovation that is available, but just not being deployed. So the four P's, just to repeat is preventive, meaning that we have to be a lot more proactive. And very often we see them coming like prostate cancer, very often colon cancer, heart attack, stroke. These are things that you can very often you can predict to a certain extent, meaning if you have as a guy, you know, older than 40, you should think about your prostate, you should think about prevention and not just wait until that unfortunate day that your doctor says, OK, that's it now. And when you think about how we prescribe medicines, very often we use 500 milligrams of this or 500 milligrams of that. And we don't think about the age of the patient, whether it's a female patient, a male patient, whether the patient is pregnant, maybe, maybe the patient is obese so might need a lot more. This personalisation aspect, I think, shows us how much we lack true innovation and sophistication of medicine very often, even though medicine and health care is perceived in the public as this, you know, almost science fiction like enterprise, where everything is brand new and we're doing it using the latest science. So a more predictive approach that we actually look at the patient and say, OK, that it is very likely. There are a few red flags that we should look at just based on your age, maybe genetic history, family history. And the fourth P is the patients have to be less passive; health care professionals, doctors have to be a lot more inviting. We have to really let the patients participate in their health care and not just disease management, but true health care, making decisions based on also the patient's preferences, presenting different options, discussing all the options, and very often doctors, obviously they are good at a certain, using a certain technique or things they have been doing like that forever. And very often we still unfortunately, we still see clinicians talking down to the patients. And we really, especially when it comes to prevention, because prevention obviously happens to a large extent outside of the clinic without the doctor being present. So we need the patient to participate, but there needs to be a better interaction between the health care professional and the patient. Clare Delmar Absolutely. And it's really a cultural change in how we practice health care. Clare Delmar Michael, this has really been fascinating and I hope we get a chance to speak again because it's clearly a field

that is evolving. And I think particularly at this time when we're coming out of a pandemic and most of us are much more attuned to our health and the systems around us, this is only going to gain steam. Thanks for having me. Clare Delmar

Further information on Dr. Michael Sagner and a link to his book is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. A recent report on digital apps for cancer care was presented to government and NHS leaders by ORCHA Health, "the largest and most comprehensive digital health review service in the world" according to its website. Apps such as these can be embedded into cancer services to provide tremendous support to patients and ease the healthcare system at a time of tremendous backlog." The report cautions, however, that 74% of the apps have not been updated in the last 18 months, meaning that the vast majority have not kept pace with medical, data or usability guidelines. This is a concern, and, as the report states, "underlines the pivotal role cancer apps can play in supporting cancer treatment journeys – with 40,000 fewer people in the UK alone starting cancer treatment in 2020 due" to the pandemic." So how do these apps help patients? The report says, "We believe there is massive potential for intelligent apps such as these both to help patients and provide excellent returns on investment to the NHS." It cites evidence from Vinehealth which suggests that when patients simply track their symptoms and medications through Apps such as these, survival can increase by up to 20 per cent. It cites "another report" which found that weekly self-reporting of symptoms by patients led to a seven-month increase in survival, but raises caution, citing "a real problem with patients randomly selecting low quality apps from publicly accessible app stores such as Apple and Google Play." Among the apps updated within 18 months, ORCHA reviewed 190 of the most downloaded, testing them against more than 350 health standards and measures including elements of the NICE framework, and found that only 24.7 per cent of the apps reviewed meet minimum quality thresholds. It concludes on a cautionary note "these statistics are deeply concerning, given how easy it is for vulnerable patients and carers to search app stores and stumble across apps which may give poor or out-dated advice or blatantly misuse their private data." So what does this mean for men with prostate cancer and their partners & carers? A quick search on the App Store for "Prostate Cancer" revealed over 20 apps, including: ItsaMANTHING – Prostate Cancer Prostate Cancer Manager CORAL: Prostate Cancer Risk & Survival My Prostate Health Navigator Prostate Check Ned for Prostate Cancer My Prostate Cancer Coach OWise Prostate Cancer The apps all provide a combination of information on prostate cancer, advice and support in engaging with the medical community, and structures and spaces to record personal experiences and information. The founder and CEO of PXHealthcare, Anne Bruinvels, recently joined OnFocus to tell us about the OWise Prostate app, which was designed following the success of an app for breast cancer patients. Asked what she learned from that experience, Anne commented: "What we learnt was actually really fascinating. First of all, we found out that by just having an app to support people with the tools that Owise has for both prostate and breast, people can actually have a conversation with their doctor in a better informed way, but also in a way that that makes them more relaxed because they can prepare better. Both apps, but also the prostate cancer app, contains a list of personalised questions that come up after you have filled in your profile. So in that way you can go into your consultation and your doctor's visits being well prepared and afterwards listen back to that conversation at home with family members and make much better decisions. So that's one of the things we learnt, that people could have a better treatment discussion with their doctors and with their nurses." She continued "After that, we found out that people really like to manage their condition by monitoring their trends, how they feel. So we learnt from patients who were being treated for advanced that is metastasised cancer. That actually by using the app, they could really much better gauge how the treatment was going and alert the nurses when things were going down, when things weren't working well and also at the same time, use that same app to make sure that if they felt better, they could take on more. And yes, we have always been incredibly pleased with the really helpful feedback that we've had from users. So the app is continuously being updated with useful feedback from users" The EAU (European Association of Urology) asked a team of urologists to examine the role of digital apps in prostate cancer management. "PCAs (Prostate Cancer Apps) are currently in its infancy and do require further development before widespread integration into existing clinical practice. There are concerns with data protection, high readability standards and lack of information update in current PCAs. If developed appropriately with responsible governance, they do have the potential to play important roles in modern-day prostate cancer management" The authors also cautioned "Despite the potential benefits of medical health apps in general and PCAs specifically, the potential for harm is real. A majority of medical apps targeted at patients and the general population haven't had scientific validation. Misinformation can lead to anxiety,

over-diagnosis and over-treatment.” We asked several popular and respected cancer community leaders what they thought about the use of digital apps, and to what extent these are used among their community members. Tony Collier, a dedicated runner, is no stranger to digital apps, particularly those that provide information on running performance and links with fellow runners. As an active blogger and social media influencer, he is also effective at using digital media to build communities. He told us that he had trialled one and felt that “it wasn't giving me anything I didn't already have or know”. Elvin Box, who actively campaigns for Movember, is mainly focused on giving all men access to early and regular PSA tests. He'd like to see an NHS approved App that includes a Home Blood Test kit, “that enables people with a prostate to monitor their PSA levels with sufficient knowledge to know when their GP needs to refer them to a Urologist, i.e. take the GP OUT of the key decision making process & get the potential prostate cancer victim an audience with an expert for the vital risk management element of the diagnosis as quickly as possible” Chris Lewis leads a large and dedicated community of people living with all kinds of cancers, and says he knows very few who actively use digital apps – with one notable exception. Squeazy is a pelvic floor strengthening app which does one thing well – it provides a structure and discipline for men and women to do simple, regular and repetitive exercises to strengthen their pelvic floor. Chris spoke of a perceived digital divide among cancer patients, particularly older people, and felt that most cancer patients he knows crave human interaction when dealing with their diagnosis. “Just because you can doesn't mean you should” he commented on developing apps for cancer patients, adding that “not every problem is solved with an app”. All three questioned how the data generated from apps will be used, suggesting that trust could be built around using this data in an open and collaborative way for research into improved diagnostics and treatments for prostate cancer. Do you have experience and thoughts on using digital apps for prostate or other cancer management? Black Men and Prostate Cancer – 2x higher risk of developing it and 2.5x higher risk of dying from it The facts speak for themselves: Black men are twice as likely to develop prostate cancer as white men and 2.5x more likely as white men to die from it. Researchers are trying to understand the biological and behavioural reasons for the difference in incidence and outcomes. Current policy from the NHS is to offer Black men increased access to PSA testing. And here's the problem: Black men appear to get screened less for prostate cancer than white men even though they're at higher risk; and they participate less in clinical trials that drive research into the causes of disease like prostate cancer. There are many opinions about why this is, converging around a culture of mistrust in the Black community. A recent review of diversity in American clinical trials concluded: “Many reasons have been put forward to explain the difficulties in enrolling African Americans in clinical trials. Chief among them is distrust of the medical establishment and fears of exploitation in medical research in this population (Am. The infamous Tuskegee Study, in which the US Public Health Service deprived hundreds of African-American men of syphilis treatment so that researchers could study how the disease progressed, has cast a long shadow. In some communities, African Americans may also lack sufficient information regarding what clinical trials can offer and the safeguards in place to protect the privacy of their information. Beyond distrust and lack of information, substantial logistical hurdles can also impede fuller clinical trial participation. For example, some individuals may have limited access to the cancer centers that are the hubs of clinical studies, or they may lack the ability to take time off work to take part in a trial.” The research shines some light on a legacy of mistrust and exposes areas that are less understood but the facts speak for themselves and support the urgency to encourage more black men to get screened for prostate cancer and to participate in research aimed at understanding their increased risk. The pandemic has spotlighted these issues, drawing attention to vast health inequalities across racial lines, often quite brutally manifested in both the UK and USA. Two stand out – deaths from Covid19 have been greater in the black community, and take-up of vaccination has been lower. A recent Opinion piece in an American medical journal examined why: “There seems to be a distrust of doctors and research in Black communities in the U.S. and beyond A Black law school professor talked about the reluctance of Blacks, even those who are health professionals, to undergo COVID-19 vaccinations despite high death rates in the Black community. She said ethicists and medics blame this on the infamous Tuskegee experiment involving Black men with syphilis, but that she doubts that many people know anything about the Tuskegee experiment.” It references Willie Underwood, a highly respected Black American Urologist who himself had prostate cancer, and has commented publicly on the disparities between black and white men in screening and treatment for prostate cancer. “the Black community has many issues to overcome regarding the stigma of prostate cancer and other cancers, homophobic fear of digital rectal exams, and mistrust of the medical community and researchers” He goes on to say “We need to encourage more young men to get themselves checked, to at least get that

baseline in so they know what their status is, and then follow up on there," he said. "Many of the men, if they weren't being followed in some way, they wouldn't know there's a problem, such as their PSA's spiking or the digital exam showing there are some rough spots or a growth." Conversations with former patients give us more insight into why men in the Black community are reluctant to get screened for prostate cancer. Both were diagnosed around the same time and started out in similar positions in terms of the nature of their diagnoses, and both went on Active Surveillance --- but met with very different outcomes. Fortunately he was suitable for HIFU, which he underwent with TFTC Consultant Urologist Raj Nigam, and, as he says, 'never looked back'. His friend also became disillusioned with AS and when he sought treatment his prostate cancer had progressed, requiring more radical treatment. Fortunately this was successful and he is well and active, but both men felt "cheated" in being put on AS. Del says "we both left it for a year and a half and in the end (my friend) was not a suitable candidate for HIFU anymore as his cancer had advanced. Anything can happen in a year – it could mean life or death." Indeed, there is widespread strong opinion about AS for black men. Willie Underwood is particularly vocal: If Black men have more aggressive cancer, then why would you treat them less aggressively?" Del adds: "My friend and I were both on Active Surveillance and left it for a year and a half before looking into HIFU but so much can change in this time. I feel fortunate that I could still have the HIFU treatment, but my friend found out he couldn't as his cancer had advanced. I now advise everyone to get their prostate checked and act as soon as possible – the earlier you catch it the more treatment options are open to you." Del also told us that many Black men – all that he knows – are reluctant to see a GP for prostate screening, mainly because they don't want to have a DRE performed by a male doctor. In his case he specifically asked for a woman to undertake the procedure, and suggests that a simple change in communication to Black men about screening reflecting this preference could make all the difference in improving takeup. If you're a Black man with experiences you'd like to share about prostate cancer screening and treatment, please get in touch. And as a call to action, we encourage all black men to engage with research being undertaken by Prostate Cancer UK. An interview with Anne Bruinvels An interview with Anne Bruinvels, founder and CEO of PxHealthcare Founder and CEO of PxHealth Anne Bruinvels joins OnFocus to discuss the launch of Owise Prostate, a digital app designed to support men with prostate cancer. <https://owise.uk/prostate/> Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. A digital app made with and for men prostate cancer Clare Delmar Hello and welcome to OnFocus brought to you by The Focal therapy clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Joining me today is Dr Anne Bruinvels, an expert in personalised medicine who founded PX Healthcare in 2012. During that time, she was also executive director at the European Personalised Medicine Association, where she realised that cancer patients' experience following diagnosis is much poorer than it needs to be. And she founded PX to address this by correctly informing and supporting patients throughout treatment and recovery. Its first product was an app for breast cancer patients, which has been successfully rolled out in the NHS, leading the way for Owise Prostate. And Anne's here to talk with me today about how this product will help men with prostate cancer. Thank you so much for joining me today. Anne Bruinvels Wonderful to be here, Clare, thanks very much for having me. Clare Delmar So let's jump right in. What is Owise Prostate and why should men use it? Anne Bruinvels Owise for prostate cancer is an app that's been essentially co-designed and co-developed with men with prostate cancer who indicated they really needed support from day one of diagnosis with signposting and with essentially personalised information to support them through their whole disease pathway. So it is an app that people can download for free and then they can start using it by putting in a few profile details. And this was one of the things that several of the men demanded to have essentially, they said we really need something to help us have a better conversation with our doctor. And then it's essentially a tool that has lots of things in one place, and that includes a place to keep their treatments, to have things in their diary, to make secure audio recordings of their conversations with their doctors. And then the real feature that lots of men like is that people can track and trace how they respond to treatment. So people who have had treatment and for example, they've had issues with incontinence or with pain or with fatigue. They can be reviewed back at any time, obviously by the users themselves, and then they can be shared in real time with their doctors, with their nurses or with any other trusted family members who they would like to inform about their wellbeing. So men say it's essentially one thing that really keeps them on track and really supports them with their treatment. Clare Delmar Gosh, lots of questions popping up. But before I dig in, I know I spoke a little bit about your background in the intro, but can you tell us a little bit about what motivated you and

inspired you to develop this? Anne Bruinvels Yes, absolutely. And while doing that, I became really passionate about the fact that lots of people who are affected by cancer get different treatments. Having said that, very few people have access to personalised information and people always have to read a whole lot of things about things that don't concern them about much more aggressive treatments, for example, or treatments or diagnostic tests that may not be appropriate to you. So I thought if it's easy for me to find those things because I'm trained in this field, it's very difficult for other people to find it. For me, it then became really important to make sure that people could have the right information at the right time and then also use these mobile tools, because this was sort of eight years ago when we started developing these things initially for breast cancer, as you said. And so we felt it was really important for people to also make sure it became their tool that they could populate with their data, they could review their data and if they want to share that data with others. And so then in the long run, we believe that that data in a fully anonymised way could be really supportive for both the patients, but also for medical research in general.

Clare Delmar So, I mean, what are the lessons you've learnt thus far from the breast cancer app and its use? Anne Bruinvels What we learnt was actually really fascinating. First of all, we found out that by just having an app to support people with the tools that Owise has for both prostate and breast, and people feel much more at ease when they use it. They can actually have a conversation with their doctor in a better informed way, but also in a way that that makes them more relaxed because they can prepare better. Both apps, but also the prostate cancer app, contains a list of personalised questions that come up after you have filled in your profile. So in that way you can go into your consultation and your doctor's visits being well prepared and at the same time, actually then in an easy way and listen back to that conversation back at home with family members and make much better decisions. So that's one of the things we learnt, that people could have a better treatment discussion with their doctors and with their nurses. And then after that, we found out that people really like to manage their condition by monitoring their trends, how they feel. So we learnt from patients who were being treated for advanced, that is metastasised, cancer. That actually by using the app, they could really much better gauge how the treatment was going and alert the nurses when things were going down, when things weren't working well and also at the same time, use that same app to make sure that if they felt better, they could take on more. And yes, we have always been incredibly pleased with the really helpful feedback that we've had from users. So the app is continuously being updated with useful feedback from users.

Clare Delmar I was going to ask you that. I mean, that's one of the sort of qualities, I suppose, about apps, is that you're generating data all the time and you're learning about your users all the time as well. Well, particularly for prostate cancer it was important for us that we made an app, which is, by the way, not just a mobile app, but it's also what we call a web app that is a website where people can do the exact same things. Everything has to be really clear and there shouldn't be any ambiguity and that really these apps and websites should be there to take people along the way. So we make sure that everything is really easily indicated in the app, you know exactly where to click and no button is ambiguous, for example, it's really well explained. And then the other thing is that we found out that men really wanted very specific things to monitor regarding their treatment. And you can really send that again to your doctors who may be interested to know how you're doing and improve things for your own treatment, but also for the benefit of others in the future.

Clare Delmar That's really interesting, because one of the things I wanted to ask about where the sort of non-clinical aspects of prostate cancer itself and various treatments and of course, incontinence being one that men are very concerned about, sexual health being another one, and mental health being yet a third. Are there places to think about that, to address those issues on the app? Anne Bruinvels Well, absolutely. So we have the sexual health issues are also addressed in the app so people can indicate their erectile function, changes to their sex life so they can monitor that as well. And then thirdly, or what you mentioned with respect to mental health, that's really important, too. So there are also ways to monitor that within the app and to keep track of your mood, but also of the fears that people have. We know that cancer patients have a lot of fears about not just family related fears or financial issues, but also the fear of cancer recurring. So we're actually collaborating, we're very research driven at PX and working on Owise we're always trying to make sure that everything is not just what we call medical evidence-based, but that we contribute to research. So we're working with researchers in Scotland on trying to understand how we can more quickly alert people when their fear of cancer recurrence becomes an issue and they may need to take action. But it is already implemented in the app as it is.

Clare Delmar That's interesting because, of course, you'd be very familiar with one of the treatment options, or management options for men with particularly early stage or low risk prostate cancer is active surveillance. So another question I have is, like all diseases and cancer in particular

here in the UK, I'm sure you're aware that there's quite a campaign right now to raise awareness about the so-called backlog of cancer patients that has been impacted because of covid-19. There's a lot of fallout to this, not least of which is delayed diagnostics, delayed treatments. And I'm wondering if this has impacted any way on the app, if there's any way that your app might help people maybe along the lines that you've been describing, what are you seeing as a result of the backlog? Anne

Bruinvels Yes. So we started developing this app just before covid struck and then it struck and we essentially built it and it was released and launched last month. Well, I think what's really important is to understand that actually it really fills a gap. Well, really, they were trying to find a way to what they then call holistically support their patients with mobile technology, because people cannot always come into the hospital and Owise really fills that gap. It really addresses needs that they have by having this tool now that addresses so many different things that are part of their whole I don't like to use the word, but it's so easy to say the whole journey they have as a prostate cancer patient. So it really helps patients from day one, as you say, from actually diagnosis, even pre diagnosis all the way through their decision making that we call shared decision making process with their doctors. And that's the way that we try to design this, but really with the support of the patients themselves. We haven't seen anything like this because you can bring it in really from the very first moment the patient comes into the clinic. And from that point of view it is really helpful all the way through to people going back to work and starting to play with their grandchildren again. And in terms of backlog, I think we're just at the right time to launch this, but also because men are now becoming much more able to use all sorts of mobile technology. But now, every man we encounter has a smartphone in their pockets and five years ago that wasn't always the case. Clare Delmar No, you're right. And I guess the epidemic is really accelerated that and using it for so many other aspects of your life. I mean, one final question is one of the things we noticed with a lot of our patients is how important the role of their partners is in supporting not only their treatment, but all other aspects of their journey, as you say. And I'm wondering if that comes in in any way, if partners can contribute or can share in any of this information? Anne Bruinvels Oh, that's such a wonderful question, because the first thing we noticed when we started organising our workshops for cancer patients already, when we started early on, this was originated in the Netherlands, but we started working with lots of patients. And the same actually happened when we did last year or just before last year, we did our workshops with the prostate cancer patients and carers. And that was really helpful because the partner often feels a little bit powerless, like they cannot really do that much. So that way it's actually an app that can be used by the partner as well if the actual, or carer, in any way, because that way it can just be done as a collaborative tool. And that way the patient can actually delegate one of their close family members or friends, to really help them with this. So it's really a tool for both. Clare Delmar I mean, I'm really looking forward to spending some more time on it. I've spent a little bit of time prior to this conversation, but now you've definitely inspired me to look a bit further and perhaps we'll talk again with some more questions and maybe bring some of our patients into the conversation. And I look forward to hopefully speaking with you again. Anne Bruinvels Well, that sounds amazing, Clare, I would love to have patients involved as well, because for them, that's really the reason why we do it. Just perhaps I might want to say the website is <https://owise.uk/prostate/> and you can find us on social media as well. Further information on Owise Prostate is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer. An interview with focal therapy patient Delroy Wright Former TFTC patient Delroy Wright joins OnFocus to discuss his experience with prostate cancer, and to suggest some actions to both men and their doctors about testing and treatment. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact becomes a multitude of challenges and opportunities. Joining me today is Delroy Wright, a former HIFU patient of Focal Therapy Clinic consultant urologist, Raj Nigam. Del had an early-stage diagnosis three years ago and spent over a year on active surveillance before he was treated with HIFU, which he learnt about through his own persistence in seeking and pursuing alternative treatment. He says, "I believe there is not enough information out there about it, especially for Black guys. If we didn't look into these alternative treatments ourselves, we wouldn't know anything about it. It should be on the side of buses." Del joins me today to discuss his experience and the experience of men in the Black community with prostate cancer. So I rang up my doctor and I said to him, you know, is it possible for me to have a prostate check. He says, well I was kind of young to be

having it, but he says, well, yeah, we'll go with it. I said, well, you know, I said, well, nah, you can't really do that, because being a black guy, you know, we don't really have anybody just go up into your passage just like that. So I asked him if there's a lady doctor on site that can do it, and he said, yeah, and he laughed because he knew, you know, because I've got an Indian doctor, he said he knew how black guys were regarding just going up the passage. And that's when they said, well, you know, they wanted to do another examination, a more detailed examination regarding having a MRI scan. Delroy Wright: And through the biopsy now, they said that's when things came back and said, well, look, you're at stage two cancer, you know, and then you get a little bit frightened for, you know, after that. But then I think I was one of the lucky, fortunate ones that started to ring around because I had another mate who was going through virtually the same situation that I was going through, and we were able to talk about it. That's one of the reasons why I'm doing this interview today, that hopefully that the brothers will then talk to each other and go out, even though they think there's nothing wrong, still pursue and get a PSA or get a check for the local doctors to find out what's going on. Don't just leave things, you know, the NHS might tell you just leave it, but you can't leave it because there's something inside you and it could be growing. Clare Delmar: What were the things, the key things you think you learnt from that experience? I think you see when you get to around 40, 45, if there's nothing wrong with you, take out some medical insurance. You can't just leave it to the NHS to treat you, because by the time they get around to treat you, the cancer inside you, if you've got prostate cancer will be growing and then it may be too late to have any treatment diagnosed. Clare Delmar: Because isn't that what happened with your friend, that he, like you waited, but he wasn't as fortunate as you by the time he wanted treatment? Clare Delmar: I mean, Del, one of the things that I'm interested in hearing from you is did you feel any kind of discrimination at any point during your diagnosis and then follow on treatment? Delroy Wright: No, I didn't feel discriminated, what I felt was I wasn't given enough information. You know, it's easy to be said that don't do anything because as I sit here now, if I didn't do something about mine, you know, I've got a good mate of mine that because he waited, we both waited because we were sharing the same information. By the time he wanted to get something done, it was too late and he had to have his prostate out. I understand it is one in four black guys have got prostate issues they're walking around with. But actually, you know, possibly even more importantly, when they are diagnosed, they're more likely to do so with advanced stages of cancer. Delroy Wright: Well, I think it starts like I said from the beginning, you know, I was lucky. And I think maybe if there was a thing that more women were doing tests, they were carrying out the tests around the passage, guys who turned up, they would be more willing to go and have their tests if they know if they go and see their doctor, that the woman's going to go up into their passage. Clare Delmar: So let me ask you a couple of questions about that, because this is really interesting and it's not something you hear about a lot. Clare Delmar: OK, and then the second question I have is and this is at the GP, when you said the lady doctor, this is a GP you're referring to, correct? And if that is going to be an issue, I know what they're saying, I've been on the street, I know they're saying I can't have some guy putting their hand up inside me, but if it's a woman now, it's a different thing. I know in all cases not you know, it's a lifesaving examination, you know, but that's maybe one of the reasons why you don't get a lot of the black guys going in because of that issue. Clare Delmar: Do you think that that's something that, you know, you mentioned that when you talked about that with your initially male GP, he understood that and he very readily. Clare Delmar: So other than that, which is pretty important and we can come back to that in a second. Delroy Wright: I really think information like, I had to search for other information regarding your prostate or what other treatments there are out there. And I don't think the hospitals, when you go to the hospitals, they're willing to tell you or even show you that there's other treatments out there. They're only putting over what they think rather than saying, well, there is A, B and C, other treatments out there where you could explore, rather than just say, well, you know, let's wait. I just want to come back to what you said about your friend who was going through a diagnosis at the same time as you, and then you mentioned that a lot of your friends talk about this. So it's not a question of not talking about it because it sounds like you do talk a lot about it. But, you know, you've got to remember there is certain of the brothers, they won't talk about what problems they're going through. You know, they won't go to another one of their mates and say, well, maybe got this issue going on. And, you know, I feel this is one of the reasons why I'm willing to do this interview with you today. If I can show what experience I've gone through, maybe that will help others going down the line really. What you've said and particularly about women doctors at the primary care level is really, really important and something that could be adopted. But I really want to thank you for speaking with me today, because your experience is, fortunately it's been very positive for you and it's been really nice to get to know you and hear about all

the things you have to say, so thanks Del for joining me. And again, I've got to thank the doctors who's worked with me because, you know, if I didn't have them doctors, I wouldn't have known what I know now. And I hope, you know, this is something positive and carry on for other black guys out there that are going through the same situation.

Clare Delmar: Further information on suitability and access to HIFU is available on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer.

Maintaining Pelvic Health After a Prostate Cancer Diagnosis

Pelvic health is not a familiar concept or practice for most men, unlike for women who will experience significant changes in their pelvic health following childbirth and menopause, and for whom shared experience and access to support makes it a regularly discussed and treated condition. For most men, a prostate cancer diagnosis will be the event that reveals the essential elements of their pelvic health and elevate its status to high priority. Hearing the term "incontinence" in relation to their own health is anxiety-inducing and often quite scary for most men, who struggle at the prospect of losing control of one of their most basic of bodily functions and the social and lifestyle consequences that go with it. And because no one likes to talk about it, many men make decisions about prostate treatment without fully understanding what the impact on their pelvic health will mean for them.

As Prostate Cancer campaigner Tony Collier says "Sex is a major issue for men living with prostate cancer but incontinence is an even greater issue. Some days I think I was lucky to be stage 4 at dx as I'm certain I wouldn't have coped with incontinence at all. There are many men whose lives have been ruined by it" There is information out there, of varying quality and effectiveness in terms of content and tone. Prostate Cancer UK provides a fact sheet, management guide, case study and an invitation to provide commentary on this content. A detailed and practical source of information comes from Tena. While going to look there might feel like admitting defeat for some men, the site and its approach make clear to men what incontinence actually means day to day, eg wearing pads and measuring severity in the number and frequency of their use. The Urology Foundation offers a range of information and patient case studies, including advice from the experienced Jane Simpson, a continence nurse specialist with over twenty years of experience working with both men and women on improving their pelvic health and overcoming incontinence. Jane is the author of *The Pelvic Floor Bible*, where Chapter ten is devoted entirely to men's pelvic health, with particular reference to men with prostate disease. Jane joined OnFocus recently to discuss what men with prostate cancer need to know about continence and what to do about it. Finally, we've found some useful videos and podcasts to help men better understand what challenges prostate cancer will bring to their pelvic health. There are two takeaways here: one, it's really important to face up to what incontinence is and understand exactly what it means for you before you decide on a treatment option; and two, pelvic health information is available in a range of formats and media, so that most men can access and engage with something that's not the most pleasant of topics to investigate but will have a real impact on their lives. Call The Focal Therapy Clinic for help if you or a loved one has been diagnosed with prostate cancer: 020-7036-8870. Call The Focal Therapy Clinic for help if you or a loved one has been diagnosed with prostate cancer: 020-7036-8870.

Data-Driven Research & The HEAT Registry

Healthcare is continually benefiting from the growth, improvement and increased access to medical data, which, combined with advancing data analysis methods and powerful computing is unlocking questions about disease, prevention and treatment in a fast and cost-effective way. In recent years it is these datasets that are driving research, clinical discovery and adoption. Last year we looked at how "big data" was supporting research on prostate cancer and shared some examples of big data helping to identify aggressive cancer, match the right treatment to the right man, and understand how cancer cells develop, leading to better diagnosis, better treatment and better prevention. We also spoke with Prostate Pioneer, an international consortium of data providers and research organisations whose mission is to assemble, standardise, harmonise and analyse high-quality big data from diverse populations of prostate cancer patients across different stages of the disease, aiming to provide evidence-based data for improved decision-making to clinicians, healthcare providers and policy makers. Most in the urology community support the view that, as recent research suggests, "The use of digital data in large data sets will be of pivotal importance to unravel the biological basis of prostate cancer, and to improve on prevention and treatment. For the screening of asymptomatic tumours, their identification, and their treatment with better and targeted therapies, the integration of information from imaging, genomics, and biomarkers is needed" The question for our clinicians and patients is what data is available to investigate the outcomes of focal therapy, and how has this been used for patient benefit? The answer lies in the High Intensity Focused Ultrasound Evaluation and Assessment of Treatment (aka HEAT) Registry, a globally accessible, web-based platform for storing clinical data on patients treated with HIFU, managed by

Imperial College London. It provides a unique aggregation of data that is organised for the purpose of advancing the collective knowledge about the clinical impact of HIFU on patient outcomes. It is allowing researchers to rapidly accelerate the aggregate HIFU knowledge base, accumulate data from around the world on a single platform, and expedite the ability to assess outcomes. The Focal Therapy Clinic and its sister company, Prostate Care Limited, are significant contributors to the HEAT Registry. All of our patients who undergo HIFU treatment become part of this registry, as anonymised cases. The quantity and quality of data is comprehensive, including pre-treatment baseline and post-treatment followup, each with over 20 data points including PSA, age, surgeon, detailed MRI and biopsy info, and histopathology info including Gleason scoring. Two recent studies using the HEAT registry have led to very significant conclusions: A multi-centre study published in the BJU assessed the change in functional outcomes after a second focal HIFU treatment compared with outcomes after one focal HIFU treatment, and concluded that a second focal HIFU procedure causes minor detrimental effects on urinary and erectile function. These data can be used to counsel patients with non-metastatic prostate cancer prior to considering HIFU therapy. A propensity score-matched study compared oncological outcomes of Focal Therapy to radical prostatectomy in patients with non-metastatic low- intermediate prostate cancer, and concluded that, over an eight-year period, oncological outcomes were similar between focal therapy and radical prostatectomy. TFTC Consultant Urologist Tim Dudderidge was an investigator on the second study, and believes the quality of the dataset is supporting much-needed evidence building: "By taking the UK's focal HIFU registry data and comparing it to similar men who had surgery, using a statistical method to try and match up these cases so that we effectively avoid comparing apples and oranges -- we're as close as possible to matching apples with apples and so we're getting as close as you can get, in my opinion, to the kind of ideal study methodology you see in randomised control trials." Consultant Urologist Raj Nigam of the Focal Therapy Clinic points out that the HEAT registry is unique in its focus on a particular prostate cancer treatment. "We enter our patients prospectively with their parameters and their outcomes into this very structured and comprehensive database, and from that point of view there isn't a single national radical prostatectomy database, which all radical prostatectomies are entered into. So it's unique from that point of view that all focal therapy treatments should be entered within this particular database." It's encouraging and exciting that the HEAT Registry is building and improving all the time, and is only beginning to support the kind of studies necessary to advance adoption of focal therapy. The Focal Therapy Clinic has been a contributor to the registry from its outset and is committed to its continued development and application. Our patients can be proud that they are actively contributing to the benefit of future prostate cancer patients.

Coping strategies with Jane Simpson, incontinence nurse

Continence nurse specialist Jane Simpson on what men with prostate cancer need to know about incontinence

Continence nurse specialist Jane Simpson, author of the Pelvic Floor Bible, joins OnFocus to discuss what men with prostate cancer need to know about continence and what they can do about it. The Pelvic Floor Bible is available here: <https://www.amazon.co.uk/Pelvic-Floor-Bible-Everything-Problems/dp/0241386535>

Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. A continence nurse specialist, Jane has run a private practice at the London Clinic in Harley Street for over 22 years, where she treats men and women, young and old, with all forms of incontinence and pelvic floor dysfunction. She's the author of The Pelvic Floor Bible, published in 2019, a best selling guide to improving and maintaining pelvic health, and is a member of The Pelvic Floor Society, The Association for Continence Advice, The International Continence Society, the British Association of Urological Nurses and the Association of Coloproctology of Great Britain and Ireland. As you can see, Jane knows all things continence, and she's here with me today to talk about what men with prostate cancer need to know about it. It's a great privilege to be on this podcast with you.

Clare Delmar: Well, you're such a specialist in this area that we all know is taboo, but this is something you literally live and breathe and you've seen so many people go through. Maybe you can start by telling me what your experience as a public health specialist with men diagnosed or recovered from prostate cancer has been.

Jane Simpson: So as you said, I've been working in this field for over 22 years, largely at The London Clinic. And originally when we started caring for men with prostate cancer, all of the surgery was open surgery, which required a lot longer in hospital. And we've moved on hugely since then doing robotic radical prostatectomy, sometimes

radiotherapy, HIFU and various other types of treatment. But over the last 22 years, I've looked after thousands and thousands of men who have been treated for all types of prostate disease, not just prostate cancer with pelvic floor issues. And so for men to suddenly have these problems was quite shocking for them and a learning curve for me at the beginning. It's a brave new world to suddenly find you have to wear a pad or a nappy and you can't control your bladder, which you've always done your entire life. So I think it's a really important area which is still under talked about unless you suddenly find yourself in that position. We're very lucky to also now have good charities support and good medical support in giving you the options for treatment.

Clare Delmar: So what would you say are the most common challenges for these men?

Jane Simpson: Without question of a doubt, it has to be erectile dysfunction and stress incontinence. Men have gone through their lives controlling their bladder, as I just said, and being able to get an erection when they felt like it. And to suddenly find that those two things might be not working is very frightening for them and very challenging. And he was I would have thought that erectile dysfunction was more important to him, but his continence was much more important to him. And a lot of guys will tell me, well, I'm not really worried about erectile dysfunction till I have my continence back. And family life, clearly, is part of that, because controlling your bladder and being able to have a happy sex life are very important in family life and work life too, thinking about going back to the office wearing a pad that might leak and wet your trousers is, is something that men... women have had periods and pads and babies and we've dealt with that through our lives. I mean, do you think that men fully understand what incontinence means when they're considering treatment options for prostate cancer?

Jane Simpson: I'm not sure that they do, and actually The Urology Foundation did a little study a couple of years ago and they found that two thirds of the British public didn't really know where or what the prostate gland was. Never mind what would happen to you when you were thinking about treatments for the prostate gland. And I think that the cancer part of it clearly at the beginning has got to be the most important issue. And it's only when you start then unravelling it and deciding what treatment you're going to have, that you start thinking about things like incontinence. What's very good is over the last possibly 10 to 15 years, we have started seeing men before the operation and actually trying to make sure they really do understand. Understand what the pelvic floor is, it's a hammock of muscles that is attached to the pubic bone at front and your coccyx at the back and sort of to the two bones that we sit on side to side. It's a hammock of muscles which in men works perfectly well to help with erection functions and also keeping us continent, stopping us passing wind when we're out and about. And I think men sort of often think they'll just sort of be totally incontinent, leak everywhere, which isn't true. And he started playing tennis and he came back to see me and said, well, I don't understand it. He played a relatively high level and clearly he hadn't thought, gosh all that jumping up and down playing tennis is putting a great stress on his pelvic floor. So even though he knew that stress incontinence was a downward pressure on the pelvic floor, the weakness of the muscles postoperatively, he'd still gone off and played a lot of tennis. So I think it's one of those things that I think in general we put to the back of our minds because we think it won't happen to us.

Clare Delmar: Yeah, indeed.

Jane Simpson: And it clearly doesn't happen to a lot of men ongoingly. It happens to quite a lot of guys in the short term while the muscle recovers and bruising goes down. But it clearly, even if you don't have any incontinence after the operation, you must must do your pelvic floor exercises.

Clare Delmar: Do you think that this is something that has to do with the language? That the language and communication around incontinence possibly inhibits understanding and acceptance? And when I talk to men who've had the operation, they talk about wearing nappies, that they've never leaked urine before. If you look on the television, there's lots of little adverts for Tena Lady, but you never see adverts for men. And actually, I'm going to just read you a very short quote from a patient of mine who I think sums up this question very well. He says, "My prostate first made its presence felt during my mid 50s when having a wee ceased to be what it was. What had always been a powerful jet dwindled to a mere trickle and three or four effortless tries were needed before my bladder felt empty. Like most men, when things go wrong below the belt, I was overcome with squeamish embarrassment and told no one." He actually ended up having surgery and a radical prostatectomy. He says, "Female stress incontinence is discussed quite openly, even with jolly little TV ads. But nothing is ever said about the male version."

Clare Delmar: We find this all the time.

Jane Simpson: And I think that sums up about communication to do with men and incontinence.

Clare Delmar: Indeed.

Jane Simpson: It is with women, I think, particularly with things like Instagram and Facebook groups to do with menopause, to do with women's health. I'm part of that world, and it's there all the time and I quite often do a little Instagram for men, and I never really get a lot of response back from that. I'm rather unusual in that department.

Clare Delmar: But I think it's language and communication can... You gave a really

good example there, but it extends even deeper and more, I think, pervasively into our lives. And one of the things that we've talked about before is even something as prevalent as public toilets or should I say not prevalent because so many of them are closed. I mean, obviously in women, but we're talking about men here, who suffer from incontinence and really, really impact their lives in a negative way. Jane Simpson: It actually does. And I had to take him because the guy rings up and says it's going to take three hours to do this job. So if you're a man who had no choice but to sort of hang about outside in the cold, then Autoglass have closed their loos. But if he did, he was abandoned there for three hours. Clare Delmar: Yes. Jane Simpson: I think that sort of public loos for men, they don't ever think about it before they've had this particular issue and suddenly it becomes actually quite important. And interestingly, I've had a lot of conversations with guys about the fact that male loos don't have bins in them. If you go to a ladies loo, there's a sanitary bin to put your sanitary towel in, or your tampon or whatever. And I think even if they can find a loo that's open, you know, men's loos are urinals with then some cubicles, so they'll go to the cubicle, and then realise, oh, my God, what am I going to do with this pad? Because there's nowhere to put it. Clare Delmar: It is very subtle. Jane Simpson: So things like that are actually rather alarming and meaningful. But I think the other issue about communication that's so interesting is as men are even considering treatment and whether they use less invasive treatment like what we offer or radical treatment, they need to understand what incontinence would mean, should they choose a treatment that might bring that on them more severely. And I think that's what we find a lot of men just aren't in a position to really understand that. Jane Simpson: I think so. And then if you're just told, well, this is the option for you, you hope that men are given all the options. And I'm always fearful of the word Dr Google and that we must be careful about how we use that information because there's a lot of disinformation out there. However, there is good information in places like The Urology Foundation, the prostate cancer charities, Movember movements and things like that, which actually give good evidence-based information for men, which before I mean, what would you have done, gone to the library and read Grey's Anatomy? I mean, there wasn't... At least we are moving forward in our communication and understanding. And for us as medical practitioners, that in itself is challenging because obviously guys come and tell us, well, I've read about this and that, what do you think of it? And so it makes sure that we all at the top of the game, too, because you need to know what's happening and hopefully, clearly we do. Clare Delmar: What would you do to improve the situation? You've seen, you engage with men both on their emotional side and their mental side and their physical side. How would you improve the situation? Jane Simpson: So I think it started with my book, my Pelvic Floor Bible, when I wrote it, the Penguin editors were a bit surprised that I wanted to include a chapter for men in it. I said, I'm not writing this book without including men, because clearly men have problems with incontinence and pelvic floor dysfunction, whether that's either erectile dysfunction or stress incontinence or other types of incontinence in fact, the overactive bladder, when you can't get to the loo in time, you have urgency. It's largely stress incontinence that affects men post radical prostatectomy or prostate surgery. So clearly I try to see them all before any form of treatment and explain what the pelvic floor is, how it works, how it will be affected by the treatment that they have. But clearly, there's lots of evidence to say that men with a healthy pelvic floor, if they understand how it works, will have a better light bulb moment of making it work again when they've had whatever treatment it is. If stress incontinence isn't improved with just pelvic floor exercises, I do sometimes use electrical stimulation, dependent on the treatment they've had and the level of disease they have, this sometimes is contraindicated, but there are sort of pairs of shorts you can put on called Inovo. So whether that's weight, whether it's constipation, because bowel is clearly a part of the pelvic floor and can definitely affect it, whether it's what they're drinking and getting fit as possible prior to the treatments. And I think if you maximise lifestyle, understand how your pelvic floor works and then look after it properly afterwards, it will reap rewards. And I also talk to them clearly about the correct type of pads to wear in the short term post treatment, because I think if you come out of the operation, you need to have the kit to hand so that you are totally prepared and then you will actually feel better and recover better if you have good evidence-based knowledge and information about how to care for yourself. Clare Delmar: Well, Jane, it's been really interesting. And again, it's lovely to talk to somebody who is so evidence based about a topic that a lot of people don't want to talk about. It's been a real pleasure. Jane Simpson: It's been a great pleasure, Clare, and it's my passion in life, caring for people with urinary problems and pelvic floor dysfunction. It's still very under-reported, and under-treated and any raising of awareness we can do gladdens my heart, so thank you. Clare Delmar: Further information on Jane Simpson, her practise and her book is on our website, along with the transcript of this interview and additional interviews and stories about living with prostate cancer, please visit

www.thefocaltherapyclinic.co.uk. Get an independent second opinion before accepting prostate cancer treatment. All men who come to our clinic do so following a diagnosis of prostate cancer and a recommendation for treatment – mostly from the NHS, sometimes from a private clinic. Indeed, they seek us out because they wish to explore alternatives to those recommendations. We provide, by default, a second opinion. In considering a patient for focal therapy, our doctors review a range of information, including PSA, MRI reporting, biopsy report and histopathology. This “pathway” information completes a story of the location and severity of a patient's prostate cancer. And this is where we often find both problems and opportunities. Imaging – not all MRI scans are equal. Variability in scanner settings, sequencing, radiographic technique can compromise image quality. Radiological reporting varies considerably across the NHS in both the quantity and quality of information gleaned from imaging. Biopsy method – the gold standard is a transperineal fusion biopsy and anything else compromises a precision diagnosis. Histopathology – labs and lab techniques vary which can compromise Gleason scoring and optimal treatment programmes. Suboptimal imaging, image reporting, biopsy method and histopathology will lead to suboptimal treatment recommendations. We often redo the imaging pathway and end up with a very different diagnostic result, supporting very different treatment options. Even when the quality of data is good, interpretation is subject to experience and opinion – the very stuff of medical professionalism. In any case, all of our patients' cases go through our rigorous MDT involving urological and radiological input to arrive at a comprehensively reviewed treatment recommendation for each patient. It's worth noting that a second opinion is sought by the patient – not offered by the doctor. Many are reticent, often for fear of “offending” their doctor, but there are lots of reasons why and these are addressed in guidance from cancer charities and other medical bodies. Cancer Research UK offers a comprehensive guide to seeking second opinions on a prostate cancer diagnosis, outlining pros and cons and providing contact points for help. Others are stronger in their guidance, “A second opinion is an important part of becoming educated about your prostate cancer and your treatment options. The more you can learn about your diagnosis and your treatment options, the better chance you have of receiving the most appropriate treatment. Prostate cancer is now more treatable than the past, but there are also many more treatment options and more complicated procedures. This is especially true for treatment of early stage localized prostate cancer where there has been constant technical innovation in both surgery and combination hormone and radiation treatment. Getting a second opinion will help you understand these options and help you make an informed decision about which is best for you.” More often it is conversations with and comments from other men that incentivise a request for a second opinion. TFTC patient Mark Stubbs would have gone down a very different route with his prostate cancer diagnosis if he hadn't sought a second opinion: “I'm actually a stronger advocate of a second opinion now than I would have been at the time of my diagnosis. It was only really when I discussed with Mr. Tim Dudderidge – a telephone consultation – that he actually suggested revisiting the biopsy samples. And he basically said, look, we've rechecked the samples. It's coming out at Gleason 7 rather than Gleason 9, he said, which does give us quite a few more options in terms of nerve sparing during surgery and also sparing the lymph glands, which to me was priceless. If I'd have probably stayed in the NHS loop, I've got a feeling I wouldn't have got the same level of treatment. I wouldn't have had the second opinion and they would have probably operated assuming that the cancer was Gleason 9. So really the second opinion, I think, was absolutely pivotal in the choice of treatment.” Another patient, Ray Braithwaite, felt his initial experience at diagnosis was rushed and impersonal, and had doubts about the treatment options he was recommended. He had a very different experience with TFTC Consultant Urologist Tim Dudderidge: “He listened. And we spent about 20 or 30 minutes and Tim went through all of the potential alternatives, including the surgery and the radiotherapy and the HIFU. And he was also able to tell me about Gleason and PSA and the stuff that I should have been told about months earlier, I think.” In Graham Ogilvy's case, a different biopsy changed everything about his initial diagnosis and treatment options: “the NHS were very good about giving me the records and the MRI scan I had so that Mr Nigam could see that. The MRI scan he thought was of a very high quality, etc., but did require to be another biopsy. And this was very interesting because this was a different biopsy from that that is performed in Scotland. It's more exact, it's a transperineal, I think they call it.” If you have any doubts about your diagnosis, are concerned about the impact of your recommended treatment on your quality of life, please get in touch. Urologist Tim Dudderidge on Outcomes from Prostate Focal Therapy Treatment. Consultant urologist Tim Dudderidge joins OnFocus to discuss what factors contribute to a patient's recovery from prostate cancer treatment, and how this varies across treatment options. He refers to a recent study of patient recovery from focal therapy, evaluated as functional.

outcomes:<https://pubmed.ncbi.nlm.nih.gov/31971335/> What determines recovery? Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Tim Dudderidge consultant urologist at Southampton University NHS Trust and The Focal Therapy Clinic. Tim is a recognised innovator in advancing both the imaging and diagnostic pathway for prostate cancer and minimally invasive treatments, including focal therapy. We're going to discuss how these advances are giving rise to more choice for patients and how these choices impact patient recovery from prostate cancer treatment. Tim, welcome and thanks so much for joining me today.

Tim Dudderidge: Thank you for having me.

Clare Delmar: So on that note, if you could give me some idea about how recovery times vary across treatment types?

Tim Dudderidge: Sure. Well, it's obviously one of the big things that people ask and when I'm describing the different treatments there's a lot of things that we go through. But one of them is how the treatment goes, how long you spend in hospital and what people can expect with their recovery. So when I'm talking about surgery, we talk about normally a short stay in hospital where people may stay for one or two nights. But they do obviously have as well as the catheter, which stays for one week, they have a degree of surgical pain from the small incisions. It's not usually too bad, but people have to take some degree of painkillers and we're very keen to avoid opiate type painkillers as one of the big problems in the United States where the use of opiates is very common. Those kind of painkillers are normally used for a few days and people are definitely more restricted in their physical activity. But they might, for instance, just be limited to moving around the house and maybe short walks outside. I normally tell people that they can get back to full physical activity after about six weeks. And during that time, anything involving abdominal muscles, cycling on a normal bicycle, can be more strenuous for the abdominal wall. And certainly anything that involves heavy lifting or straining should be avoided until six weeks. When people have surgery, when the catheter comes out, normally the first problem they encounter is stress incontinence. I mean, I'd say probably two in 10 of patients having surgery who've got some degree of nerve sparing might actually be pretty dry from the word go. But that still leaves the majority of people having some degree of leakage and that can be just a few drops or needing one or two pads a day or something. And that is more typical in patients who've had really wide excision surgery or when they've got anatomical factors that might lead to that. And that definition of using pads is one that's a bit kind of sort of smoke and mirrors, because actually many of the men who we define as not using pads. When this is looked at closely by Caroline Moore's group and we contributed to that, they actually found that being truly pad free was actually at one year, 60 percent of men. And then sexual function recovery is a very tricky one to describe because with surgery, it really is dependent on the pre surgical function and what degree of nerve sparing is undertaken. And that's normally tailored to the individual person's cancer location and the bulk of disease. But as a rough estimate, I'd say people that are having bilateral nerve sparing who have good function beforehand can expect probably about a 60 percent chance of regaining erection function plus or minus the use of Viagra type drugs. But obviously, as soon as you start taking nerves away, then that will come lower and lower.

Clare Delmar: So how does focal therapy compare to these other forms of treatment in terms of these definitions of recovery?

Tim Dudderidge: So focal therapy is substantially different. It's a day case procedure and people might stay overnight if they have social issues that require that, but from a medical point of view, you don't really need to have any inpatient stay and people can go home after a few hours from the anaesthetic. They'll go home with a catheter and we keep the catheter in mainly because of a bit of prostate swelling that goes on after the treatment. And that can limit the flow of urine and cause retention of urine if we didn't let things settle down first. There is a risk of urine infection, which is probably greater if it weren't for the fact we give people antibiotics usually for a week. And that's partly because of the combination of the presence of dead tissue after it's been treated, the presence of a catheter, which means that there's colonisation of plastic, usually when we leave it in the body and so the presence of that next to the dead tissue would be an infection risk. Probably another 10 percent of those patients having to have further antibiotics, something like that.

Clare Delmar: And what about continence that you referred to earlier?

Tim Dudderidge: So incontinence is really not a problem. In fact, these kind of issues and sexual function and urinary symptoms have been studied quite carefully by the UK Focal Users Group. And there's a publication by Catherine Lovegrove and many of the co-authors from the Focal Users Group. And she showed that for this group of men, leak free

continence, which is the most sort of stringent definition of continence, this group of men started off with 77 percent of men saying that they were leak free and after the treatment, that went down just to 72 percent. So it is interesting, actually, that already quite a lot of men having some degree of leakage. But when you looked at use of pads, the group started off with 98 percent being free of using pads, and that dropped just a little bit to 94 percent. So really quite little impact on urinary continence function.

Clare Delmar: Do you think, though, that patients are typically informed on these kind of recovery metrics? If I can define it that way, when they're offered treatment, do you think they really understand? Like the use of pads, for example, is almost a metric that you're using?

Tim Dudderidge: It's extremely important that men having surgery are told about incontinence. And so that's why I tend to use this sort of measure of the proportion of people who become pad free or just using a safety pad over the course of time and trying to explain to people that there's no set time for them. And I think if you explain that people do get the idea that we can't give them a set time for them and it's a bit of an unknown and it could be quick. Whereas with focal therapy, it really is you can be really quite confident that they will experience very little change in their continence function.

Clare Delmar: So what do you think are the most effective ways to inform and educate patients on recovery? Do you think it's former patients and their testimony, or do you think it's evidence-led studies like the one you just referred to or combination of the two?

Tim Dudderidge: Yes, I think it's a combination of the two. And the trouble, of course, is if you wanted to introduce your patients to a fellow patient if you like, the temptation would be, of course, to pick the ones who've done really well. And on the other hand, if you were to introduce the patient who'd done not so well, they might get overly pessimistic view. So that's why I think it's important to try and explain in broad terms the spread of expectation. The other interesting thing that was found in Dr Lovegrove's paper was that there was a slight, if you like, worsening of some symptoms like urinary frequency. And so the IPSS score, which is what we measure to do this, went up very modestly by 1.2 points, which is after three years, that's a really minor change in urinary symptoms. And typically with surgery, what we see is something sort of similar in the beginning where frequency can be a problem. And that compares maybe with radiotherapy, where, interestingly, with radiotherapy, men can get a worsening of their urinary symptoms in terms of frequency and urgency and not storing urine well, but they don't get so much stress incontinence. So I guess the main take-home message is that radiotherapy can make the bladder storage elements problematic and funnily enough, it can affect the bowel as well. So bowel storage and I think that's unique to radiotherapy that the bowel is affected.

Clare Delmar: And so do you explain this in the way you're doing here to patients when you're informing them of the choices they have?

Tim Dudderidge: Yes, it's very important because as well as talking about how successful the treatment is, you need to talk about the journey that they go through and the kind of short term complications that they can experience, things like infections, thrombosis, bleeding, the kind of things which are temporary, but also then the longer lasting things which you are sort of stuck with as a functional change to how the pelvic organs work. And then you've got to try and help patients to tease out what's important to them overall. It's really complicated discussion, but I think if you spend enough time breaking it down into these individual components and saying, you know, this is the journey with this domain over these three different types of treatment and you just work your way through it, patients can clearly look like a rabbit in the headlights, completely bamboozled by the information. But after a while when they've had a chance to digest it and you supplement that with some reading materials, eventually people, I guess, work out which kind of treatment suits them best. And I guess you can distil it down to a bit of a trade off between those who understand the uncertainty of focal therapy in the long run, because we are obviously leaving some tissue behind and sometimes that's tissue which we know will have some low-grade cancer that needs monitoring. And so when they choose focal therapy, they understand that there's a risk of repeated treatment being needed for that and also about treatment failure in the area that's been treated itself and requiring a repeated ablation or maybe surgery. And so they trade that off with the short term, very obvious advantages in improved continence and urinary function and sexual function. And so there'll be those men who feel that they prefer the earlier recovery and a treatment which seems to be very good and durable with some degree of confidence, but not absolute certainty. But there'll be other people who prefer, if you like, the sense that there's a body of opinion that feels that surgery and radiotherapy are more tried and tested and have established long term outcomes. And they feel that they'll accept shorter term disadvantages because they feel that the cancer will get the best treatment possible in terms of eradication of the cancer. And there's a group in between who can't resolve, I can't resolve that difference. And at the moment, we're trying to randomise into the CHRONOS A study to help to resolve this uncertainty. And for those people who, like me, feel that how can you make this difficult choice between a treatment which may be better or maybe it's the

same and a treatment which has lower side effects in the short term? So I'm really enthusiastic about this CHRONOS A study.

Clare Delmar: Tim, thank you so much for speaking. Good to speak to you.

Clare Delmar: Further information on Tim Dudderidge is on our website, along with a transcript of this interview and additional interviews and stories about living with prostate cancer.

Nobody Should Die of This: Elvin Box Calling For Change and earlier detection

Elvin Box, a popular and passionate advocate for men with prostate cancer joins OnFocus to discuss learnings from his experience and how he's taking these forward to improve the experience of others.

Diagnosed in 2016, Elvin is a Movember UK ambassador and has written and campaigned extensively on a number of issues impacting men and their families as they experience a diagnosis of prostate cancer and navigate treatment options. See recent publications from Elvin here: <https://metro.co.uk/2020/02/29/kept-cancer-diagnosis-secret-12316187/?ito=article.desktop.share.top.link> <https://www.jodivine.com/blogs/perspectives/winning-back-our-sex-life-after-prostate-cancer-a-personal-story-by-elvin-box> Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

A passionate advocate for men with prostate cancer

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a number of challenges and opportunities. Joining me today is Elvin Box, a popular and passionate advocate for men with prostate cancer.

Diagnosed in 2016, Elvin is a Movember UK ambassador and has written and campaigned extensively on a number of issues impacting men and their families as they experience a diagnosis of prostate cancer and navigate treatment options. So let's jump right in, because I'm sure some of our listeners are wondering, what does it mean to be a passionate advocate?

Diagnosis was completed at the end of June in 2016, it was quite long and fraught, which I try to get across to people when I do talks, is that they kicked off in February. And every two years I was going for my health check with my private health insurer and I was instructed to go and see my GP. I didn't read the report and when I got to see the GP, I thought, we're going to talk about something else, because I had quite a bit high blood pressure. So no, no, no, no, no, for the second time in two years, your PSA, which we all know is, of course, the only blood test you can have for prostate cancer and it's elevated again. And so off I went to see a urologist because I was in private medical health very, very quickly after going through an MRI scan and then actually a brilliant biopsy with the same chap, very sadly, it is cancer. But please hurry up, because I don't think it's going to stay within your prostate much longer. You can either go and see the lovely people at Romford, go for a three year radiotherapy programme. And obviously, as my wife said, you will be chemically castrated because you have to reduce testosterone levels. Or go see the lovely people at The Princess Grace, and have a robotic prostatectomy, a radical prostatectomy that's complete.

Clare Delmar: OK, OK.

Elvin Box: We decided about two weeks before I had an opportunity to go for the operation, to do that. You've written extensively about a number of things going forward that, that you learnt from your own experience that you'd like to share. And one of them was your recovery and what you learnt, what surprised you, what you expected and what was most impactful to you and your partner? So that meant there was going to be a lot of wee around and it would mean there'd be a bit of a fight to get your erections back. Well, my Jude, you know, she scoured the web for information because I didn't want to look, quite honestly. I mean, I've often said to people, you know, when they're looking online, as they're often referred to do, it's not like you're in the frame of mind where you're looking for a holiday or buying a new car. I mean, you're in a very different emotional state and to receive this information, aren't you? I'll let you know what Jude thought was brilliantly funny was that my testicles felt like coconuts, about the same sort of texture, everything. I mean, one of the things about talking to you is that, you know, you speak and you've written so, so generously and openly and extremely honestly about a number of these topics that have emerged from your own experience with prostate cancer and that includes mental health that you're touching on and sexual relationships. So what message are you trying to communicate to other men in your role as ambassador for Movember? And as Jude said, you've got to tell them that you are not an archetypical prostate cancer survivor. But sadly, I have other stories to tell now of Peter Cuthbert, a wonderful guy, had exactly the same operation as me. And so I tell people now that sadly after an eight year fight, Peter sadly passed of prostate cancer. Rob phoned me up from his hospital bed and he said, I'm in Kingston hospital, I've been diagnosed with prostate cancer. You've actually got an erosion of your bone in the back of your knee because that's where the prostate cancer is now attacking you. And of course, your own, what aspects of prostate cancer diagnostics and treatment in the UK obviously, do you see as particularly urgent for attention from government or the medical

community? And number one, I don't want any more argument about who should and who shouldn't and when, if you can have one, have a PSA. Wherever I can, I let people know is to you as a person with a prostate, as we now say, you should be allowed to have without any shadow of a doubt a PSA from the age of 50. I believe and also I mean, I've got on really, really good authority is that, listen, it could take ten years the tumour in a prostate, can take ten years to actually evolve and actually get aggressive. And the second thing is that I say to guys and anybody who will listen to me now is that once that's been had, you must if there's any concern, give the guy or the person with the prostate, give them an MRI scan. Another great mate, Peter Coca, great guy, he got in contact with me a year after, a year after I'd had my operation and we went through it and said, did they give you a scan? Clare Delmar: Do you find that men are really very receptive to this because they wouldn't be told otherwise? Clare Delmar: Yeah Elvin Box: One of the things I was getting upset with is that when the medical profession were talking to me, even though I like to think I'm an intelligent bloke, I've got a master's degree. I had to come out with Jude and say, did that mean, for instance, does that mean you can't get an erection? Clare Delmar: Yeah Elvin Box: I don't really want to be listening to this and you're struggling all the time. You must take your partner or one of your partners, someone you love, or loves you, because you're not going to hear this. Elvin Box: So I said, you got to have that and unfortunately he had one of these TRUS biopsies. You know, all they give you is a local anaesthetic and Peter said it was an absolute damn agony. Clare Delmar: Yeah Elvin Box: Well I'm not happy with that, Peter, because when you get a scan, they're going to be actually knowing where there is potentially tumour. And then I said, whatever happens, make sure they give you a scan, so if they in any way believe it might be out of your prostate, you've got to have another scan to make sure it hasn't gone to your bones. I mean, what you're saying is that, to be honest, is often seen as the standard of care here. But you're also saying is that it isn't actually offered, you know, across the board to everyone in every place. So how are you integrating these issues, like the MRI, like the transperineal biopsy, like the sexual health issues, like bringing your partner? Elvin Box: What I'm trying to do and it's going to do more of it now it's getting to the second part of this year. I'm absolutely determined through wonderful people like you Clare giving me the oxygen of publicity in any way, shape or form. So and I get a good support from Movember because they know I'll speak wholeheartedly about the situation. And that's what I'm going to ask from the experts, because I'm absolutely adamant that nobody should damn well die of this, you know, I'm at lengths to people to say, I want you to understand that, yes, for God's sake, please don't tell me I'm lucky to be alive. And that's why I want to make sure that nobody dies of a tumour inside a gland that's not much bigger than a golf ball. All I'm asking for to give somebody, number one, they've got to have a PSA test at forty, forty, and then allow them one every year for crying out loud and remind them. And you think it's.. You give them an MRI scan and you make sure that you give them a transperineal. And you make sure that nobody ever, ever, ever does open surgery again as of tomorrow, you dare do open surgery on a person with prostate cancer because you have no chance of saving the nerves that give that person with the prostate an erection again, they're flawed, that's it. Clare Delmar: Well, you're hitting the right issues and it's people like you that have to really cut through because as you say, men are often too afraid or too traumatised initially to even ask. I mean, I think we'll have to do another one of these conversations, because I know you've got a lot to say. I want to thank you so much for speaking with me, because it's always such a pleasure to talk to you. Further information on Elvin and links to his work with Movember UK is on our website, along with the transcript of this interview and additional interviews and stories about men who are living with prostate cancer. Prostate Cancer Side Effects, Incontinence, Impotence, Depression In the many interviews and conversations we've had with our patients over the last year, few, if any, have concluded without mention of one or more of the "Big Three" side effects that accompany a prostate diagnosis and some forms of treatment – incontinence, sexual function and mental health. We talk about these all the time with patients because they are integral to choosing optimal treatment and they underpin a thorough investigation of suitability for Focal Therapy. It's always sobering to speak with men who haven't been meaningfully informed about side effects who, once they overcome their initial embarrassment, are overwhelmingly relieved to talk about how these side effects will impact them and their lives. One of our blogs last year described the "whole man" approach our doctors adopt when engaging patients - referring to the multiple aspects of a man's health and lifestyle that come into play when he undergoes any form of treatment, and which taken together are crucial for any chosen treatment to be successful. Broadly, these can be categorised as physical, mental, and behavioural. We continue to interrogate and engage patients, campaigners and Health Care Professionals on these issues to refresh and reinforce our holistic approach to patient care. Patients like Perry Letcher and Mark Stubbs speak openly and honestly about their experiences with the Big Three,

while campaigners Elvin Box and Tony Collier advocate on behalf of patients and their families with charities and government organisations. Health Care Professionals Asanga Fernando and Lorraine Grover are dedicated to supporting patients in their mental and sexual health, respectively. Both advocate for better integration of support into the diagnostic and treatment pathway. These sources of dedicated support are important, because prostate cancer and its treatment will impact mental, sexual and urinary health, and we want to support men in making decisions fully informed on what these side effects are the likelihood of experiencing them. It's not only the information itself but how it's presented that cuts through to patients, and for that reason we inform on side effects through interviews, videos, and regular blogs as well as medical studies and reviews.

IncontinenceSex is a major issue for men living with prostate cancer but incontinence is an even greater issue. Some days I think I was lucky to be stage 4 at dx as I'm certain I wouldn't have coped with incontinence at all. There are many men whose lives have been ruined by it" says prostate cancer campaigner Tony Collier. A recently published study of 1600+ men diagnosed with localised prostate cancer over a 10 and 15-year period reported that "urinary incontinence was particularly prevalent and persistent for men who underwent surgery, and an increase in urinary bother was reported in the group receiving androgen deprivation therapy from 10 to 15 years" Incontinence often causes more embarrassment and worry than other side effects – and unlike women who find it annoying but a common part of life especially after childbirth, men have a harder time with incontinence, partly because together with sexual dysfunction it feels like an assault on their manhood. A persistent lack of public toilets adds to the problem although, counterintuitively, also provides a platform to campaign for change and speak about the problem openly.

2. Sexual function and health

Evidence abounds on the sexual impacts of prostate cancer treatments, and it's often grim for men undergoing radical procedures: The most recent National Prostate Cancer Audit published earlier this year reported that "following radical prostatectomy, the mean sexual function score was generally poor at 24 on a scale of 0-100, an improvement of 1 point compared with the previous round of reporting in 2018" And "following radical radiotherapy, the average sexual function score was generally poor at 18 on a scale of 0-100, an improvement in 1 point compared with 2018" And another review of UK men concluded "There is an urgent need to ensure that all men are offered, and have equal access to, sexual care support, with referral to specialist services when required" Fortunately there are sources of sexual health support for men and their partners. Sam Evans and Lorraine Grover offer different approaches to engaging men around their sexual health and have lots of experience working with men undergoing prostate cancer treatment.

3. Mental Health

Compromised Mental health is perhaps the least talked about side effect of a prostate cancer diagnosis and often works inversely in its severity to that of incontinence and sexual function. For example, men under Active Surveillance will endure fewer challenges to their urinary and sexual health than they will with more radical treatments, but often suffer greater challenges to their mental health. A recent BMJ review of depression and anxiety in prostate cancer patients reported "Our findings suggest that the prevalence of depression and anxiety in men with prostate cancer, across the treatment spectrum, is relatively high. In light of the growing emphasis placed on cancer survivorship, we consider that further research within this area is warranted to ensure that psychological distress in patients with prostate cancer is not underdiagnosed and undertreated"

Oncological psychiatrist Asanga Fernando of St George's Hospital London is on a mission to change this. Writing in his recent study on the need to integrate mental health support with cancer care he points out that "Surgical, radio-oncological, and medical anti-cancer therapies have developed at pace and scale in recent years, yet there remains a huge unmet need for mental health in cancer care." He concludes with a call to action as a clinical community we need to drive a shift in culture towards measurement of patient quality of life as a marker of treatment effectiveness. Anyone diagnosed with prostate cancer is likely to experience one or more of the Big Three, to a varying degree. They need to know about it - and feel confident talking about it with their doctor and partner. The combination of their understanding of the condition and how they feel about it will underpin treatment choice, recovery and quality of life afterwards. The good news is that there are variety of people and resources available to help in both understanding and processing feelings about the Big Three. As always, talk to us about how you're experiencing the prospect or reality of the Big Three.

Psychosexual Specialist Lorraine Grover on Sexuality after Radical Prostate Treatment

How can people with prostate cancer be supported in their sexual identity and relationships? Lorraine Grover, a Psychosexual Nurse Specialist, joins OnFocus to discuss how a prostate cancer diagnosis and treatment impacts sexual identity and sexual relationships. For over 25 years Lorraine has been a passionate driver in helping to improve the way sexuality and sexual function is managed within healthcare. She has expertise in managing male sexual dysfunction and has a special interest in caring for patients diagnosed with

prostate cancer (and whenever possible their partners). Sexual difficulties can have both psychological and organic causes and she is able to consider both aspects of management. Learn more about Lorraine Grover here: [Lorraine Grover Info](#) Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood, often avoided and even ignored. Joining me today is Lorraine Grover, a psychosexual nurse specialist who for over twenty five years has been a passionate driver in helping to improve the way sexuality and sexual function is managed within health care. She has expertise in managing male sexual dysfunction and has a special interest in caring for patients diagnosed with prostate cancer and whenever possible, their partners. Sexual difficulties can have both psychological and organic causes, and she is able to consider both aspects of management. Lorraine has a diploma in psychosexual therapy and for several years worked in the NHS, providing nurse led erectile dysfunction clinics at St George's Hospital, London and Wickham Hospital, Buckinghamshire. She now provides a private consultation service to help men and women overcome difficulties with sexuality and sexual function, which she argues is too often an underestimated area of health care. Lorraine, welcome and thank you so much for joining me today.

Lorraine Grover: Thank you, Clare. This is, I think, a very exciting partnership because I know and we've talked about this prior to this interview, how much our patients and their partners care about this. But I'm really excited just to sort of start this conversation with a few questions that I think would get people really thinking and really interested in pursuing further. So I'm just going to pick up on what I mentioned about our patients, what they tell us, and just to make an observation that preserving sexual function is something that our patients, almost all of them care a lot about and voice to us. In fact, I would say it's probably at the top of their concerns, second only to preserving life itself. What's happening here?

Lorraine Grover: Well, sadly, I think that is often the case, actually. I feel a lot of men have said to me over the years that they would rather be sexually potent, whatever that definition is to them and alive, being sexually active, than not being sexually active and having their cancer cured because of the effect of the treatments of managing prostate cancer, which is so sad to hear when actually if the subject was raised with them, they would know that there are lots of things to be considering about sexuality and prostate cancer. But what's so reassuring is the patients telling you and you reaching out to bring about change for them too. I'm really pleased patients are being proactive in raising their voice because that's how hopefully we will bring about some change.

Clare Delmar: Indeed, but I would say when you say they're raising their voice, which they are, absolutely they are. I would just simply qualify that by saying it's because we're asking them.

Lorraine Grover: Yeah, yeah. And I'm always banging that drum to health care professionals when I lecture, when I talk to them that we need to bring this subject up very early on in the patient's pathway. Right at the point I think of diagnosis.

Clare Delmar: I mean, do you see any variation in your experience like anything that you could even categorise like some practitioners are better than others, some locations are better than others?

Lorraine Grover: Yeah, definitely.

Clare Delmar: How would you describe that variation?

Lorraine Grover: It's been very much the surgical patient, the man having the radical prostatectomy historically will have some discussion about it's going to impact on your sex life and it can be as simple as that. And so I tend to have seen more patients over my 20 odd years from the surgical background. And sadly, within focal therapy, there are very few patients that I have seen over the years. I'm as interested to know from them when I do what their experience has been because I'm learning all the time. Understanding the methodology about the treatments for prostate cancer and the impact on sexuality, this is important for us to know in health care as a professional as well as the patient. So I would say top of the league at the moment tends to be more the surgeons, but it can be quite matter-of-fact and doesn't really look at emotion and sexual wellbeing, it will be about functional outcomes.

Clare Delmar: Yeah. Again, looking at the NHS, where you've been a practitioner for many years and you've spoken openly about the impact that prostate cancer has on sexual function, mental health and most importantly, sexual relationships. What's been the reaction to your approach?

Lorraine Grover: Some health care practitioners have welcomed my thoughts with open arms and embraced me and others have been very against me, I feel, which I think is really sad. I think that can be a bit of a power struggle for some people, and it's almost seen as letting go of patients, of their patients and actually no one owns a patient. But patients automatically got to see me in my clinic at St Georges when they were going to be having treatment for their prostate cancer. And in fact, I even saw patients with erectile dysfunction from a GP point of view, they saw me. And I naively thought that, OK, when I ended up leaving the NHS, which was actually family reasons caring for my elderly parents who were ill, and I

just naively thought that in the private sector these patients would be welcomed with open arms to have their sexuality addressed and I'd be part of a team, which is what I love doing. I think practitioners are very individual and I like nothing better than being part of the team, because prostate cancer management is being part of the team. The focal therapy, you know, as we've talked about the imaging, the position, all that's being done, what management plan the patient's going to have, what impact the partner has. There are different aspects that our professional accountability allows us to provide and we should be sharing that and enhancing patient care moving forward. Clare Delmar: Indeed, I think that's absolutely right. And as I said to you before, I mean, one of the things that we've seen with focal therapy patients is the very nature of the treatment invites these conversations with patients. Lorraine Grover: Yes. Clare Delmar: So it's not a question of either or. It's a question of, you know, this is a treatment that has these benefits and these potential risks. And one of the benefits is the preservation or the reduced risk of any compromising on your sexual function or your sexual relationships. One of the things that I'm aware of and we've talked a little bit about is how many of the people who approach us well, in our case, about focal therapy, but I know in your case about sexuality and sexual relationships are actually women and the partners of men with a prostate cancer diagnosis who are searching for a treatment that won't compromise their sex life. And I often think these women are the forgotten protagonists in their partner's prostate cancer story. How have you been able to help them? Lorraine Grover: Well, I mean, just giving the partner now, you said women, I appreciate that in heterosexual relationships, it will be a female partner. But I think same sex couples, the LGBTQI community, people need a safe environment to be able to talk about their sex lives and to be able to have that discussed with the health care professional. And so, as you've mentioned women, I will follow that through that women having the opportunity to talk to somebody about the impact of prostate cancer has had on the man in their life's personality, their health, their fear, that opens up all sorts. It could be, I'm seeing a patient in their 50s where their partner may be in the menopause or premenopausal or has had her own ill health, has never had an opportunity to talk about sex with anybody. And I'm part of that team, hopefully, and I address it and they go, wow, I've never had this opportunity to talk about things. So with women, I'll be talking about arousal, desire, lubrication, what helps them to reach orgasm. So a lot can be done for the partner. Clare Delmar: And do you see that, I mean, just picking up on your point that in many couples have done things in your words, you know, in a certain way for a very long time. So do you think that this actually opens up new opportunities for them as a couple? Lorraine Grover: Yes. Clare Delmar: For their own sex life? Lorraine Grover: 100 percent. I've had couples go since I've had my prostate cancer diagnosis, I've now got a better sex life. I've had people say I've still got an active sex life since my prostate cancer treatment diagnosis 10 years ago because we've changed things. I probably would have just thought sex has gone off our radar as we got older, if I hadn't had access to know about this information. I always said to people, this is a recovery and discovery area for you, both of you, I need to find out what their needs are. We're not always on about things like vaginal penetration, getting a stiff erection, but rekindling intimacy for a lot of couples is something that is really liked. And it makes that journey for the individual with prostate cancer to feel the caring, the loving and open up these opportunities of discussion. So it's certainly not all bad news and the partner must be brought into the consultations if it's wanted, some don't. Clare Delmar: Really encouraging to hear that. So what would you like to see changed in the way men are offered treatment for prostate cancer, given what we've just been talking about? And how do you think this crucially important aspect of their lives and their identities can be better addressed? Lorraine Grover: Well, I think often sex is the third thing discussed. That cancer diagnosis occurs, and you've got to look at the continence and the sexual side of things together. And I strongly believe that going forward, that a sex therapist, whether it's from a background of nursing or it is a sex therapist, is part of a multidisciplinary team and that enables professional accountability, allows the language. I, as a clinical specialist in erectile dysfunction, years ago was running this erectile dysfunction clinic. So I hope that going forward, things like what we're doing today will make people think and think about their own practise and think about how they can improve care for patients. And don't be fearful of sharing the patient, whether it's in the NHS or in the private sector, with other members that can really improve the journey for that man with prostate cancer or that person, because we've got trans people as well, obviously with prostates. It's really important for patients' mental health, for their relationship, for their own sexual being. It changes in our lives with all sorts of things that make that change. Clare Delmar: Lorraine, that's all we have time for right now. And I know that so many of our listeners will be really, really encouraged and inspired by what you've had to say. So thank you very much. Lorraine Grover: You're very welcome. Clare Delmar: Further information on Lorraine Grover and her practise is on our website, along with the transcript of this interview and

additional interviews and stories about living with prostate cancer. Men with Prostate Cancer are keen to maintain their sexual function, are their doctors listening? From our conversations with almost 1,000 men who have approached the Focal Therapy Clinic about prostate cancer treatment, we know that many, if not most of them consider the preservation of their sexual function, sexual identity and sexual relationships second only to the preservation of life itself in considering their treatment options. They also tell us that, despite its importance to them, the impact of prostate cancer and treatment on their sex life is usually discussed from a purely functional perspective – and sometimes not at all. Most welcome a conversation about what to expect in terms of all aspects of their sex life, so that they can understand, share with their partner, and make a treatment decision they won't regret. Why is this, and how can we help these men? Evidence abounds on the sexual impacts of prostate cancer treatments, and it's often grim for men undergoing radical procedures: The most recent National Prostate Cancer Audit published earlier this year reported that: "following radical prostatectomy, the mean sexual function score was generally poor at 24 on a scale of 0-100, an improvement of 1 point compared with the previous round of reporting in 2018" And: "following radical radiotherapy, the average sexual function score was generally poor at 18 on a scale of 0-100, an improvement in 1 point compared with 2018" One doesn't need much more evidence than this to understand how these treatments will potentially impact his life, but it can be hard to take in when a man and his partner are under stress or when they have questions about how to manage these possibilities and don't know where to find answers. Prostate cancer charities provide some support. Prostate Cancer UK provides a range of resources to help men and their partners answer questions on the impact of their diagnosis and treatment on sex and relationships. Tackle Prostate Cancer also addresses issues around sexual function and discusses how to seek psychological and sexual counselling. We've gotten to know two individuals who are dedicated to advocating for and supporting men going through prostate cancer treatment on their sexual needs and concerns. Lorraine Grover is a nurse with over 35 years experience working with urologists and urology patients. She qualified as a sex therapist in 2003, and has helped many men and their partners discuss and understand what is happening or likely to happen with a prostate cancer diagnosis. A lot of men have said to me over the years that they would rather be sexually potent, whatever that definition is to them and alive, being sexually active, than not being sexually active and having their cancer cured because of the effect of the treatments of managing prostate cancer, which is so sad to hear when actually if the subject was raised with them, they would know that there are lots of things to be considering about sexuality and prostate cancer", she says, and adds, "I think we've still got a long way forward. She feels strongly that men are too often counselled around sexual function and not sexual relationships: "It's been very much the surgical patient, the man having the radical prostatectomy historically will have some discussion about it's going to impact on your sex life and it can be as simple as that." Lorraine emphasises the importance of involving sexual partners in these discussions: It's crucial for women to have the opportunity to talk to somebody about the impact of prostate cancer has had on the man in their life's personality, their health, their fear, that opens up all sorts. It could be, I'm seeing a patient in their 50s where their partner may be in the menopause or premenopausal or has had her own ill health, has never had an opportunity to talk about sex with anybody. And I'm part of that team, hopefully, and I address it and they go, wow, I've never had this opportunity to talk about things." Lorraine feels these discussions can have very positive impacts on a couple's sexual relationship and often improve it: I've had couples go since I've had my prostate cancer diagnosis, I've now got a better sex life. I've had people say I've still got an active sex life since my diagnosis 10 years ago because we've changed things. I probably would have just thought sex has gone off our radar as we got older, if I hadn't have had access to know about this information. She's in the business of promoting sexual health and pleasure through toys and products, many aimed at cancer patients. Her blog series addresses the needs and experiences of cancer patients in a refreshingly direct and honest way, and she provides much-needed support to men and their partners through a wide network on social media. What is so encouraging about Lorraine and Sam is their positivity and proactive approach to supporting men in their sexual life while diagnosed with prostate cancer. All have a deep understanding of the problems and challenges these men face, but also have constructed approaches to not only preserving sex as is but to making it better. All are active campaigners on social media and producers of content to share with men and their partners. Lorraine Grover is at @lekgrover Sam Evans is at @SamTalksSex If you'd like to talk to us and learn more, please get in touch. Prostate Cancer Advocate Tony Collier on Positivity and Motivation Through Exercise Tony Collier, ambassador, awareness speaker and fundraiser for Prostate Cancer UK, joins OnFocus to to share his views on exercise for men with a prostate cancer diagnosis, borne out of his

personal experience as a dedicated runner and that of his many supporters and followers on social media. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. The mental and physical benefits for men with prostate cancer Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often avoided or even ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Tony Collier, ambassador and awareness speaker and fundraiser for Prostate Cancer UK. Tony is a dedicated runner and a passionate believer in the transformative benefits of physical exercise. He's here to share his views on exercise for men with a prostate cancer diagnosis born out of his personal experience and that of his many supporters and followers on social media. Clare Delmar: Well, not so much where I am, but I know we both had our morning runs and we see each other on Twitter to compare notes on our respective daily runs. Clare Delmar: So you have been incredibly motivational for lots of people and you're also a master on social media. And I wanted to just tap into that today and get you to share some of your insights, both that you've gained from yourself and from your experience with all the people you know. And I think we just start off by commenting on your running, because that seems to be your main form of exercise. When I was forty five, I had a medical from my company and it turned out that they said I was borderline clinically obese and my blood pressure was so high that I'd be on drugs the rest of my life if I didn't do something about it naturally. And the gym where I played a bit of social squash had a very informal running club and I decided to join them. And then two years later, we became a properly affiliated running club and a love of running was born. Tony Collier: It was in Amsterdam in 2007 and Amsterdam has become a place that's very much part of our life because my brother-in-law lives there and I've actually since run the marathon again before my diagnosis and then before I think back in 2019, my entire running club went over to take part in the Amsterdam marathon festival, but I just ran the 8k because marathons are a bit of a challenge nowadays, but absolutely adored running and really became quite proficient at it and got down to a PB for the marathon of 3:23. Tony Collier: Which I set when I was about fifty four and I was still running competitively. So how has your experience with prostate cancer affected your attitude if not so much your performance but your attitude towards fitness and running? And the oncologist said, yeah, you'll be able to run, but you'll be a lot slower, because hormone therapy is going to cause you to slow down and you won't be able to run as far because of issues with bone density. I sort of lost the plot a bit because from being one of the faster runners at the running club to suddenly being one of the slower runners through no fault of my own, I found really difficult. But you know some people would be really happy with twenty six so I don't complain too much. My friends in the running club, who I would consider it to be comparators, the benchmark and I see what times they're doing and I'm thinking I should be faster than that. But I can't, and hey ho, I think the most important thing from my viewpoint was staying involved with the running club, staying involved with running. But actually, I think the most important part was that running was really good for my mental and physical well-being. Like this morning, this incredible runner's high because you're running great, the skies are blue, the sun shining. And you can't ask for anything more in your life and then another day you go out and try and do a run and it's just a complete miserable failure. I've reached the point where the failures stop mattering anymore and you live for the good runs. Clare Delmar: I mean, the other thing about running as a form of exercise, of course, is that it's been the least, if at all, affected by lockdowns. Tony Collier: I think the most amazing thing that we've noticed during lockdown and this is something that my running club wants to capitalise on, is the fact that there are so many more people out running than ever before. Clare Delmar: So, I mean, your work as an advocate for men with prostate cancer has connected you with hundreds, I mean, correct me, maybe it's thousands of people affected by and living with this disease. So what are you hearing from them about exercise and what messages do you want to send to them? Tony Collier: I think if we just sort of park the prostate cancer a little and just think about cancer in general. There is a whole conversation happening now with health care professionals about the benefits of exercise with people living with and beyond cancer. It's very clear that some people were massively unfit before they had their cancer diagnosis, and that limits what they can do post cancer diagnosis. Now, not everyone... Last year I climbed Ben Nevis, since my diagnosis I've run the London Marathon. And this year I'm taking on a 100 km ultramarathon, which I'm going to do as a walk with a little bit of running. And I think that's a really important thing that people need to get in the mind, that, you know, not everybody can climb a mountain, not everybody can run a marathon, but everybody can do some form of exercise. And I think the most important thing is get the heart rate elevated, even if it's just literally sit to stand from a

chair, do that 20 times and see if it elevates your heart rate. And I really try to encourage people to do something that works for them and to look for areas where they can get support. And I've been really blessed to become a patient representative Prehab for Cancer in Greater Manchester. Tony Collier: Prehab was originally an initiative set up in 2019 and the idea was for three particular tumour groups - they didn't go for the big tumour groups for obvious reasons, it was only a pilot scheme. Immediately somebody gets a diagnosis of cancer, they go into a prehab programme to get them fitter for surgery, and then when they come out of surgery, they go into the sort of post op phase and then they go into rehab. And what we were trying to do was trying to prove that basically, even with only a six week window between diagnosis and surgery, you can make a massive difference to people's fitness levels. Tony Collier: The idea basically is that people see it as part of their treatment plan and it's not compulsory. They have specialist cancer rehab trained personal trainers in all leisure trusts in Greater Manchester. Myself and one of the other patient reps did some focus groups for the patients who had been through the programme. And I remember vividly one 72 year old guy, he said, I've never been in a flipping gym before in my life, he said, but I can't see me ever not going to the gym. So what the guys do is either an incremental shuttle test or a six minute walking test to assess people's baseline fitness. And then over the six week period prior to surgery, they basically do a programme that's specifically designed for that individual that fits in with what they're capable of. And what we've seen is the baseline level is increased significantly preop, and obviously when they come out of surgery, they drop back down below baseline, but then go into rehab once they recover from surgery. And what we're finding is their recovery is much quicker and they get back above the pre surgery levels very quickly. Tony Collier: The most amazing outcome of this, of course, is that patients are getting out of hospital more quickly, which is wonderful for the NHS. And that's actually part of what we're trying to prove to the NHS commissioners, that this really works, it's saving money. Clare Delmar: I mean, it's almost a form of social prescribing as it would seem to fit into that agenda, perhaps. And I think one of the patients said to me, you know, I was out of bed inside of four days, he said, and I was told would probably be 10 days. And the other people around me who hadn't been through the programme were still in bed when I left. And what evidence of links between exercise and prostate cancer specifically motivates you? I mean, obviously, what you're telling me is one area, but is there anything else that that you can cite that is particularly motivating? Tony Collier: Well, I think exercise is obviously really important for prostate cancer, particularly for men who are having prostatectomies, because obviously pelvic floor exercises before surgery are really, really important so that people gain continence more quickly. I think the biggest thing that motivates me to sort of encourage people living with and beyond prostate cancer is about mental wellbeing as much as physical wellbeing. I think it's just amazing to get out into the fresh air and just get the heart rate elevated, even if it's just a fast walk. And that's the message I really try to get across to people who are living with and beyond prostate cancer. I was given a worst case prognosis of two years, and I exercise like I do because I think it will extend my prognosis. I mean, we touched on this a few minutes ago, but the past year has presented so many challenges to engaging in exercise, both obviously on an organised level, but even as individuals and for those who can't go out and take a run or for some reason find that difficult, it's really important that you have a set of other, whether they're chair based, or other. Tony Collier: It's really interesting because at the first lockdown, I literally had a real sort of mental meltdown because life was just put on hold. And I had lost my running mojo, and my wife said to me, at the sort of end of April, why don't you try to run 5k every day in May? So at the moment I'm up to day 306 or something like that of actually running or hiking every single day since 1st May, some days I've done both. I mean, I noticed that because it is Strava that you use where you share you're running and hiking routes? But I think the other aspect of lockdown that's been really difficult is I'm one of the two coaches at our running club and the other one is now living in Lanzarote. So I basically took up the cudgels of dealing with all the issues as far as covid was concerned for the club, and I became our covid compliance officer. That has presented lots of challenges because the club is actually split between two particular areas in South Manchester, partly in Trafford and partly which is Greater Manchester, and partly in Cheshire East. And that for me, was a massive organisational problem that I had to deal with as the covid compliance officer within the club and the coach. And I'm really proud that we were the first club locally to get back running as a group and we carried on running as a group until this lockdown. Our next club run is the Tuesday and we are going to go for it and then we'll be back running together in a covid compliant way to start off with, that means small groups. Tony Collier: It means away from other people, but we will be back running as a group, and I do think running as a group is incredibly motivational. But well, I will look forward to seeing your Strava updates and maybe I'll be joining you on Strava and sharing my probably rather pathetic runs

compared to yours. And thank you so much for coming along and sharing your incredibly motivational running tips and exercise tips.

Clare Delmar: A transcript of this interview is available on our website, where you can also access additional interviews and stories from men living with prostate cancer.

Dr Asanga Fernando : Prostate Cancer Patients need access to Mental Health Support

Dr Asanga Fernando, Consultant Cancer Liaison Psychiatrist and Clinical Director of the Advanced Patient Simulation and Clinical Skills Centre at St George's University Hospitals NHS Trust, London, joins OnFocus to discuss his work on integrating mental health support with prostate cancer care. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Towards a more holistic approach to patient's wellbeing

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and not often talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. I'm Clare Delmar, joining me today is Dr Asanga Fernando, consultant cancer liaison psychiatrist and clinical director of the Advanced Patient Simulation and Clinical Skill Centre at St. George's University Hospital, NHS Trust London. Dr Fernando is also an honorary researcher at King's College London and has published his work on integrating mental health support with prostate cancer care, which is what we're going to discuss today. And I know a lot of our prospective patients and their families are going to be really interested to hear what you have to say. So I think I might just jump right in and ask you what you see as the most common mental health challenges that are faced by men with prostate cancer. Well, I think there are several I think the biggest across not just prostate cancer, but cancers as a whole is depression, really. And when you look specifically, I think a really damning statistic of our time is that 73 percent of cancer patients diagnosed with depression, and this is across tumour types in the UK a few years ago, don't receive any adequate evidence-based treatment for their depression. Cancers across the board, about 17 percent of cancer patients suffer with depression at some point during their cancer journey. We know it's increased slightly pre-treatment, dips a bit during treatment and increases again after treatment. And we know that, again, anxiety, there's a huge number of prostate cancer patients with anxiety. And again, we see there's heightened levels of anxiety, pre-treatment, dips during treatment and picks up again after treatment. But I think depression and anxiety are key, key challenges facing the prostate cancer community, but not just those. I mean, if I may say, when you think about prostate cancer, it's actually a journey that embarks on several potential treatment modalities, including surgery, radiotherapy, androgen deprivation therapy and chemotherapy. And actually, if you take each one of these treatments, actually, they can all have mental health and psychological impacts. I mean, if you take something like radiotherapy, some studies show that six months post radiotherapy, potentially one in 20 people could suffer from severe depression, up to 16 percent severe anxiety. We know that actually with ADT, there's a good degree of cognitive impairment with some agents. Now, of course, that's a lot less with more modern agents, but we know that there's a huge array of different mental health challenges. So it's not just the diagnosis of prostate cancer, but the different treatments that also are likely to sort of make this a challenge. And also, I mean, if you add to the mix the fact that we're in a pandemic as well, I think that's also something to be aware of. And my final point, I guess, in terms of the main challenges facing the mental health of prostate cancer patients is it's all well and good sort of thinking about mental health, but we've got to overcome this sort of barrier of looking at mental health separately. So it's all about the patient and actually whether a patient is depressed, anxious or whatever. The key thing with all of this is there's a marked change to a patient's level of functioning, so what they were like before. And actually I think as a clinical community, I think, we need to sort of think about how we can sort of better map onto those changes in functioning due to a number of different reasons, if that makes sense. I just wanted to pick up on your list of treatments and the various levels of both depression and anxiety that you cite. Is there a reason for that or do you have a few thoughts about the mental health challenges facing men undergoing that regime?

Asanga Fernando: We know that active surveillance has its own sort of mental health morbidity in terms of anxiety and things like that. And I guess the reality is, though, in terms of the sort of the published literature and things like that, there's a relative paucity of information around that. The bottom line is with prostate cancer, depression is the number one take home message and thinking about the different aspects of treatment and how we can better optimise management of psychological health during that cancer journey, if you like.

Clare Delmar: Which leads me to my next question, which is how are these being addressed and managed within the clinical community or are they at all? So, I think, the reality is they are being addressed, but the clinical community has been rather sort of myopic about this and rather slow to address these

things, so good that psychological support now sort of exists at most sort of cancer centres up and down the country. But, you know, I'm going to make the argument that we need a bit more, we need a bit more specialist sort of mental health support specifically. I'm very lucky to work in a team with psychologists and counsellors, but certainly there are specific needs. If there's a specific group of patients with specific challenges that need psychiatric help. We need to make the argument that we need more specialist mental health support, but also that we need to think more about functioning and the sort of other side of things. So psychosexual support certainly, the impact on relationships, looking at finances, all of these things. And I think crucially as a community, one of those sort of bugbears is that the mental health impact shouldn't be seen as an added luxury, and it kind of is. But the fact that we as a clinical community have sort of only recently seriously begun to think about the mental health impact over the last 10 or 20 years, I mean, 10 years really, and begin to see that. But the reality is we still face this inequality where the mental health aspects of things are not seen as important. And I think the reality is, though, clinicians are having to recognise that there's a change with that because, of course, their patients tell them. Their patients tell them that they've had changes to their functioning, their patients tell them that they can't take treatment X or that taking treatment Y led to them feeling like this and had an impact on their mood and an impact on their relationship. And I think actually what you're seeing here is the clinical community begin to wake up to the fact that, hold on, patients are saying this, it's time that I think clinicians really need to listen to this, because after all, we don't operate in different silos. I think a urological surgeon or a neuro-oncologist isn't just concerned with a prostatectomy or what's going to be happening with a particular sort of chemotherapeutic agent or ADT, but actually wants to improve a patient's functioning. And until you recognise that a key consideration in that is their mental health, you're not really going to improve that. So it seems like it's kind of a combination of awareness, acceptance and resource and sort of optimising that will lead us to sort of a more holistic approach to patients function and their wellbeing? In terms of resource, I mean, that's a funny one because, you know, I'm not sure that argument ever properly truly holds with regards to something like this. Unless you demonstrate the case, you're not really going to be building on that awareness and acceptance. And I think the resource, the reality is when you do look at the statistics, when you do look at the impact that this is having on patients lives and functioning, there's a need to think about allocating that resource in a better manner. One of the issues, though, is you have to bear in mind that as a clinical community, we tend to work in silos. And which is why my job is quite unique in that I'm a mental health professional employed by an acute hospital trust, which is I think is a great thing and not employed just by mental health, which is far less stigmatising. And actually the reality is we tend to work in silos and because we work in silos, don't forget the services are often commissioned and sit in the structure in which services are governed are often in silos as well. And I think, you know, that's one of the things that we've been doing in a pretty novel way at St George's. We've been using innovative sort of ways of using education, using sort of fantastic actors who are sort of trained by patients and carers and thinking about approaches like simulation, innovative uses of tech as well, to really sort of promote an integrative aspect of learning, which is having a big impact actually, in terms of clinicians, whether they be surgeons, whether they be neuro-oncologists or others, really, really looking at the mental health of prostate cancer patients. I mean, even your brother-in-law got a job title, perfect living example of the kind of approach that you advocate for. Yeah, I was going to ask you about some of these approaches to supporting patient's mental health, and you've given some examples of tech. Can you talk a little, maybe just give an example of one specific area of support where you've seen real impact on patient's mental health? I think the reality is after any cancer diagnosis, I mean, NICE guidance that says that actually you'd expect about one in four people to need some sort of level of psychological, emotional or mental health support after one year of diagnosis, which is a lot more than I thought it would be prior to me working in this area. Now, of course, that's not to say that everyone needs to see a psychiatrist, because that's simply not true. And actually, most people will require lower level counselling and psychology and only very few will require psychiatry, actually. It's just really thinking about the fact that actually different people will require different things. But certainly there's been some fantastic work looking at sort of supporting patients with depression. And I think whilst there's been a lot of work in supporting patients with depression, whilst there's been a lot of work in terms of sort of specific drivers, in terms of depression awareness, in terms of things like that, the reality is, though, we're still in a position where we need to do more and we need to engage with specific communities, the black British community, South Asian community, sports communities. We need to think about how we could better map onto data and think about things from that point of view. So actually, it's not necessary or correct that a psychiatrist screens people's mental health all the time. What we need to do

actually is better at normalising it so that actually GPs, CNSs, others can sort of really understand: Hold on, here's someone who needs a little bit more help and support. It's about sort of training the people that the patient sort of comes into contact with first. And I think just actually mapping and letting people know that there are greater levels of support that are actually evidence-based and actually can be very, very helpful indeed.

Clare Delmar: So bringing this back now to the patient level, what would be your advice to a man newly diagnosed with prostate cancer and how to support his mental health? And I guess, you know, really, really, you are the expert in navigating your own cancer journey. As this dialogue evolves, more and more clinicians are becoming aware of the impacts of mental health, the impacts on functioning. And often it will be your wife, it will be family, it'll be workmates and others telling you that something's changed. When we think about someone who's depressed, we're taught as medical professionals to think about changes to their sleep, their appetite, weight loss, et cetera. But actually in cancer psychiatry, those things are less of an issue because actually they could change as a result of the cancer or some of the treatments. The key sort of things that are pretty reliable markers actually are feelings of negativity that manifest in changes to someone's functioning. So, you know, if you if you've got someone who's a lifelong Chelsea football fan who can't follow Chelsea anymore, feels no willingness to follow Chelsea or someone who takes real pride in getting up to go to work as a car salesman, and they can't do that anymore. And I think it's very tempting at this time to sort of emerging from a pandemic where isolation has been the sort of aim of the game for the last year or so to think, well, actually, I'm here on my own and I don't have the friends that I used to talk to. And I think actually all of us as a health care community are getting a lot more savvy at being able to sort of, you know, point you in the right direction if you just sort of say something's wrong here. But listen to your friends and talk to your friends, actually talk to the people around you, because, you know, they might pick these things up even if you don't. And I guess that's a bit simple, but that's good advice from a mental health point of view.

Clare Delmar: Excellent advice and very encouraging and very encouraging to see you in the role you're in and supporting other people in the clinical community to embrace that. And I look forward to speaking to you again, this is such an interesting area, and I know a lot of our patients are really, truly interested in it.

Clare Delmar: A transcript of this interview is available on our website, where you can also access additional interviews, blogs and reviews of several of the issues we've discussed today.

In Remembrance of John Mallard John Mallard's passing last week has special significance to those of us pushing boundaries in imaging-led healthcare, and prostate cancer in particular. He pioneered the development of MRI for cancer detection, something that has literally revolutionised the diagnosis and treatment of prostate cancer. John Mallard was the first professor of medical physics at Aberdeen University, appointed in 1965, where he led a team that developed the first whole-body Magnetic Resonance Imaging (MRI) scanner. A year earlier, Prof Mallard had published work in the journal *Nature* on his research which indicated that magnetic resonance imaging, which uses strong magnetic fields and radio waves to produce detailed images of the inside of the body, might be able to diagnose cancer. He told the BBC in 2018 "The driving force for us was the fact that we had X-rays that were telling us everything about bones, but we had absolutely nothing that was telling us about the soft wet tissues within the body. While the technology behind MRI was developed in the 1970s by the late Sir Peter Mansfield and his team at the University of Nottingham (who later shared the Nobel Prize in Physiology or Medicine in 2003 with the inventor of the technique, US chemist Prof Paul Lauterbur), it was John Mallard's team in Aberdeen that was responsible for developing the world's first full-body MRI scanner, "cobbled together with copper pipe from a local plumber and a tube from a children's play park", according to Prof Tom Redpath, who was a young PhD student at Aberdeen studying under John Mallard. Their prototype, the world's first whole-body MRI scanner, resides at the Aberdeen Royal Infirmary, and is pictured below. It was first used on 28 August 1980 on a local man who was battling terminal cancer, and went on to scan more than 1,000 patients before it was replaced by an updated model three years later. Prof Redpath retired nine years ago and told the BBC "It's completely unlike a modern MRI scanner - there is no plastic facing to it, so you can actually see the guts of the thing and recognise the pieces of coils and copper and magnet that would actually make up a modern scanner." Mallard's team at Aberdeen went on to develop Positron Emission Tomography (PET) which can produce detailed three-dimensional images of the inside of the body. Revisiting John Mallard's transformative contributions to medicine through the development of MRI reminds us of the challenges and opportunities that define the process of innovation. Once demonstrated, however, further development and application surged ahead, transforming radiology and diagnostics in multiple areas of healthcare. It also underscores how long new innovations can take to demonstrate benefit, and the need for determined people – scientists, technologists, clinicians,

healthcare professionals and industry leaders to drive them through, sometimes at the risk of their jobs and reputations. This has certainly been the case in the application of MRI to prostate cancer diagnostics, first identified in the early 2000s and approved by NICE as a standard of care in 2019. Finally, John Mallard personified the significance of the UK as a centre of innovation in science and technology, and MRI in particular. His genius, creativity and dedication has led so much of the innovation driving our advancements in prostate cancer diagnostics and treatment that have since taken place here in the UK. A discussion with Dr Sam Merriel

Dr Sam Merriel joins OnFocus to discuss how GPs are supporting men in their prostate health and explores some avenues for improvement. He is also a clinical senior research fellow at the University of Exeter, investigating ways of improving the early diagnosis of cancer in primary care. He has published research on prostate cancer diagnosis and management, and his current Cancer Research UK funded research is exploring the potential of GPs using prostate MRI to aid in the early and accurate diagnosis of prostate cancer. Please find below a written transcript of the interview and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Primary care for prostate cancer

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Dr Sam Merriel, a GP practising in North Somerset in southwest England. He's also a clinical senior research fellow at the University of Exeter, investigating ways of improving the early diagnosis of cancer in primary care. Dr Merriel has published research on prostate cancer diagnosis and management and his current Cancer Research UK funded research is exploring the potential of GPs using prostate MRI to aid in the early and accurate diagnosis of prostate cancer.

Clare Delmar: I think this is a really, really important issue, particularly during the covid era where we've seen some critical links, some connected and some may be disconnected between primary and secondary care. So if I can kick off by just mentioning that most of the public is aware that GP referrals for men with suspected prostate cancer at one point last year dropped to their lowest in over 10 years.

Sam Merriel: So you raise a really, really, really important effect of the pandemic that we're seeing acutely in primary care and in GP practices. So, yes, the urgent suspected cancer referrals have dropped right off and haven't recovered back to sort of pre covid levels for what we would expect. And if you look at referral rates prior to the pandemic arriving in the UK, GP referrals for suspected cancer were going up year on year. We've certainly found in general practice, particularly early in the pandemic, that people stopped coming to see us for a lot of things that they usually would. And I think certainly my experience with my patients, it seemed like a lot of them thought that the NHS is too busy to deal with these other things right now. We are worried that people out there have serious problems or serious symptoms or things that are building up that we would normally be picking up early that we haven't because people aren't coming to see us as much as they used to for understandable reasons. But we want to put the message out there to everyone that, you know, your GP practice is open, they can see you, they want to see you. If you have any symptoms, regardless of what it relates to, please come forward and see us, you know, we're not a national coronavirus service. And I can understand for men with issues that might relate to the prostate, some men might naturally think, oh, you know, waking up three or four times a night to wee at my age is just normal and everyone does it. But actually, you know, if you've got symptoms related to your prostate or related to your waterworks, we still want to talk to you about it because it might be something that needs to be looked into further.

Clare Delmar: So are online GP consultations the answer to this and if they are, how do you advise men who might be hesitant to engage that way?

Sam Merriel: Obviously, when the pandemic hit and general practice had to change the way it practised, almost overnight, we went from mainly seeing patients face to face with a little bit of telephone consulting and some practices had started to offer online consultations. So now the vast bulk of people we consult with is by telephone or via video consultation or online through email and other web based forms. And that might actually, in some ways for some people, improve their level of access because, as you say, some people might be hesitant to come forward to talk about symptoms such as those that could relate to the prostate face to face. But if you feel more comfortable speaking to us about that or speaking to GP about that by the phone or on a video consultation or just by email, that now is an option and those options will remain open to people going forward. I mean, I think as GPs, we're also very cognisant that not all of our patients are tech savvy. And something we know about prostate cancer is that age is one of the biggest risk factors. So I know some of my older patients still don't have a mobile phone, so I still have to pick up the phone to ring them. We'll still be talking on the telephone, but yes, online consultations are here now

and they will be here to stay. I mean, there's guidance from multiple sources, some of which seems conflicting, both to patients, I think, and possibly GPs. I think the thing to keep in mind is at the moment for GPs, the PSA test is the only test we have available to try and detect prostate cancer early. And I think GPs are very cognisant about the importance of detecting cancer early, but they're also very wary of putting men through unnecessary investigations. And there are definitely examples of men who've come and got their PSA done and it's been abnormal and we've sent them off and they've got their cancer diagnosis. But GPs are aware of the limitations of the test, too, in that some men with prostate cancer will have a normal PSA. And equally a man who has a raised PSA, we know that a lot of men with raised PSA is it's raised for other reasons that don't relate to prostate cancer and the diagnostic tests of having a prostate biopsy and now we've got MRI available. So I know I personally use a very simple sort of one page leaflet from Public Health England that outlines the potential benefits and the potential harms of going through a PSA test. GPs often use what's called the Prostate Cancer Risk Management Programme, which has been developed over a long period of time and has quite detailed information about how to use a PSA test, how to interpret it as accurately as you can, and what other things to think about. Yes, the opinions vary, but the guidance in terms of for men with symptoms is very clear that in any man who comes forward with a symptom that might relate to their prostate, it might relate to prostate cancer, we should be offering a PSA test, that should be made available. The issue of screening men who don't have any symptoms, that's a screening test, that's a bit more controversial. But I think all GPs would have the conversation with the man about, you know, OK, you want to have this test. Let's talk about what the test might mean and what the consequences might be if it's a positive test. Sam Merriel: It's a good way of trying to detect it early and we need to be conscious of it. Sam Merriel: I guess because the evidence says that going out and saying, well, all the men in our practise should come and get a PSA test, the evidence is that it might... I mean, I do know that some practises as part of a sort of the NHS health checks, if a man comes along or men who have monitoring tests for other chronic conditions, such as diabetes or high blood pressure, we might talk to them about do they have any symptoms that either relate to the prostate and should we think about adding a PSA test in. But I think a lot of GPs do feel that quite strongly, that we need to have an informed conversation with a man and not just tack it on as an extra blood test without actually informing them that this is what the test might show. And this is what the potential consequences could be if we do this test and we feel we have to have that conversation, but we're more than happy to do it. Clare Delmar: So what would you expect then to be a GP's minimal level of knowledge, if I can put it that way, on further prostate diagnostics and treatments? And what would be, in your opinion, best practise in guiding a patient following a raised PSA result? Sam Merriel: So as I said earlier, the tests we have available in primary care is essentially the PSA or examining the prostate. In terms of further diagnostics, I mean, I think I touched on prostate MRI, which is a relatively new test not currently available to GPs. Sam Merriel: So I don't think all GPs would know why a prostate MRI is done or what that adds. But in terms of the MRI's specific role, in terms of trying to identify tumours and guiding biopsies, that is still being disseminated amongst the GP community now. And then in terms of treatments, I mean, GPs are currently not involved in treatment decisions and recommendations that still sort of guided by the cancer specialist team. But GPs are involved for a lot of men once a treatment decision has been made and it's been started by the hospital team in terms of delivering hormone therapy, in terms of organising PSA blood tests for men on active surveillance. But other specialist treatments like chemotherapy for advanced prostate cancer is not something that we typically get involved with. I mean, there's as you know, even just as recently as last week, there's been some recent developments on prostate MRI as a potential screening device. And I guess one of my questions is if, as you say, the GP community may not be as aware as prostate MRI is, we might like, do you find that a lot of patients are aware that they've done their own research and the dialogue sort of between the patient and the GP informing each other has advanced? Sam Merriel: I think that is starting to happen because the NHS is now rolling out their MRI. So NICE guidance to say that men where they're able to have an MRI should be offered one before they get a biopsy. So I think as that becomes the standard of practise across the NHS, more and more patients will become aware of it. And they'll also start to see men who've gone been referred, come back having had an MRI, but not gone any further because the MRI didn't show anything suspicious and the decision was not to go on to biopsy. Even if the GP doesn't have an in-depth knowledge at that point, they would go away and look up some reputable sources and come back and have that conversation. Clare Delmar: So in some of your research and things you've published, you've advocated for sort of a holistic approach to patient health when it comes to caring for men with prostate cancer and that this is best supported through something called continuity of care. So how would you

advise men to engage with their GP practise if this isn't available to them or it's been compromised, as it has been during covid? Sam Merriel: So continuity of care, so having a GP, or a member of the GP team, who knows you as a patient and knows your full history and then is there for you going forward is a challenge that we are grappling with as a profession. So the traditional model of having a GP available 24/7, seven days a week with the amount of workload that we have in primary care, that is not feasible anymore, that would burn every GP out in the UK. So we're finding other models of trying to deliver the best care we can and a lot of practises still really value continuity of care. So someone who is ultimately responsible for that patient, will receive all the correspondence from the hospital specialists and the community care providers. So if patients feel that they don't have a strong relationship with the GP they're seeing at the moment, then I mean, what I would encourage you to do is think about which GPs have you interacted with in your practise? Which ones do you feel like you've got along well, that you have a good rapport with and whenever you ring up ask to see that GP. It's true that we won't necessarily get to see you the day you ring up and ask for an appointment. But it's entirely possible for a lot of issues that we can arrange for the next available appointment to speak to that GP that you have a good relationship with and then take that forward. And I think with what we talked earlier about the widening options of accessing your GP through online consultations and email consultations and things. Some of those non-urgent things that don't have to be dealt with on the day that you ring the practise. You know, if you have taken up the option of an email consultation or the option of a follow up phone call, that will happen. And that will be a way to build rapport and a relationship with a GP that in your practise.

Clare Delmar: So some people refer to the GP as a gatekeeper as opposed to a more engaged practitioner, sort of responsible and advocating for their care. Do you think that we have every reason to be encouraged about that more engaged model moving forward? Sam Merriel: The gatekeeping model goes: How do we find the best way to get the patient the help they need? And then sometimes that can be delivered with your GP or with another community service, and sometimes that requires referrals to a specialist and that's bread and butter for GPs is trying to help a patient find the best available treatment for them and the right treatment. I am hopeful with these wider options for accessing your GP going forward, that it might actually make it easier for people to speak to a GP that knows them and stay in touch with them regularly.

Clare Delmar: I mean, one idea that's been floated around from a number of various institutions are the polyclinic idea where you... Is that something that you've given any thought to? Sam Merriel: So when you say the polyclinic idea, did you mean in terms of having other community specialities like physiotherapists... Clare Delmar: And diagnostics and so for example, the MRI would be available locally in a public clinic as opposed to a hospital. And there is a strong push from the NHS to try and make services available more in the community. And part of the idea behind primary care networks is that they have some extra funding available to bring in. Yes, more diagnostics, more community specialists, more extra services into the local community. So, for instance, in our practise, we now have two physiotherapists who come and work in our practise and patients can book directly in with them if they have a problem with their back or their shoulder or something that we could assess or the physio could assess. We do need more resources if we're going to start doing things like diagnostics in the community. But there's discussion about diagnostic hubs in the community within the NHS that might mean going forward, your GP can organise more tests for you locally rather than having to send you up to the hospital to get the tests done like an MRI.

Clare Delmar: A transcript of this interview is available on our website, where you can also access additional interviews, blogs and reviews of several of the issues we've discussed today.

Active Surveillance in a Changing World Over the last few weeks we've begun to see some new questions emerging around Active Surveillance (AS), arising from four areas: The completion of over 800 interviews with patients who have come to the Focal Therapy Clinic, conducted over the last 8 months 2 recent clinical studies led by Imperial College London More evidence on mental health support needed for men with prostate cancer during the pandemic and in particular for those on AS More evidence on the experience of black men and AS All men with prostate cancer have the right to choose the treatment best suited for them, and with this right to choose comes a clinical obligation to provide information and counsel. New information and evidence often emerge in bursts, and this recent burst has placed an emphasis on questions that all men and their clinicians need to raise when considering AS.

1. Clinical studies: Two studies have been published within the last month that raise new questions about AS. The first compared oncological outcomes of men undergoing focal therapy v men undergoing radical prostatectomy over an eight-year period, and the results showed the outcomes to be very much the same. Question: Will this new evidence support FT as a real alternative not only to RP but to AS as well? TFTC Consultant urologist Alan Doherty thinks so: Focal HIFU does give you this great ability to say to a patient, why would you just watch this thing?!

can understand why you might not want to go all the way to have a radical treatment that will give you a good chance of curing you, but nevertheless will give you quite a few side effects. And as technologies are getting better and MRIs are getting better, you are able to sort of keep a very close eye on the prostate where you've treated the target lesion." The second study showed results on Prostagram, an imaging -based screening programme for prostate cancer developed by Imperial College London. Prostagram was tested on over 400 men across the UK, comparing different ways of scanning the prostate and optimising a technique, which led to very encouraging results -- Prostagram picked up twice as many prostate cancers compared to the standard PSA (prostate specific antigen) blood test.

Question: What effect will the eventual adoption of Prostagram have on treatment for prostate cancer? Alan Doherty thinks it will have a significant effect: The adoption of Prostagram will increasingly reinforce the acceptance of focal therapy and the rejection of Active Surveillance, as target lesions are identified early getting more precisely determined as the diagnostic pathway unfolds, and a non-invasive curative treatment is available.

2. Comments from our Patients A significant number of patients interviewed by TFTC over the last six months commented on their experiences with AS. One patient stood out in his openness and honesty. Perry Letcher talked openly about his short-lived experience with AS. Initially he was positive about it, "at the time I was relieved because I had been worried that I had a life-threatening illness", he told us. And at the time, you know, when I was told active surveillance, that seemed perfectly logical and I was perfectly happy about it. Yet soon after Perry felt differently, struggling with the mental and emotional strain of his diagnosis which he began to feel was not treated at all v actively monitored.

TFTC Consultant Raj Nigam feels strongly about this. "Having gone through the process of diagnosis, and then being told he doesn't need to do anything and yet he has cancer, is too much for some men. They simply find this hard to accept, and they cannot live with the not knowing"

Question: Do patients undergoing AS need more support in their overall wellbeing, and ongoing counselling on their suitability? Perry thinks so: "I think one of the big issues with Active Surveillance is that one's perception changes over time...and I think that it's very easy for the NHS to say, you know, he's on active surveillance and that's OK and we'll just leave it, not realising that that person can have massive changes in their own feelings about how it goes".

3. Focus on Mental Health Covid19 has placed a spotlight on mental health in the general population, and in the case for men with a prostate cancer diagnosis, either undergoing or awaiting treatment, it has underscored the importance of integrating their mental health needs into the management of their disease. A recent study at St George's Hospital London outlined how this might be done: as a clinical community we need to drive a shift in culture towards measurement of patient quality of life as a marker of treatment effectiveness. It appears that despite recent developments in cancer treatment, many of which have improved patient survival, the clinical community has been rather myopic in failing to adequately consider how investing in the mental health of cancer patients can improve patient experience, Quality of Life, functioning, and even engagement. This involves doing things differently, namely thinking innovatively and more effectively integrating mental health and psychological wellbeing into routine cancer services.

There has been an increase in men going on AS programmes over the last year, as other treatments are restricted due to Covid. As TFTC Consultant Marc Laniado comments, "Being on active surveillance, a lot of people would get worried that they're going to miss the opportunity to have a successful treatment."

Question: Is the mental health of men undergoing AS often compromised, and are some more at risk than others? According to Willie Underwood, a urologist in Buffalo New York who was diagnosed with prostate cancer at age 48, the answer is yes, and black men are particularly vulnerable. "If a man will be in 'PSA prison' every time he gets his PSA checked, he's going to go through mental anxiety and living hell, then he might as well get treatment because you'll be able to go on with the rest of your life and feel more comfortable."

Dr Underwood, who is black, cites evidence that black men are also at higher risk of depression and anxiety after a prostate cancer diagnosis.

Experience of Black Men A recent Opinion piece in a popular medical journal referred to a study published late last year which tested the hypothesis that African-American men undergoing AS are at significantly higher risk of disease progression, metastases, and death from prostate cancer compared with non-Hispanic white men. The researchers found that 59.9% of African-American men experienced disease progression compared with 48.3% of white men. In addition, 54.8% of African Americans required treatment compared with 41.4% of white men. Both were statistically significant increases.

Dr Underwood was baffled by what he perceived to be mixed messages. On one hand, they say that AS is good for Black men, and, on the other, express the accepted wisdom that prostate cancer in Black men is biologically different and usually more aggressive than in white men.

Question: Should black men undergo AS treatment at all? Dr Underwood suggests not. "If Black men have more

aggressive cancer, then why would you treat them less aggressively?" His colleagues add that Black men tend to resist AS, suggesting that the idea of coexisting with prostate cancer has been a hard sell in communities of all colours in which doctors have promoted the mantra of "early detection saves lives. They added that there has been a historical mistrust of the medical community and researchers in many black communities, which is also coming to light in the deployment of Covid19 vaccines. What are your experiences with AS? Alan Doherty offers an alternative view on the focal therapy vs radical prostatectomy study Alan Doherty, Clinical Director at the Birmingham Prostate Clinic, and recently voted one of the UK's top ten prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail, joins OnFocus to discuss the recently published study led by Imperial College comparing outcomes of men undergoing focal therapy and radical prostatectomy. Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer, and thinks the study's real impact will be felt amongst men considering active surveillance. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Focal therapy as a middle ground treatment Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Alan Doherty, clinical director at the Birmingham Prostate Clinic and recently voted one of the UK's top 10 prostate cancer specialists in a national poll of consultant urologists published in the Daily Mail. Alan has been an innovator, advocate and dedicated practitioner of precision treatments for prostate cancer. And we're going to talk about the impact of a recently published study that's produced compelling evidence on the benefits of focal therapy. Alan, thanks for joining me today. Alan Doherty: Pleasure. Clare Delmar: So this study is about two weeks ago, not even, and it was led by Imperial College and a few of your colleagues, as you well know, were lead investigators on this. We've certainly had a lot of patients interested in it because it's certainly raised more awareness around focal therapy. And it compared to focal therapy to radical prostatectomy in a cohort of men over an eight year period. So what's your interpretation of the results? Alan Doherty: Thank you for inviting me on to discuss these things. I think specifically about this particular study is that we've got to be very careful over-interpreting what it actually says. And I think the first thing I would say is that if oncological outcomes are the important criteria to a patient, well, then they do need to think long and hard about focal HIFU as an option. I think the second thing is that the way that the study was designed wasn't really a comparative study. It was looking at what happens to two hundred and fifty patients from Imperial College if they have focal HIFU performed to the highest standard probably available in the country, insofar as they will have superb radiologists, they'll have people who are dedicated to the treatment and then they try to match that with a group of people who had radical prostatectomy. And there are so many flaws in trying to compare them in this way that I'm not so sure you can make a comparison to the point where it's actually that meaningful in terms of oncological outcomes. That being said, you know, it nevertheless does show that patients with early disease do well, virtually whatever treatment they have. I think there's more and more evidence really to reinforce the fact that active surveillance shouldn't exist anymore as a treatment option because the patients who are keen to have a treatment and want to minimise side effects, and it's becoming more and more clear that the sort of oncological outcomes which you get, and this study supports them, are very good. But as I said, I'm not convinced that this should be seen as a comparative study with surgery because they offer very different things. And the only reason that you should fail after that is if you've got micro metastatic disease. And the other one aims to just treat one part of the prostate where you can see a cancer and realise that there may be a future time when you need to treat another bit of the prostate if another bit of cancer occurs. But I don't think that should be, in my personal view, that shouldn't be the primary focus of a patient choosing focal HIFU. Clare Delmar: It's interesting because you're sort of reframing how the results were presented or how the conclusions were presented. Do you think the results underpin the same message for men considering either radical prostatectomy or active surveillance, i.e. that focal therapy is a middle ground approach or a middle way it's often described, with the benefits, but not the risks of either of those other alternatives. Alan Doherty: I think you've got to be careful what you claim to be the oncological benefits. And you're absolutely right that the side effect profile from focal HIFU is dramatically better than the other treatments. And you're also right to say that a lot of studies are framed in such a way that the conclusions can be over-read, and I think one has to be very careful in doing these sort of interpretations, because if you read the words that the authors choose, they're very careful in how they

choose their words. But the failure was defined by who had either whole gland therapy or salvage radiotherapy or treatment for metastatic disease with hormones, but who decided that? So patients who generally choose focal HIFU and these treatments are not going to be treatments who are going to put their hands up and have salvage treatment in a hurry. So there's always a threshold level at which somebody decides when to have another treatment. Clare Delmar: Back to this middle way, though, argument. I mean, there is an argument that focal therapy, given its kind of position, is a mid way, might appeal, particularly to men who might otherwise choose active surveillance. I think active surveillance should virtually no longer exist, because, first of all, it should be a rarity that you pick up a prostate cancer where the MRI scan hasn't found a target lesion. And if there is a target lesion, then why would you just monitor it when you can successfully treat it? You see, one of the things that this study doesn't necessarily highlight is that there may be fantastic success in treating the target, but what about the surrounding tissue that look normal on an MRI scan? Well you have to have a very good MRI scan to reassure both the patient and the clinician that the surrounding tissue isn't involved. So, you know, you're absolutely right that active surveillance is a strange concept in a way, because you've gone to all the efforts of finding a cancer and then you say, oh, no, you can leave it. Focal HIFU does give you this great ability to say to a patient, you know, why would you just watch this thing, you know? OK, I can understand why you might not want to go all the way to have a radical treatment that will give you a good chance of curing you, but nevertheless will give you quite a few side effects. And as technologies are getting better and MRIs are getting better, you are able to sort of keep a very close eye on the prostate where you've treated the target lesion. As you say, it's giving patients another option and I think that's fantastic. Clare Delmar: What I find interesting when I talk to you about focal as an alternative to active surveillance, and I know you even have stronger views about active surveillance full stop. It often makes me think that there's a narrative emerging around the process of determining a patient's suitability for focal therapy. And I guess what I mean by that is that it seems to be driven by a more holistic view of his health, including his mental health and his lifestyle choices, and that this may give added benefit to patients. So you often find that engineers, for example, like a solution to their problem, are quite enthusiastic about choosing surgery as that solution. You'll get other people who are much more concerned about their quality of life and their sex life, for example. And you say, well, it's not up to me and I'm not you, so you need to sit down with your family and write a list of your priorities, see what you could live with and what you couldn't live with. And then the urologist is there to help patients through that journey to highlight to them. You know, another interesting point is that a lot of patients want to be proactive and slow down the growth of a tumour. And this cancer is usually a very slow growing cancer that doesn't necessarily cause, you know, the disasters which the patients think they do because the patient's anecdotal experiences do affect them big time. So if one of their friends has recently died of prostate cancer, they do put cure much higher up the list and they probably would be prepared to take a higher risk of an adverse side effect, but it is a trade off and people need to understand that. And, you know, somebody is perhaps already impotent might not put that much value on minimal side effects, because they might be much keener on just being done with it once and for all. And to know that after surgery, the PSA blood test is zero and that gives them a lot of, you know, reassurance. And it might just be a psychological treatment just to make them feel that it's out of their body. And my experience, and I think I've been guilty of this as well, is that we are very much taught to treat cancers with a curative obsession. I think, I mean, the fact that the NHS doesn't strongly support focal therapy is because they're worried that the oncological outcomes might be not as good as surgery, which is really pretty much why this latest paper was put together. Because, we are trying to get that information to reassure the powers that be that it is relatively safe. But in a way, that misses the point here, which is that not everybody is obsessed with getting cured. So even if the cure rates were not as good, even if the oncological outcomes are not as good, does that matter? It just doesn't make sense, especially when it's such a safe treatment, I'm talking about focal HIFU, as long as it's done properly. Clare Delmar: So that's a very different argument. But I mean, you're kind of coming to the positive aspects of having focal HIFU if you are suitably qualified. I mean, given all this, what would your message be to men with a localised prostate cancer diagnosis following this? Or does the study not really change your view or does it reinforce your view? Alan Doherty: The study doesn't do either, really. I think what it really just keeps reinforcing is my view that patients need to just be clear on what they want and not be bullied into making a decision on a highly curative treatment that might affect the quality of their life, certainly in the short term and probably in the long term. And I think a doctor needs to be prepared to change and move his own goalposts to focus on what's good for the patient. Because that really is the ultimate thing is that the patient needs to understand the issues. The other take-home

message, I think, is that you have to have top quality interventions because everything I've said is dependent on that. You have to have if you're going to do surgery, make sure your surgeon knows what he's doing. If you're going to have the focal therapy, make sure that the treatments are contoured by a radiologist who knows what they're doing so that you hit the target, make sure that you can follow things up properly. If you have a high quality treatment, they're all pretty good with sort of slight differences in how they prioritise outcomes. But that's the important thing, is make sure that you understand the issues and that you're confident that the treatment you're getting is delivered at a high quality.

Clare Delmar: Well message received. It's always important to get a different view and especially one that's so well considered and backed up by all your years of experience, so thank you so much.

Alan Doherty: Thank you, Clare.

Clare Delmar: A transcript of this interview is available on our website, where you can also access additional interviews, blogs and reviews of the Imperial study we've been discussing today. We often talk about focal therapy as the "male lumpectomy", comparing advancements in techniques that have enabled targeted treatment for breast cancer to those for the prostate. The recent publication of an imaging technique called Prostagram extends the comparison further to screening, potentially leading to a world where men undergo prostagram screening for prostate cancer as regularly and routinely as women undergo mammogram screening for breast cancer. According to the investigators at Imperial College London, "The prospect of a male equivalent of the breast mammogram or so-called 'prostagram' has been a long-standing goal in prostate cancer diagnostics. Image-based screening has been adopted for other common cancers including mammography for breast cancer and low dose CT for lung cancer screening. TRUS was touted as the original 'male mammogram' in the 1990s but did not prove to be effective as an independent test. If the performance characteristics of a standard mpMRI can be replicated in the general population this would address some of the issues with PSA as a screening test." While mpMRI has become the standard of care for prostate cancer diagnostics, it has not been adapted to screening. Cancer screening is for people without current symptoms, while cancer diagnostics are for people with current symptoms that are suspicious of cancer. Regular screening coupled with quick diagnostic testing helps to ensure that cancer is caught early, giving the patient the best chance of successful treatment and recovery. The Imperial team tested Prostagram in a study of over 400 men across the UK, comparing different ways of scanning the prostate and optimising the technique, which eventually led to finding the best approach to score the prostate. The study participants were aged between 50 and 69 years, and included a significant cohort (32.4% of total participants) of black men who are at increased risk of prostate cancer. All were invited for prostate cancer screening, using both the new scan and other established methods, from October 2018 to May 2019. Results showed that Prostagram picked up twice as many prostate cancers compared to the standard PSA (prostate specific antigen) blood test. The team was especially pleased with the demographic diversity of the trial participants: 'A major achievement for the trial was the recruitment of ethnic minority and lower socio-economic participants broadly equivalent to their proportion within the community, which could be replicated in future general population screening trials.' A more extensive trial involving 20,000 men is in development, and if results from this study are similar or better than those produced in the recent study, there will be a clear pathway to the widespread implementation of Prostagram into the general population. Prostagram's impact for men and their healthcare is potentially huge - reducing under- and over-diagnosis of prostate cancer and allowing for precision-led and more personalised treatment – eg focal therapy. Consultant Urologist Tim Dudderidge foresees multiple benefits for both treatment and workflow: "The Prostagram study opens up a new chapter in the screening, diagnostic and treatment pathway for prostate cancer. Precision screening will improve the detection process increasing diagnosis of clinically significant disease and reducing unnecessary detection of insignificant disease. It's likely that focal therapy will emerge as a preferred alternative to surgery and radiotherapy for many men with localised prostate cancer. The other exciting consequence of an image-based screening programme could be the acceleration of AI supported reporting systems for both MRI and pathology. This will provide the framework and free time for radiologists and pathologists to provide image-based reports to help guide treatment planning." Alan Doherty, Director of the Birmingham Prostate Clinic and Consultant Urologist at TFTC, regards the development of Prostagram as a boost for precision treatment which challenges the future of Active Surveillance: The adoption of Prostagram will increasingly reinforce the acceptance of focal therapy and the rejection of Active Surveillance, as target lesions are identified early getting more precisely determined as the diagnostic pathway unfolds, and a non-invasive curative treatment is available. Prostagram raises many questions about acceptance, adoption and treatment adaptation, and it will be exciting to watch how and when this step-change innovation will deliver direct benefit to

men's health. We've seen mpMRI revolutionise the prostate cancer diagnostic pathway over the last ten years and with it improve treatment options, particularly for men with early-stage, localised prostate cancer. We are getting closer to a time when the Prostagram is as convenient and routine as the Mammogram. The Role of the GP in Supporting Prostate Care Like last week's blog about mental health support for men with prostate cancer, this week's is about how an already variable and, for many, unsatisfactory situation has been exacerbated by Covid. Covid has changed the rules of access to GPs and there is evidence people are not going as often as they would otherwise. The Daily Mail reported last September that GP referrals for prostate cancer dropped by 50% during last year's lockdown. There has been a vocal, celebrity-backed campaign from the NHS and Cancer organisations that "the NHS is still open" and to contact your GP if you are worried. We enthusiastically support these campaigns, and urge all men who are concerned about prostate cancer to contact their GP and request a PSA test. This is also an ideal time to think about best practice in primary care, and address what men should expect from their GP in supporting their prostate health. We have a wealth of comments and feedback from our patients about their experience and expectations with their GP, which we've consolidated and summarised below.

1. PSA test As there is no national screening programme for prostate cancer in the UK, men's experience with the PSA test is highly variable in terms of when, where and under what conditions it is available. So many men tell us the PSA test was offered to them only as part of other investigations and their gratitude for what was a serendipitous event is powerfully felt. For clarity, Public Health England's Prostate Cancer Risk Management Programme says that every man over the age of 50 has the right to a PSA test after a discussion of the pros and cons with a doctor. Our advice is to ask your GP for a PSA test if it is not offered to you, but before you do, understand what it means and what you want to happen next if its result causes concern. Few if any of our patients were advised of focal therapy from their GP, and learned about it through their own, mainly online research. While this is not unusual, what is concerning is the limited information shared about Quality of Life impacts from the various treatment options that were presented. Many of our patients felt they were not adequately counselled on the sexual and urinary functional outcomes they potentially faced, and how these could be managed from a physical and mental health perspective. While it is easy to tell men to go online and find out more, most men are in shock when they hear they might have prostate cancer and are compromised, initially, in their capacity to process new information. That's why it's crucial to give men effective and digestible information immediately so they can build their knowledge and develop the confidence to access more. Predict Prostate is a tool provided by the NHS that shows how different initial management strategies affect the percentage of men that survive ten and fifteen years after diagnosis. It's the perfect platform for discussion and further investigation, and we'd like to see it used more at the GP level.
4. Knowledge of specialists and variations in diagnostic procedures and urological practice. Many of our patients tell us they are referred to a specialist without discussion of the variation in practice that continues across the UK, which can be considerable in the stages of the diagnostic pathway and ultimate treatment. Men need to be pointed in the right direction in terms of understanding the importance of imaging, imaging reporting and biopsy approach, each of which will determine his treatment choices, and is essential to making his choice of specialist and asking the right questions about his care.
5. Active Surveillance support For men that are referred to a specialist, diagnosed and put on an Active Surveillance programme, the GP becomes an important part of his life as his PSA levels are regularly tested. Many men find this stressful, often struggling between their continued status as a "cancer patient" and the mutual responsibilities that go with it. GPs might consider engaging AS patients more at each visit through broader monitoring of changes in mental health and lifestyle. Sam Merriel, a GP and a Clinical Research Fellow at the College of Medicine and Health, University of Exeter, has been working with GP practices on approaches to support men with suspected and diagnosed prostate cancer. Writing recently in the British Journal of General Practice, he says "Most patients place a high level of trust in their GP - it is one of the privileges of our profession that we build relationships through continuity of care, and some patients seek their GP's opinion on big treatment decisions for conditions such as cancer. Continuity of care increases our understanding of the complexities and nuances of the patient's medical history, their preferences for treatment, their social circumstances, and their quality of life" He continues "Men value receiving clear information about their treatment choices for prostate cancer. Discussions with a specialist are important, but prostate cancer patients also want to be able to talk to a healthcare professional about any questions or concerns that arise prior to or during their treatment. GPs can play a role here, and can use their knowledge of the patient regarding their personal priorities and communication style to give information in a manner the patient is more likely to understand." Supporting the Mental Health of Prostate Cancer Patients More

and more people have experienced periods of poor mental health during Covid, manifested as anxiety and depression arising from a continuing sense of uncertainty, fear and for many, an unbearable waiting for things to get better. This will sound very familiar to many men with prostate cancer, with uncertainty and fear all too common, and the unbearable waiting has only been exacerbated by Covid as appointments, tests and procedures are delayed and cancelled. This, and the increase in both Active Surveillance and Hormone Therapy offered as treatments, has been a double whammy for the mental health of prostate cancer patients over the last year. In a recent OnFocus discussion, TFTC Consultant Urologist Marc Laniado describes what he's seen over the last year: "Being on active surveillance, a lot of people would get worried that they're going to miss the opportunity to have a successful treatment. So hormonal therapy, although it will slow the cancer, it's not necessarily a fantastic treatment for prostate cancer because of those side effects" A recent journal article at St George's Hospital, London, highlighted the need for mental health services among prostate cancer patients and explored opportunities and approaches to address how mental health can be integrated into prostate cancer care. It points out that while surgical, radio-oncological, and medical anti-cancer therapies have developed at pace and scale in recent years, there remains a huge unmet need for mental health in cancer care. It highlights an urgency for more effective clinical integration of relevant services, which must be informed by patient choice and clinical need, and accessible throughout the patient's whole cancer journey. The author, Dr Asanga Fernando, points out that "as a clinical community we need to drive a shift in culture towards measurement of patient quality of life as a marker of treatment effectiveness. It appears that despite recent developments in cancer treatment, many of which have improved patient survival, the clinical community has been rather myopic in failing to adequately consider how investing in the mental health of cancer patients can improve patient experience, Quality of Life, functioning, and even engagement. This involves doing things differently, namely thinking innovatively and more effectively integrating mental health and psychological wellbeing into routine cancer services" He cites two areas of opportunity for better integration of mental health into prostate cancer care. One is investment in clinicians' mental health, which is often under continued strain and where direct experience of mental health support would inform good practice. Second is adoption of emerging digital technologies to support patients in their emotional journeys through prostate cancer treatment. Perhaps a silver lining to Covid19 is the emergence of a widespread, open and honest discussion about mental health. Now it's time to recognise how this impacts men with prostate cancer and address it with all patients. Landmark Study Shows Focal Therapy is as Effective as Radical Prostatectomy Consultant urologist Raj Nigam discusses the focal therapy v prostatectomy study's impact Raj Nigam, Consultant Urologist at the Royal Surrey NHS Trust and the Focal Therapy Clinic, joins OnFocus to discuss the landmark study led by Imperial College London that was published last week to much acclaim. In its outcomes, design and impact, this study is a breakthrough in supporting better choice and ultimately better care for men diagnosed with localised prostate cancer. Download the study here: [Focal Therapy v Prostatectomy study](#) Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Raj Nigam, consulting urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy Clinic and an investigator on the landmark study led by Imperial College London, published last week, which compared outcomes from focal therapy to prostatectomy. Clare Delmar: So this is really quite an achievement last week for this study, it received lots of media attention and it seems to have had some very, very powerful outcomes. So essentially the gold standard of a study comparing two treatments is something called a randomised controlled trial. And nobody worldwide has managed to do that, comparing any of the existing treatments for early localised prostate cancer. And the reason for that is that to randomise a patient properly, you have to offer him three or four brown envelopes within one brown envelope. You have to ask the participants in that trial to say, right, you're going to choose a brown envelope as to which treatment. And most men would say, well, hang on, I'm not going to allow a brown envelope to choose for me whether I might become incontinent or not or whether I might not have a successful cancer outcome. So most men would say no, I would really want to know exactly what the treatments are and then make a decision together with my physician as to which direction I want to go in for. The cancer outcomes at three years, at five years and at eight years were very similar between what we regard as the most radical treatment in terms of removing the whole prostate versus a minimally

invasive treatment called focal therapy. We've always suggested that there were less side effects with the focal therapy, but in terms of cancer outcomes, you need longevity. And we now have very good data going out to eight years, which shows that actually from a cancer control point of view, the two treatments appear to be very similar. So one of the other things I understand is equally as remarkable about this study is that the design of it was, if not unique, it was pretty unusual. And essentially what we do in the absence of a controlled trial is that we look at databases of focal therapy and compare them to databases of laparoscopic radical prostatectomy in this instance. And what we try and do is match one participant in the focal therapy arm to one participant in the radical prostatectomy arm. Now, that is more difficult to do than you might think because there are so many different factors. So age is one thing, their PSA reading, the grade of the cancer, the stage at which it was diagnosed. All of these can be confounding variables and to match them accurately is a very difficult and tricky statistical exercise. So you are left at the end with approximately 250 patients who have had focal therapy matched on a one to one basis with radical prostatectomy, with all similar parameters or almost identical parameters in the two halves.

Clare Delmar: So the database that you used for HIFU, the men who had had focal therapy, HIFU focal therapy. Now my understanding is that was based on, again, a rather unique database called the HIFU Registry.

Raj Nigam: So it's basically called the Heat Registry, which is a UK based nationwide registry, which many of us were involved with at the outset when it was set up. And it is partly a requirement of the National Institute of Clinical Excellence valuated high intensity focused ultrasound so that every treatment that is performed by the participants in that database is recorded and the patients are followed up over that period of time. So that we know quite clearly that if any patient fails that particular treatment and I'll come on to what we defined as failure in these in this particular study, it is then recorded and the outcome of that patient is recorded. Some of us within The Focal Therapy Clinic and so on have been participants in this particular registry right from the outset. And we enter our patients prospectively with their parameters and their outcomes into this particular database. From that point of view and so far as, for example, there isn't a single national radical prostatectomy database, which all radical prostatectomy is to enter into. So it's unique from that point of view that all focal therapy treatments should be entered within this particular database.

Raj Nigam: Oh, now, while we're just about to publish later on this year, almost 1900 patients that have undergone focal therapy.

Clare Delmar: And it's growing all the time, it's continually being added to, from what you said?

Clare Delmar: So that means that it's just getting to be deeper and broader data set that can be used for lots of future research, presumably.

Raj Nigam: Absolutely and we're very proud of the work that we've done so far with such a robust database. We do not know what the outcomes are going to be on the patients I'm treating tomorrow when they're entered into the database. I mean, how do you see the results of this study changing the patient experience for those diagnosed with localised prostate cancer going forward? We've always known and we have published the short and medium term functional outcomes of impotence or erectile dysfunction and incontinence in patients who have undergone focal therapy and separate observational studies have done the same for radical prostatectomy. But the oncological or the cancer outcomes have always lagged behind because it's relatively new compared to radical prostatectomy. So whereas radical prostatectomy in terms of observational studies can give you 10 year and even beyond up to 15 year data, because we got NICE approval to carry out focal therapy only in 2012, we have only got data from there onwards. And most observers would say you need good 10 year data before you can say, yes, this is an equivalent treatment. We have published eight year data in terms of a propensity score matching study, and we will continue to add to that as time goes on. But it's an excellent start at eight years to show that, in fact, it was a slightly improved cancer outcome in focal therapy compared to radical prostatectomy, but it wasn't clinically significant and therefore the two are deemed to be equivalent.

Clare Delmar: OK, so the difference then in the patient experience might be now that more clinicians will feel confident in offering this, hopefully because they see that the data is there to support that choice? So if a patient has an MRI scan and biopsies and the PSA that is suitable for focal therapy, he or she can confidently say that, look at eight years, if we were to take your prostate out in terms of radical prostatectomy, the cancer outcome would be exactly the same as if you had had a focal therapy. And in fact, that's something I just wanted to ask you as a final question, because men often are told about the choice they might have between radical treatment and focal therapy almost as a trade off between cancer control and functional outcomes such as sexual and urinary function, so do you see that this study might support a more balanced discussion on this perceived trade off? And I think that it is important to bring that up because it is not unusual for men in this country. And we know this from our work with The Focal Therapy Clinic to find that they are only offered two options, either radical prostatectomy and the radical

radiotherapy, i.e. Very few patients even have a discussion, let alone are offered the concept of focal therapy and a lot of men sadly have to find out for themselves over the internet and so on what this treatment is about and so on. So one would hope that with the publicising of this particular study that more men would become aware that there is an equivalent option to radical surgical treatment options. If they look into it further, they would see, oh, this is a minimally invasive option in which I'm likely to preserve my continence, in which I have a 15 to 20 percent risk of erectile dysfunction vs. an overall 50 to 70 percent risk with a radical prostatectomy. And, of course, we evaluate men very, very carefully to see that they are eligible if they come to focal therapy that we know with confidence that their cancer outcomes would be equivalent if they had chosen a radical prostatectomy option. Congratulations again on this really important research and we await much more using this effective database to see where this all goes.

Clare Delmar: A transcript of this interview is available on our website, where you can also download the published study that we've been discussing and access to information and insight on managing prostate cancer diagnosis. Clinical Trials: The Research Advancing Prostate Cancer Treatment Tim Dudderidge discusses recent findings of randomised controlled trials The Focal Therapy Clinic urologist Tim Dudderidge, joins OnFocus to discuss how clinical trials are designed to advance innovations in clinical practice and how they ultimately bring choice and benefit to patients. Tim discusses his involvement in the CHRONOS trials which will investigate outcomes of men undergoing focal therapy vs surgery for localised prostate cancer. He also explains how a registry of men who have received HIFU treatment in the UK is providing a valuable data resource for statistical comparisons of treatments for men with localised prostate cancer, and highlights this week's publication of a landmark study showing comparable outcomes for men undergoing focal therapy and prostatectomy. <https://clinicaltrials.gov/ct2/show/NCT04049747> [https://imperialprostate.org.uk/chronos/Focal Therapy v Prostatectomy study](https://imperialprostate.org.uk/chronos/Focal%20Therapy%20v%20Prostatectomy%20study) Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870

The evidence supporting minimally invasive treatments for prostate cancer Clare Delmar: Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Tim Dudderidge consultant urologist at Southampton University NHS Trust and The Focal Therapy Clinic. Tim is a recognised innovator in advancing both the imaging led diagnostic pathway for prostate cancer and minimally invasive treatments, including focal therapy. We're going to discuss how much of this innovation has been led by clinical trials and explore how these trials deliver new procedures and treatments to patients. So we're going to talk about clinical trials, and I think this phrase is something that most of our listeners, if not the entire world, knows a little bit more about because of Covid. And therefore, I thought it was a good time to tap into this, to talk about how clinical trials have led to some of the big advancements in prostate cancer diagnostics and treatments like focal therapy. Now, since you've been involved in many of these, I thought it would be great if you could start off by telling us about them and most importantly, just start with some definitions. So, for example, what is a RCT or the randomised controlled trial? Tim Dudderidge: So a randomised control trial is really the goal of comparative effectiveness when we're trying to tell a patient which is better treatment A or treatment B? And the reason that we have to have a randomised control trial is that all sorts of different other study designs that we use, that are usually much easier to conduct than a randomised controlled trial, they're subject to bias and confounding, and that basically means that the patient may report things differently. We may subconsciously or consciously be seeking a certain outcome from a study that leads to the data sort of tending to give us the answer that we want to hear. And that's just partly of human nature, both the optimism of patients and doctors wanting to see new things work. But of course, there are lots of examples where in the past things we thought worked and we thought the data was telling us that they worked, when you actually conduct the study really well and to this very high standard called a randomised controlled trial, that actually some of the things that you thought you believed to work actually turn out to be just as good as the sugar pill. The reason I refer to the sugar pill, which is otherwise known as the placebo, is that most of this study design came through the pharmaceutical industry. And actually what we found as surgeons is trying to incorporate this very challenging study design into surgical practices is really, I think, probably harder than it is to do when you're testing a medication, which you can design to look exactly the same. Whereas anyone having an operation, for instance, through an incision or having keyhole surgery, it's very obvious to the surgeon and the patient there's a big difference there. But really, we all want to be able to do randomised controlled trials so we

can tell patients what is better. A systematic review is something that we can conduct when we've got multiple randomised control trials. And sometimes what you find is that you run the same sort of trial multiple times in different locations around the world, is that you get subtly different answers some time. And a systematic review is a good way of trying to bring all that data together and give one final answer to that question. Clare Delmar: OK, I'm actually going to come to that in a few minutes because there is a review that I want to chat with you about. And that's why it's important when you've got a commercially funded studies, that there is a degree of separation from the company that's funding it and the people conducting the study. But it's understandable that commercial trials are there to answer commercially valuable questions and so often the study design. The study design will be very much focused around the funders objectives, but they do have independent data monitoring committees, safety monitoring committees and other structural things within the study that mean that people can hopefully regard the outcomes from those studies as being valid. But it's not uncommon for a commercially sponsored trial to shortly be followed, once something is become established, by academic funded studies to really hone down the questions. But often with surgical studies, there's not often the opportunity to repeat randomised controlled trials, because the moment in time where people have something called clinical equipoise, and that's basically both the surgeon and the doctor believing that either choice in the trial could be equally good. With surgery, once you've got a really bit of solid data that shows one operation or no operation or whatever is better than the alternative, then it's very hard to look at patient in the eye and say, we're going to put you in a randomised study when somebody down the road might be regarding that new intervention as the standard now. And so it's very important with surgery, that when something innovative comes along, that at the earliest time point possible, a randomised controlled trial is undertaken. Because if you wait too long, you may miss the opportunity to do that randomised controlled trial simply because neither the surgeons nor the patients will kind of go ahead with it, even though they might say scientifically it's needed. It might be that the funders, the health care funders really want to know if this is a good intervention or not. If you get to a certain point in time where something becomes the normal, it's very hard then to turn around and say, we're not going to do this unless you're randomised between either no treatment and an operation or treatment A versus treatment B. So I think the timing of randomised controlled trials is very important. Clare Delmar: Oh, that's interesting. Does it depend on what the trial is actually investigating? Tim Dudderidge: There is a sort of pathway that's well recognized in the pharmaceutical industry. But effectively, you, first of all, have to have an intervention where you've got a sort of theoretical basis for that intervention. And one of the earliest things that you must do is assess the safety of the treatment and to see that there's some early sign of treatment effect. Obviously you can do a safety report of an operation or something like that and make sure that people are not having too many side effects. Phase one is the typical name given in the drug study where you're establishing the dose of the drug. But in phase two studies, you're there really with a group of patients looking at the side effect profile and at the same time collecting some data on the treatment effects. And that's quite easy, for instance, when you've got something where you can monitor a scan or you can monitor a blood test, for instance, looking at cancer outcomes. And increasingly, when we're looking at ablation, where we're looking at the combination of PSA and of imaging and of biopsy results. And so you would sort of start off by looking at what's the side effect of that intervention, then start looking at some cancer outcomes in terms of maybe a one year scan and biopsy and PSA results. So you're taking as large a group of patients as you can who have met certain study entry criteria and you'll just monitor their outcomes at set time points. You've got the formal research study where everything is carefully funded to be checked at certain time intervals and everything is done by a very rigid set of rules. But then you've got a slightly less onerous form of study which can be done without some of that research framework, which is called a registry study. And that's where all the cases will be perhaps undertaken according to local practice, but then uploaded onto a study registry, which can then be scrutinised by multiple centres. And so, for instance, in the UK for HIFU, the high intensity focus ultrasound, we have had the Index study, which has been organised through UCL and Imperial more recently. And the Index study has also been complemented by the UK Heat Registry, which is for sort of non-study patients. And that's provided us with much of the UK's really good data collection on focal ablation with HIFU. But we're now moving on to a new phase where we're moving away from cohort studies to the randomised control trial and we're running the Chronos A and B here in Southampton, which is again organised by Imperial. And this is a randomised control trial with an interesting design because the objective in Chronos A, the main objective is to run a randomised controlled trial between the standard whole gland radical treatments and focal therapy and we're allowing whatever whole gland treatment, surgery or radiotherapy that you

choose to have and also either form of commonly used focal treatment. And that really is the most important thing for the UK to be focusing on within the focal therapy community is to try and see if we can recruit men to the study. And basically, that study requires me, and this is exactly how I feel, to look at a patient in the eye and someone who's got disease just on one side of the prostate, that's important disease. And say to them, I don't know what's best, for you to have focal therapy with hemiablation of the prostate with HIFU, for instance, or to have nerve sparing radical prostatectomy, because although these treatments are both quite distinctly different, the side effect profile of HIFU will be lower. But we have an uncertainty about the long term comparative effectiveness, which is why we're doing a study. On the other hand, surgery which may well have been demonstrated to have these long term outcomes that we can predict. It's just that we know at 10 and 15 years what the likelihood is of you having to have repeat treatment, whereas we don't know the likelihood of repeated treatment for HIFU yet. You know, incontinence happens very frequently, although it recovers, thankfully, in most patients. So we know that those side effects are there and the question is, is that cost worth paying? And is there a difference in the comparative success of getting rid of the cancer that sort of justifies those additional side effects? So if I can look a patient directly in the eye and say that I do both of these treatments, I am an advocate of both, I'm sitting on the fence here. And yes, you could choose you might look at the situation, say, well, you obviously prefer one over the other. But scientifically, the most robust reaction to this situation is to say, I don't know what's best. We're going to let the randomisation take care of the decision making and in the process contribute to a study where eventually we will know which is the best of these treatments.

Clare Delmar: That's interesting. What is the main investigation then?

Tim Dudderidge: The main objective is to establish that failure free survival, the comparative success in getting to a ten year time point free of any kind of disease progression and failure in the sense of having to have surgery or radiotherapy as a salvage treatment, having hormone therapy because the disease metastasises, measuring metastases, dying of prostate cancer, all of these things count as failures within the study. And we're really looking at the primary endpoint is to study that and see which is the best treatment. But the next part of Chronos is interesting, because when you pose that question to patients and you say, look, I have an equipoise position on this, a substantial number of men will come back to it and say, well, I don't, I favour focal. And I would say at the moment, I haven't really got a good feel for it, but I'd say at least half of men have a preference and don't want to be randomised, and so it is quite challenging to recruit to these randomised controlled trials because even though the doctors say to them, we don't know which is best, patients will look at the two choices and they find it difficult because it's not like looking at two different tablets that look the same. They look so different, it's very hard not to have a preference, and that's what I'm finding. So even in the hands of committed researchers, it's a challenge to successfully deliver this kind of recruitment.

Clare Delmar: Yeah, that's interesting.

Tim Dudderidge: So that's why we've got the second arm of the study, which is called Chronos B. In Chronos B, it accepts that the patient has made a preference towards treatment - focal ablation. And we've got another question we want to ask, which is can we improve the outcome of ablation with the use of drugs as sort of what we call neoadjuvant therapies? And this is something that mirrors the practice in radiotherapy where men are given hormonal therapy. So we're using one of the same drugs, bicalutamide, but also using finasteride as another drug for neoadjuvant therapy. And we will find out in the next few years whether there's evidence that using drugs like that before HIFU can actually improve the outcome, and that will be very exciting.

Clare Delmar: What do those drugs do? You mentioned neoadjuvant, but could you explain what that means?

Tim Dudderidge: These drugs are both focused at shrinking the size of the prostate before treatment. So you said that the Chronos trials are fully recruited or partially recruited.

Tim Dudderidge: The Chronos B study is very nearly fully recruited, but then we will be focusing on Chronos A and so in effect, the main research objective will be to try and encourage men to accept this clinical equipoise and allow themselves to be randomised between surgery and ablation.

Clare Delmar: Well, I'll make sure that we put a link on the website.

Tim Dudderidge: They do have a website. Well, the end of last year, beginning of this year on a review of various published information about focal therapy. And this was something through the European Urology Oncology Group, and they were quite critical of focal therapy outcomes. And this was having reviewed evidence gained not only through RCTs, but other bits of research. And I just wanted to ask you what you thought about how you would address that, because obviously a lot of these studies might have various biases or as you say, they don't have the time sort of horizons because focal therapy is relatively new that other procedures or other approaches have. So what would you say to somebody who said, well, I read this in this particular journal and what do you think about it?

Tim Dudderidge: So I think it's important to say that a systematic review is only really

helpful when you've got a lot of randomised controlled data. But I could have told you straightaway that there's only one completed randomised controlled trial. In fact, we just published another study, which would have been important in this systematic review, which hasn't been included, but I can mention that as well. But the main randomised controlled trial that they would have included in their analysis was one conducted at University College London. And that study was looking at a vascular photodynamic therapy treatment where effectively around and these were mainly basically they were low grade lesions. And using this treatment, there were some clear advantages over active surveillance, which is the standard care for low grade disease. So although I'm not sure particularly that this study has a big influence on clinical practice because PDT is not in widespread use, first of all. And second of all, I think although there was some improvement measures seen against active surveillance, I think obviously with active surveillance, you know, we do have ways of monitoring patients and allowing a smaller group of patients to receive treatment when they show signs of progression. But it was importantly the first study to show that focal therapy can have a positive influence on the management of men with prostate cancer and as a stepping stone to the current larger, randomised controlled trial that we plan to conduct with Chronos A, it sets out important principles. And I think when we study as we are in Chronos A more clinically significant disease, where the treatment effect will be much more profound. And actually we're comparing to the alternative of surgery where the side effects are so much more significant. I think we're really studying a more important health problem than was studied in that study. All of the other studies that they've kind of summarised would have been low quality studies from an evidence hierarchy point of view. And so it's not at all it's not at all surprising, therefore, that they will call for further research. In fact, that was that's a fairly obvious statement when you're looking at the field, which is only developing. But the best evidence, I think, which was missed out in this study, unfortunately, has just been published by the Imperial Group and the sort of UK focal users group which I'm part of, is this propensity score matching study, which is basically taking the UK's focal HIFU registry data and comparing it to similar men who had surgery. And they've done a statistical method to try and match up these cases so that we effectively try, instead of trying to compare apples and oranges, that we're as closely as possible matching apples with apples, and that methodology is not anywhere near as good as a randomised controlled trial, but it comes as close as you can get, in my opinion, to that kind of ideal study methodology. And so this is literally just been published in the last few days, I think this study and with prostate cancer and prosthetic diseases and hopefully you can share a link to that. 420 of those men had high intensity focus ultrasound, and they did a matching and eventually ended up with a group who matched up with 246 radical prostatectomy patients. And they found that over the course of eight years the patients had cancer outcomes that were similar between focal therapy and radical prostatectomy. And I think that this is really important data because notwithstanding the fact it's not a randomised control trial, it's the biggest and most statistically well powered answer to that question. And I think we can make a simple statement to men, which is in the medium term, it seems probable that the risk of you, if you meet the sort of entry criteria which were part of this study group's entry for HIFU, if you've got those criteria in your disease and you were to go through HIFU, you can be reasonably confident of an equivalent outcome to surgery at around eight years. It's as good as we've got at the moment, and that gives men an idea about what they can expect. Clare Delmar: And of course, give them reduced side effects, which, of course, is... Tim Dudderidge: Yes. Clare Delmar: And yeah. You know, it's always incredible to hear how much of this is actually being done here in the UK. It really is sort of a hub, if not an epicenter of this kind of work. Tim Dudderidge: Yeah. Clare Delmar: And people like you are really driving this forward. I think this is a really, really important topic and I really look forward to seeing the publication of the study you've just talked about. Thanks, Tim. Tim Dudderidge: Thank you. Clare Delmar: A transcript of this interview is available on our website, along with several links to the trials discussed. Visit www.thefocaltherapyclinic.co.uk, where you can learn about alternative treatments for prostate cancer, how we approach patient care at The Focal Therapy Clinic and access additional interviews with both patients and clinicians about their experiences. HIFU Focal Therapy controls cancer as well as Radical Prostatectomy with no side effects: New Imperial College Study We are pleased and proud that a landmark study led by Imperial College London comparing outcomes for men undergoing focal therapy and radical prostatectomy has been published this week, with considerable interest from the media. The Focal Therapy Clinic has played a significant role in this research through our clinicians and patient data. The study is remarkable in both its results and its design. The study's results are clear: comparing the experience of 335 radical prostatectomy patients and 501 focal therapy patients over an eight-year period, it demonstrated that the oncological outcomes are comparable. Designing the comparative analysis made use of patient

data from the HIFU registry, a database of over 2000 former HIFU patients maintained by Imperial College with continued contributions from the Focal Therapy Clinic. Patients were compared using 1-to-1 propensity score-matched for treatment year, age, PSA, Gleason, T-Stage, cancer core length and neoadjuvant hormone use at 3, 5 and 8 years. Failure Free Survival (FFS) for radical prostatectomy was 86%, 82% and 79% compared to 91%, 86% and 83% FFS for focal therapy at the same time intervals. Also, of note the secondary treatment rates were approximately 16% for radical prostatectomy and approximately 17% for focal therapy. Tim Dudderidge, Consultant Urologist at TFTC and an investigator on the study, believes the results are a game changer for men with localised prostate cancer who see cancer control and side effects as a tradeoff. "Most men who are suitable for focal therapy have faced a difficult decision whether to accept the relatively significant side effects of the standard treatments like surgery and radiotherapy or to accept the uncertainty about cancer outcomes from focal therapy. The data from this UK multi-centre study which we have contributed to, changes that" he said. TFTC Consultant Urologist Raj Nigam, also an investigator and co-author of the study, reaffirmed the importance of the study's results in addressing the physical and emotional aspects of side effects from surgery. "We know that radical prostatectomy has evolved into a minimally invasive surgical option over the last decade but still the functional outcomes are of concern to many men. Both of these have a significant impact physically and emotionally on men and, therefore, alternative treatments which spare men from some of these side-effects have been researched in detail and led primarily in the United Kingdom", he commented. Both clinicians agree that the evidence built through this seminal study will only get stronger as the HIFU registry continues to grow and more data is available for further study. As an active supporter and contributor to the registry, The Focal Therapy Clinic will continue to undertake and participate in research. As Tim points out, "There is still much to do to understand the longterm outcomes, but now we can say that after 8 years from treatment the risk of needing salvage treatment appears the same as if you had surgery. We will continue to recruit to the randomised control trial as this is needed to increase the confidence of answering this question but for those men unwilling to be randomised, this study can give them and their families confidence." Added Raj, "The nature of this multicentre study shows that focal therapy should be made more widely available and men should be counselled with equanimity when discussing options that they have when faced with a diagnosis of prostate cancer." Download the full report here: [Treatment for Prostate Cancer Prevents Side-effects Related to Surgery and Described as 'Single Biggest Change in Last 20 Years'](#) Focal ablative therapy - a relatively new non-invasive treatment for prostate cancer - is the 'single biggest change in 20 years' and can prevent side-effects related to surgery, a new study found. Researchers from Imperial College London studied the results of over 500 patients given the treatment to track its effectiveness. Prostate cancer is the most common form of cancer among men in the UK, with around 48,500 new cases every year and traditional treatments come with life changing side effects including sexual dysfunction and incontinence. Focal therapy uses ultrasound or cryotherapy to specifically target cancer cells in the prostate gland without damaging surrounding tissue. The team say hospitals also stand to benefit, as the treatment can be delivered in a self-contained area and most patients can recover at home. However, the treatment comes at a hefty price, with specialised machines costing around £500,000. While focal therapy has been available privately and on the NHS for several years, only 0.5 per cent of prostate cancer patients use it. This is because few public hospitals are equipped to administer the novel treatment and doctors have remained sceptical due to the lack of long-term data. Imperial College researchers gathered enough evidence to support what has been described as the 'single biggest change' in treating prostate cancer in 20 years. Senior author Dr Matt Winkler said: 'As a prostate cancer surgeon I know far too well the devastating impact of erectile dysfunction or urine incontinence on the lives of many men after prostate cancer surgery. We are proud to provide colleagues and affected men with information that may make it easier to avoid radical prostate removal or radiotherapy. There are two kinds of focal therapy depending on the size and location of the tumour in the prostate - a small gland which sits below the bladder. One uses a high intensity ultrasound (HIFU) to heat up cancer tissue with millimetre precision, while the other uses cryotherapy to cool it down. 420 patients who were treated with HIFU and 81 with cryotherapy and in both cases the risk of sexual dysfunction and incontinence was much lower than with traditional treatments. Professor Hashim Ahmed, a leading prostate cancer expert from Imperial, said focal therapy carries up to ten-fold reductions in urine leak and sexual problems. 'Importantly, for the first time we have shown that it has similar cancer control at radical prostatectomy, at five to eight years after treatment,' he added. Each suite costs £500,000, which is much less than the millions needed for surgical and radiotherapy equipment. Prost8 UK's founder Paul Sayer chose focal therapy

when he was diagnosed with prostate cancer in 2018 at the age of 62 and said 'i am all but unchanged from my pre-cancer self'. 'As a result, I am now driven to make sure as many men as possible know about focal therapy and, more importantly, can access it when needed.' The findings could improve quality of life for the 12,000 men who are diagnosed with prostate cancer early every year and 10,000 who return for treatment after radiotherapy. Promoting focal therapy when possible would also free up hospital beds, which have been in short supply during the pandemic, the researchers say. Dr Winkler said: 'After diligently collecting data over the last 10-years, we can now for the first time provide comparative evidence of equivalent cancer control rates for up to five to eight years.' While our method does not provide the highest level of evidence, a randomised controlled trial, it is as good as it gets at this point in time. Focal Therapy Treatment for Prostate Cancer Avoids Side-effects A non-invasive treatment for prostate cancer that prevents side-effects should be urgently introduced across the NHS to give thousands of men a better life, scientists say. Prostate cancer is the most common cancer among men in the UK, with about 48,500 new cases a year. It is usually treated with radiotherapy or surgery, which can have side-effects including sexual dysfunction and incontinence. An alternative, focal therapy, has been heralded as the biggest advancement in treatment for decades. It is as effective as the commonly used treatments but does not cause the same side-effects, new research shows. Marc Laniado Discusses the Impact of Covid-19 on Prostate Cancer Care Reduced referrals and rationed services The Focal Therapy Clinic consultant urologist Marc Laniado joins OnFocus to discuss the impact of Covid19 and lockdown on prostate cancer services and patient care. The backlog in diagnostics and treatments for men with prostate cancer is real and a major challenge to the NHS, and men must be aware of what's available to them. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact becomes a multitude of challenges and opportunities. Joining me today is Marc Laniado, a consultant urologist with The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a vocal advocate for focal therapy from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital and has contributed to several pivotal clinical studies and trials on prostate imaging and focal therapy. He's here today to speak with me about the impact of covid-19 and lockdown on prostate cancer services and patient care. I mean, we're now sort of in week, gosh, I can hardly remember now, but I think we're in week three, is that correct, of our third lockdown in the UK. And I'm interested in hearing your views about how you see the cumulative impact on prostate cancer diagnostics and treatment services in the UK as a result of both the infection rate and the lockdowns that we've had to endure. So I think we all saw that with the first lockdown, there was a drop in referrals and drop in treatments, which then sort of recovered a little bit. There have been some estimates that it would take about two to three years to catch up with all the diagnoses that have been missed out during this time. And also, well, one of the problems has been that men, they don't characteristically go in to see the GP and say, look, I'm really worried about my prostate, please do some tests. Usually what most men do is they come in with some other symptom and they often might mention, might query, and, you know, maybe you should think about testing my prostate or should I have the PSA test. So, of course, now with general practices, understandably not able to do face to face consultations, or having to minimise the consultations to the really very urgent. A lot of these, if you like, unusual opportunities to get tested for prostate cancer don't happen. So you're saying that even in the sort of normal times, so to speak, PSA tests and prostate health checks were really kind of almost like an add on or almost like a serendipity? It's been by chance often that men have had a PSA test and have been found out potentially to have prostate cancer. We've lost out hugely on that opportunity to diagnose men at the point when treatment can be potentially minimally invasive and very effective with fewer side effects. Clare Delmar: I mean, the thing is, you know, given what you said, you see exactly what you said in these very frightening headlines about cancelled procedures. So do you think that might inspire men to think about it more like, wow, I better do something about this or, you know, how should men who are concerned about their prostate health react to these headlines? But if men are concerned, they should still actively go to their GPs and ask to be seen or spoken to on the phone or have a video consultation, you know, the normal symptoms that we would normally be interested in are, for example, certainly losing weight, but urinary symptoms in general, passing urine more frequently, urgently, slow urinary flow, etcetera, spending more time in the toilet than your peers. And in the

appropriate age range, anything up to around 75, 80, a PSA test would normally be appropriate if they have urinary symptoms. And PSA testing is really the only way to diagnose men at a point when prostate cancer is going to be easily curable, treatable. If men wait until they have really severe symptoms, severe urinary symptoms or start getting weight loss before being tested, it is very, very late and it makes our options much smaller. So I would encourage all men who have symptoms or are worried about it to get their PSA tested.

Clare Delmar: So something I wanted to ask you, as you've mentioned, how the quantity of services is clearly being impacted. But I'm also hearing that the quality of service is suffering, in some cases even more and often inappropriate treatments are offered and recommended to older men, for example. I mean, because there's been, if you like, "rationing" of cancer services in some places, you know, understandably, again, because older men have a shorter life expectancy, to some extent, they've been less prioritised perhaps in some places in the diagnostic pathway. And now we're often, unfortunately, saying that, you know, perhaps, you know, we'll wait and see what happens over a period of time. Looking at surgical priority levels, everyone in the hospital has been asked to follow surgical prioritisation. Diagnosis of prostate cancer is relatively low down that priority level unless there are really severe issues going on.

Clare Delmar: So, Marc, last year, one of the things we heard from a lot of our patients was being placed on active surveillance a lot more. And we seem to have seen some indication that that has been increasing and what you've just said suggests that's true. But one of the outcomes that's been revealed to us a lot, but often not to the public, is that there's been a lot of compromising on these patients' mental health that active surveillance has actually kind of really run them through the wringer on their mental health. What have you seen since this and what would you advise men being offered active surveillance during this period?

Marc Laniado: Well, if you've been offered active surveillance, hopefully the cancer is low risk. But certainly if you're on active surveillance, you should do all the conservative things to reduce the chance of cancer progression. So diet, lifestyle, certainly what you should be looking at, apart from that, you should be looking at maybe other treatments that you can have during this period which are not so affected by covid restriction. So, for example, now, in many cases, surgery to remove the prostate is not possible because theatres have been used up to look after covid patients. Many people are being delayed on the start of radiotherapy because radiotherapy shouldn't be interrupted. So patients have been put on hormones sometimes if they're not just on pure active surveillance. But there are other treatments which can be done as day cases, as we know, for prostate cancer, for example, focal therapy is one of them and that can be done under short general anaesthetic as a day case. And for people who have the appropriate cancer, it's a very effective treatment, especially for those men who are potentially also on active surveillance. So I think there are other options available to them should they wish to have definitive treatment to treat the prostate cancer. Being on active surveillance a lot of people would get worried that they're going to miss the opportunity to have a successful treatment. Equally, I mean, some men have been put on hormonal therapy to tide them over during this time. So hormonal therapy, although it will slow the cancer, it's not necessarily a fantastic treatment for prostate cancer because of those side effects. So there are ways to get round the problem of active surveillance or the inability to get treatment now, if people want to take it up. So on that point, I'm just wondering, you know, looking at some possible silver linings here, do you feel that the events of this past year I mean, obviously there's been some negative aspects like the backlogs and some of the inappropriate treatment, but there's also been some positive signs and various innovations in digital and other uses of technology. I mean, do you think that these have enhanced the benefits of focal therapy or back to what you were saying about people who aren't comfortable being on active surveillance might be seeking alternatives like focal therapy?

Marc Laniado: Very interesting you say that Clare, because we've all been propelled into video meetings of one kind or another. So there's been much greater use of the internet and remote means of doing consultations and potentially treatments. Certainly because patients are now more comfortable doing video meetings or phone consultations, it means that patients throughout the country have the opportunity to speak to various experts of any different kind. But equally, if you don't have focal therapy on your doorstep, so to speak, you can now have a consultation like I did last week from someone in Scotland whilst I'm in Windsor.

Clare Delmar: So you have their imaging and you have their other files, PSA, et cetera, and you can begin to look at that digitally, as it were. So we work with, as a group, we work with some of the best radiologists in the world and they can look at imaging taken from all parts of the country and give their opinion on it so we can now identify men who are potentially suitable for focal therapy and discuss that treatment much more widely than we ever could before, which I think is a big advantage for patients. But I have to say, it's always nice to see a patient in the flesh so to speak, and I think, where possible, I still prefer to do that.

Clare Delmar: Well, Marc, on that positive news, thanks so

much for speaking with me today. The future's looking good and I'm sure we'll all be passed that soon and moving forward with fantastic new treatments and offering men more than they ever had before. A transcript of this interview is available on our website, along with several links to Marc's approach to treating men with prostate cancer. Visit www.thefocaltherapyclinic.co.uk, where you can learn about alternative treatments for prostate cancer, how we approach patient care at The Focal Therapy Clinic and access additional interviews with both patients and clinicians about their experiences.

How Longevity Science Could Improve Prostate Cancer Treatment

We are increasingly approached by older men who have been diagnosed with prostate cancer and whose age seems to be the main driver of the treatment they are offered, overlooking their overall health, fitness, and outlook. It's a very common – and a very emotional – complaint, especially coming from men who are 70+ and extremely fit, mentally alert, sexually active and positive about life. These men may not be your “typical” 70-year-olds -- which begs the question, what is typical? Not everyone has access to a clinical team that draws out the broader and deeper information that comes from a holistic approach to patient engagement, and which ultimately delivers a more personalised treatment plan. But the emerging science of longevity may help us to better understand many aspects of older men's health, which in turn may lead to more appropriate, and personalised, treatments for diseases such as prostate cancer.

Biological age vs Chronological age

Chronological age is what we all know as the amount of time passed from your birth to a given date, measured in years, months, days, etc. Also known as physiological or functional age, biological age differs from chronological age because it is based on factors other than just the day you were born, and these factors are, unlike the length of time that you've been alive, things you can influence and even control.

BioMarkers

Biomarkers are biological molecules found in blood, other body fluids, or tissues that provide signs of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition.

Longevity scientists are identifying biomarkers and developing techniques to measure, analyse and evaluate biological age with them.

Data-driven health

Longevity scientists work with vast amounts of data to build predictive models on ageing. The more data on any individual that's collected over his lifetime, the more can be understood and predicted about his health which creates opportunities for more personalised interventions.

Prevention/self-care

Many of the biomarkers of ageing can be impacted by changes in individual behaviour, including diet and exercise. Longevity scientists have undertaken numerous studies to demonstrate this, and advocate for individual ownership of health data so people can build a deeper understanding of the links between their health and their behaviours. This in turn can lead to more self-advocacy and confidence in seeking information and second opinions about their healthcare.

Language and engagement around ageing

Tina Woods, an expert on longevity research and policy, describes this as perhaps the most important element of integrating the science of longevity into our lives and practice. The language of ageing can get very emotive and contentious, -- terms like “elderly” “frail” and “aged” are increasingly seen as offensive and even discriminatory -- and as language is our means to communicate it's important to address this and develop a language that both respects and motivates all individuals and societies as they age.

Tina joined a recent OnFocus podcast to discuss how the language of ageing influences our thinking and behaviours. Most longevity scientists are aiming to give all of us the tools to control our own health and healthcare, and for clinicians to provide more personalised approaches to medical interventions. If this approach to your age and health interests you, you can investigate further by going here: International Longevity Centre UK. <https://ilcuk.org.uk/health-and-care/life-expectancy/> The Sinclair Lab <https://genetics.med.harvard.edu/sinclair/people/sinclair.php> APPG Longevity <https://appg-longevity.org> Lifespan IO <https://www.lifespan.io>

Tina Woods on How The Science of Longevity Might Impact The Treatment of Older Men with Prostate Cancer An interview with a leader in the fast-growing field of longevity science Tina Woods, founder of Collider Health and author of *Live Longer with AI*, joins OnFocus to discuss the changing narrative around ageing, the emerging science of longevity, and how this could impact conversations around treatment for older men with prostate cancer. Tina is an acknowledged leader in the fast-growing field of longevity science. Her recent book *Live Longer with AI* is a top seller on Amazon and, as founder of the All Party Parliamentary Group on Longevity at Westminster she is at the heart of government policy on ageing and living well longer. <https://appg-longevity.org> https://www.amazon.co.uk/dp/B089QPJW63/ref=dp-kindle-redirect?_encoding=UTF8&btkr=1

Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

How a changing narrative of ageing could lead to more personalised medical care

Clare Delmar: Hello and welcome to OnFocus brought to you by The

Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Tina Woods, founder of Collider Health and author of "Live Longer with AI". Tina is an acknowledged leader in the fast growing field of longevity science, and she's here to chat with me about the changing narrative around ageing, the emerging science of longevity, and how this will impact treatment of men with prostate cancer in the future. Tina, welcome to OnFocus and thanks so much for joining me today.

Tina Woods: Thank you, Clare. It's good to be here.

Clare Delmar: So what I'd like to do is start off with some definitions because this is really not quite nascent, I think we're getting into something a little bit beyond that, but it's still quite new to a lot of people and certainly to our listeners. What is longevity science and what do you recognise is something I've heard you talk about before, which is the longevity dividend?

Tina Woods: You've got quite a lot of terms and definitions in there, which actually is an interesting first question to start off with, because what I've realised as I've been more involved in this industry over the last three years or so, when we first started talking about longevity, a lot of people used to link it with sort of radical life extension, with sort of, you know, people would sort of think about sort of Silicon Valley and all the sort of, you know, investors and entrepreneurs who are also looking at this as a way to kind of maximise your lifespan.

Clare Delmar: Yeah, or even immortality sometimes came up.

Tina Woods: Yes, exactly. So it was kind of linked with that, and it's early days and all the billionaires who wanted to live forever and all the rest of it. And I think most longevity scientists and entrepreneurs working in this field would see it quite differently now. And I think where it's really at is on looking at health span sort of maximising the quality of your life and minimising morbidity, compressing morbidity so that basically you make your life better for as long as possible and the side effect is an increased lifespan. And we can probably go into a little bit about the whole kind of basis of age in science, but it's more the sort of the biotech end of it. The AI driven drug discovery is also encapsulated in the sort of longevity science, geroscience, rejuvenation, biotechnology, gene therapy, geroprotectors, regenerative medicine. These are all kind of elements and aspects that you would kind of put into that more kind of longevity science basket. But the way that I see longevity is a much more, I guess, complex industry, actually, because in the end, if we're really talking about people living a healthier, longer life, you also have to think about all the wider determinants of health and what goes into that. So it's about the quality of your life and your environments, housing, your financial wellness. It actually spans quite a huge number of different industries and fields, you know, the quality of care that you get when you need more support and that kind of covers up age tech. So I think, you know, it really comes down to how broad or how narrow do you want to go when you're talking about longevity. But if you want to describe living a longer, healthier life, you do actually have to go quite broad because there's so many factors, and my particular interest is about really understanding the wider determinants of health and, of course, the developments that we're seeing in data and AI, of course, are really shedding light and they're giving us far more insight into what it is that is keeping us healthy and well. What it is that's preventing and what we can do in our own part of preventing or delaying chronic diseases, and that includes the disease that we dread most, which is dementia, but obviously includes cancer and that as well. I think the problem with using ageing, as I have been finding, having been in this industry for three or four years now, is that it just automatically gets linked to a more kind of negative view of growing older just because of ageing in the way that it's sort of linked to all these other sort of terms like...

Clare Delmar: Kind of like decay?

Tina Woods: Yeah, exactly. And actually one of the projects I would really like to do is the whole language of longevity, the longevity lexicon.

Clare Delmar: Indeed. So one thing that has come to my attention in this very broad field that you describe is this distinction between chronological age and biological age. So can you explain what this means and just speak briefly about how you think that this difference could impact treatment for diseases in older people.

Tina Woods: Sure, I mean, we all know what chronological age is, that's the use that we've been living, so I'm fifty six. But a biological age is a term that's getting used more widely, and it's all linked to understanding the whole scientific basis of ageing. So there's a very, very important scientific publication published in Cell in 2016 that describes the nine hallmarks of ageing, which goes into some detail about the biological basis of ageing. So genomic instability, how stable our genes are, is one element people might have heard of. So these are all different types of ageing, sort of free radicals, for example, and creating some of the damage or DNA damage. And a lot of the time it's depends on the stresses, the environmental triggers and stresses that we expose ourselves to, but also inherently to what we're given by our parents our inherent sort of genetic code, but actually a lot is within our control. And that's a really interesting part of understanding ageing is actually there's a lot

more that we can do than perhaps we ever realised. So it's a better measure of describing how healthy you are and it's a better way of describing sort of your trajectory and having, I guess, a healthier, longer life. So there's a lot of research that's taking place and trying to ascribe what is your biological age. And I think it's one of those things that will evolve very, very substantially over the years to come, again aided by artificial intelligence and the scientists who are working very, very hard to uncover what is it that puts us at risk of ageing. And of course, the really interesting, I guess, thesis is all the chronic diseases that we talk about, like hypertension, cardiovascular disease, diabetes and indeed dementia are all linked to the underlying pathology and physiology of ageing. So there's an enormous amount that we can do in terms of our lifestyle choices and the environments in which we live in. I mean, I think the food that we eat and the amount of exercise that we get are relatively easy to control. And if you are at a disadvantage and you live in terrible housing which is damp and you're in overcrowded housing conditions, obviously that's an element that is less in your control because, of course, housing and stresses, you know, they've done a lot of research that shows that if you're in overcrowded situations, if you're in a stressful environment where you're worried about crime, these all actually have an impact on how your body responds to these stresses. If you're having problems at work, if you're... and all the things that we're seeing with covid, all have a bearing on how your body responds to all these stresses. So they all link back to this whole understanding of what creates, you know, how fast we age. So in simple terms, your biological age is an inherent measure of your innate health status.

Clare Delmar: So, OK, so one of the things I was actually thinking about was that if you could differentiate between chronological and biological age and say you met a man who was 70 or two men that were chronological aged 70 in our accepted definition of chronological age, but they had very different biological ages. One was significantly "younger", I'm putting that in inverted commas because we all have different definitions of what that might mean. Could you envisage a world where that then is accepted and would then lead to very different treatments? Because one of the things that we see, particularly in men over 70 and this has been exacerbated by Covid, is that there's kind of a one size fits all policy on treatment for prostate cancer, particularly localised. And this seems to be irrespective of lifestyle, personal circumstances or sometimes even disease specifics. So what I'm wondering is, how do you see the science as it gets more specific and accepted changing that? And could you see that being more than even triaging where you said, well, this guy deserves better treatment because he's got a younger biological age to something that enables us to become more personalised? Do you see that as a future in medical treatment, like real personalisation?

Tina Woods: I mean, as biological age becomes more established and is backed up by the evidence, because a lot of this, of course, is all in animal models and all the rest of it. I mean, I think it's coming and I think the inherent concept is definitely one that will resonate with anyone who is trying to designate a good strategy for a person who is suffering from cancer or indeed wants to stay healthy for as long as they want to. I think, yes, it will help triage but also will help design a programme for that individual person that will best meet life goals. So I think if we're talking about position in medicine, personalised health care, in the end it's all about, you know, following a regimen, whether it's through your own means, through preventative health or through the treatment that you want from your clinicians and your hospitals and what have you, it all comes down to what you want from your life and your life goals, because what someone might want from their life of being able to run a marathon every day will be very, very different to someone who basically just wants to be able to walk down to the local shop every day. But I think we already use sort of performance status to decide, you know, what treatments a person should get, in their cancer care. So there's no reason why some of the tools that we have which are emerging about age could be very, very useful because, you know, we know that you can there's groups like Nightingale Health who I wrote about in my book, I mean, through a series of blood biomarkers, they can very accurately estimate how many years you've got left to live, which is fascinating.

Clare Delmar: Yeah, yeah. I mean, that leads me on to this kind of well recognised concept we often see in medical treatment and particularly amongst older patients, which is survivability. And, you know, I guess one of the ways I could potentially see this changing the whole approach to survivability is exactly what you're talking about, that it's more about longevity and what you're capable of delivering in the years ahead.

Tina Woods: Absolutely. I mean, you know, the whole two sides of the same coin, you know, the actual underlying disease process is that the route for cancer is the same as aging. So it's kind of interesting when you think of it that way, you know, sort of the cells gone rogue, some of the underlying mechanisms are exactly the same as when cells are undergoing the whole sort of aging process. But I think in the end, it's about understanding with the knowledge that we're acquiring, with the tools that we've got, to target the best possible preventative health, but also management strategies, whatever

you're being hit with. Because, of course, what they're saying is that all these chronic diseases, including cancer, they all share the same root underlying some of their processes. Clare Delmar: So I guess I'm kind of coming at this from, you know, men who come to us and already have been diagnosed with cancer. But there's such vast differences in sort of where they are, what their personal lifestyle is, et cetera. And yet it seems to be quite random about who gets what treatment, because those conversations are not quite uniform. And I just wonder if biological age is a method of actually standardising those conversations? And which kind of leads me to my final question, which is all about how you actually begin to get this dialogue. And I know that you have recently, I guess, two years ago established the APPG, the all party parliamentary group in Westminster on longevity. So what are its aims and how do you see it having most impact? Tina Woods: Its broadest aim is it's about delivering on this government goal of achieving five actual years of healthy life expectancy by 2035 while minimising health inequalities. And the reason why we formed the APPG was to look at a strategy because there's government money going into that goal. So this is through the UK Research and Innovation Round Challenge programme, for example, for Healthy Ageing is one strand of ageing society grand challenge where government is investing three hundred million pounds to essentially sort of invest in this particular area for, you know, for the UK to succeed and lead in the world, for example. But what we realised, this is the reason we set up the APPG, is that there is no real strategy. So over the course of about 9-10 months, we brought together leading scientists, business people, policy professionals, et cetera, and a number of leading groups like Kings Fund Health Foundation, Genomics England and about 50 organisations. We all came together to look at what are the handful of things that we must do to be able to deliver on this goal. But I think fundamentally the biggest impact we're going to see is actually seeing what all of us can do in our own ways to deliver on this goal, because a lot of it comes down to the public and just having the mindset that actually the science and technology as we've got it now and being driven in huge part by A.I., for example, which is my particular interest, you know, we've actually got the tools and the knowledge now to be able to do far more than we ever dreamed was possible at an individual level, but also the population health level. So coming together, we can do a lot more to be able to see a), the opportunity of living a longer, healthier life, not see it with the dread that we used to and see it in a much more positive, optimistic light, because there is a lot that we can do. And I think a lot of it is it comes down to knowledge, you know, politicians, you know, people, business leaders and CEOs. You know, we all suffer from not being able to keep up to date with everything that's taking place. And then, of course, covid has accelerated the scientific discovery that we're seeing already with vaccines and also the treatments that we're seeing. And of course, the other interesting part of that is all the scientists in longevity have realised pretty early on that those who are getting impacted by covid were those, yes, who were older, but actually linked to that, was this going back to the root of ageing? It's the whole physiology and pathophysiology of the ageing process and the chronic diseases. So people hit hardest by Covid are the ones who were in ill health, which is why we really need to tackle ill health as an absolute priority. We were in the massive health longevity publication just before Christmas talking about our Healthy Nation. So we need to tackle preventative health in a massive way. Clare Delmar: So do you think that covid has actually in some ways, you know, it is almost counterintuitive, positive way highlighted older people and not just about preventative, but the science that enables us to treat older people in more personalised ways. Tina Woods: So I think covid has been, despite the horror of it and the terrible impact it's had on the world, there are quite a few silver linings that are coming out of it. a) It's shed a spotlight on how important our health is as an asset that we must protect and do more to protect it. It's really put a spotlight on how we need to invest much more in preventive health and to keep healthy and well. It's also highlighted how ageism has... we can't ignore it any longer, we have to tackle that. Clare Delmar: Indeed. Tina Woods: So that has shed light. And of course, we've seen that with the policy response to everything that we're doing in care homes now and getting vaccinations to our most vulnerable citizens. So I think there's a lot that we can take away from covid that are really positive. Clare Delmar: Tina, it's been a real pleasure to have you on the OnFocus programme today. I mean, it's not only illuminating, but I suspect it's only the beginning of many conversations around what's clearly an emerging and fascinating topic. So thank you so much for introducing us to it. Tina Woods: Well a huge pleasure, Clare, and thanks so much for the chance to chat. Clare Delmar: OK, a transcript of this interview is available on our website, along with several links to Tina's work on longevity and her recent book. Visit www.thefocaltherapyclinic.co.uk, where you can learn about alternative treatments for prostate cancer and how we approach patient care at The Focal Therapy Clinic. Also, you can access additional interviews with both patients and clinicians about their experiences with prostate cancer. Prostate Cancer in a Covid World By Alan Doherty, Consultant

Urologist at The Focal Therapy Clinic and The Birmingham Prostate Clinic. As Covid-19 changes our lives in every conceivable way, inevitably, in the field of prostate cancer, we are working through significant change. We are becoming a little more adept with the technicalities of zoom and accustomed to consulting without being able to physically see and examine patients. We have new protocols focused on how we manage the relative risks of prostate cancer and Covid-19, against benefits. If a patient's PSA reading is below 20, we are advised to avoid further diagnostics and repeat the test in three months' time. If PSA is above 20, the guidance states the patient should go onto hormone treatment to halt disease progression. This is, of course, a difficult trade-off between different risks of Covid-19 and prostate cancer. The judgement is that within three months, by having hormone treatment or active surveillance, there will be no real impact on the patient in terms of overall survival or quality of life. But it is not easy; many men do not want to go onto hormone treatment as a first line approach and for those assessed as being low or intermediate risk, being told to go home and return for another test in three months' time does not always sit well. In some of the private hospitals where we operate, providing they are Covid-free, we are able to carry out diagnostics and urgent treatment. We are advised to avoid TRUS (trans-rectal ultrasound biopsies) due to the risk they carry of sepsis. At BPC, the TRUS has not been part of our diagnostic pathway for many years, due to infection risks and imprecision. The MRI scan – always a key part of our pathway – is likely to become even more important in assessing whether a biopsy is required. We have consistently emphasised the value of a high-quality MRI scan in the prostate cancer assessment process. Now more than ever, the need to be precise about who needs a biopsy and who does not is critical. Events at sports clubs where charities have offered free PSA testing are unlikely to return soon and may, in fact, never return in the same way. We often see patients who come to us and are diagnosed with prostate cancer after one of these events; they would otherwise not have had any indication anything was wrong. This may have an impact if these opportunities to identify prostate cancer via screening at an early stage are lost. At the same time, men of all ages have become increasingly comfortable with video communications as a result of Covid. This may increase the way patients connect with specialists such as urologists, going directly to consultants for advice and opinion. We have been offering telephone advice and guidance at the Birmingham Prostate Clinic for several years; we have always supported patients seeking a second opinion and those considering accessing our service from distant locations. It is likely that a long-term consequence of this experience will be more movement in this direction: people feeling increasingly confident to consider different treatment options and to access services that closely reflect their priorities, rather than choosing on the basis of a service which happens to be within your locality.

Colin Stokes MBE on Founding One of the UK's Leading Prostate Cancer Charities How The Prostate Project has supported developments in diagnosis and treatment Colin Stokes MBE is the indefatigable founder and honorary chairman of The Prostate Project, a charity established in 1998 and dedicated to improving the experience and outcomes for men with prostate cancer. Based at the University of Surrey and closely linked to the Royal Surrey Hospital, it has made a significant impact on both research and patient experience with prostate cancer. In this interview Colin emphasises the importance of localism and focus in the work of his charity, and demonstrates how this approach has helped to establish the Royal Surrey and the Stokes Centre for Urology as a world-class centre of excellence in prostate cancer research and practice. <https://www.prostate-project.org.uk/about.html> Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Helping men to beat prostate cancer Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today for our first podcast of 2021 is Colin Stokes MBE, a former prostate cancer patient and founder of The Prostate Project. Established in 1998 with the aim of giving men a better chance of beating prostate cancer, The Prostate Cancer Project has raised over 10 million pounds and helped the Royal Surrey County Hospital achieve Centre of Excellence status in the treatment of prostate cancer. It has provided equipment and specialist nursing staff to the Royal Surrey, St. Luke's Cancer Centre, and Frimley Park Hospital and runs an active patient support group in the Guildford area. Colin is here to talk with me about how charities like his play a vital role in research and patient support. Colin, welcome to OnFocus and a very happy New Year to you. Colin Stokes: Well, Happy New Year to you. And thank you very much for talking to me about The Prostate Project. Clare Delmar: Excellent, and well, I'm looking forward to it, so let's dive right in. And I think the best way to start is I've given a very brief summary, but perhaps you could open this

discussion up by telling us about how you established The Prostate Project and what its mission has been and is currently. Colin Stokes: Yeah, well, in 1997, I was exceptionally lucky to have a minor lump on my face and a very up to date and observant doctor, the GP I went to, decided that he would check my prostate and found that I had prostate cancer. And during the meetings with John Davies, he was very... We got along quite well and we talked about prostate cancer and he outlined the shortage of capital equipment for treatment and diagnosis in the Royal Surrey. And so we said, well, the simple contract was: you keep me alive, I'll raise you some money. So he promised to do his bit and I said, well, in that case, I'll do that after about nine months.... It wasn't nine months, six months after I had the operation, because then the choices were pretty limited and I had open surgery removal. And he told me the issues in more detail about the fact that I had one ultrasound machine, very old one, of course, but it was good at the time. And he explained that whenever... they'd only got one in the hospital, which meant whenever there were two of them doing clinics they had to push the ultrasound between them, and all that sort of stuff. And he got five or six of his friends and I got five or six of my friends and The Prostate Project was born. And really, as you rightly said, it was right from day one about giving men a better chance of beating prostate cancer. So any decision that the trustees made was always with that absolutely firmly in their minds. Clare Delmar: OK, wow. So a question I have is that 23 years ago, 1998 doesn't sound that long ago, although I suppose it was 1997 when you were diagnosed. Colin Stokes: 23 years. Clare Delmar: 23 years. And what would you say are the biggest and most positive developments since then for men? Colin Stokes: Probably if I look back and think a) what I had to go through in order to be properly diagnosed. On a Saturday morning, I remember going to see John and having this put up my backside and having the biopsies taken. Now, that was a pretty unpleasant experience. Clare Delmar: Absolutely. Colin Stokes: ...and probably had a lot of danger about it I suspect in retrospect. But you couldn't think of it then, and I suppose these days the huge advantage of accurate and more effective diagnosis, the dropping of the use of a biopsy as a diagnosis tool, largely, it is used, but it's not the first thing that happens. It's one of the major moves and the latest move where we've just bought the Royal Surrey, a ultrasound and it melds together with the MRI scanning into computerised version. Clare Delmar: So that's the fusion biopsy system? Colin Stokes: Well it fuses the two images. If you can imagine originally when they had the ultrasound and MRI scan, they had two scans to look at and they had to try visually to put the two scans together. They have the machine that gives them an absolutely crystal clear picture of where the cancer is in the prostate. And so their ability to then if they need to take a biopsy, it's a procedure done with either local or full anaesthetic and then they go straight onto the cancer and they can find out exactly how aggressive it is. So that bit of it, the diagnosis, is dramatically better. Clare Delmar: Yes, indeed. Colin Stokes: And then, of course, the choice I had was you had yourself cut open to take it out or you have radiotherapy, as I remember. I mean, it's a long time ago. Clare Delmar: Yeah. Colin Stokes: But I mean, I can remember he showed me the options and it was as far as I was concerned, it was take it out, let's get rid of it, which is what we did. Clare Delmar: Yeah. Colin Stokes: That's the huge advantage: advances in diagnosis and treatment has been amazing. Clare Delmar: And would you say you've been very much part of that journey through The Prostate Project? Colin Stokes: In a very small way, I mean, but this has been a world movement. And what's found out in California or Melbourne or South Africa is soon understood throughout the world. The number of seminars and discussions and interchange going about that's really what made it successful. Each step in that world effort just adds to the importance of continuing to improve and never thinking your at the end of the journey, you're on the journey but not at the end of the journey. I mean, every person who gets prostate cancer should have access to every opportunity of treatment because with every person it's personal. And what I would want and what John would want and Bill would want and Graham would want, will be different. Clare Delmar: Absolutely. And of course, the individuals you just listed, each of their capacity to find information online, which, of course, really didn't exist 23 years ago. Colin Stokes: That's right. Clare Delmar: That's a big part of the journey, isn't it? Colin Stokes: You don't hide things. There is something that is crucial to The Prostate Project, which has been also in the base of its thinking and ambition and dynamism, is that this is about turning the Royal Surrey, St Luke's Cancer Centre, and then after a couple of years which is when we joined up with Frimley Park, turning them into a centre of excellence, a world centre of excellence that will give men a better chance of beating prostate cancer. And we look at what others do and we look at how other charities operate, and our difference is that we have remained focused to that area. Clare Delmar: That's interesting. So I was going to ask you about The Royal Surrey, which is where this whole journey began, both for you personally and for the project. So tell me, for example, about the Stoke's Centre for Urology, which you've now established and how that's contributed to the world class Centre for Excellence. Colin

Stokes: Can I take you through a bit of the history? The first thing that happened was we realised that this was not going to last for a year and we weren't going to just raise £350,000 and we were going to close down. So the first thing that happened was we realised that not only should we be working for the Royal Surrey, but Frimley Park Hospital, which is up the road, has a very effective urology department. And it was right that both should be welded together, not competitive but working as a duo. And then we went and talked to Prostate Cancer UK in about 2001 or what was then a group of various charities amongst them. And we realised that actually the function of a local charity, like The Prostate Project, was not to advance world acknowledgement, but to make it effective here in this location. Then we realised that if you want to be really effective, you've got to have a powerful research arm. Just across the road from the Royal Surrey is Surrey University. Clare Delmar: Right. Colin Stokes: A highly capable technical organisation. And in 2006, having raised two million pounds, we funded the development... With the University of Surrey, we funded a research group, which has been in existence since then and is 25 people strong or thereabouts, it's sometimes 20 because it has PhD students in it, but it's around 20 plus medics there. And they are operating as a research organisation under the aegis of the University of Surrey. Clare Delmar: And is that funded entirely by the Prostate Project? Colin Stokes: It was a mutual funding, but they couldn't have done it without this and we couldn't have done it without them. So it was a highly beneficial mutual activity. Clare Delmar: And they're still continuing their research? Colin Stokes: Absolutely. Clare Delmar: And what are the highlights of their research? What are some of the things that they've been investigating? Colin Stokes: I'll tell you one of the things that's happened fairly recently. You get metastases from a prostate cancer, cancer of the prostate, it moves to lymphs, it moves all around the body, to the bones, goes to spines. And I'm sorry, I don't remember it, but if you get metastasised prostate cancer and then try to treat it as is prostate cancer it ain't going to work, or it might not, it sometimes does. So that to me would be a highlight because nobody else in the world but the guy in the Royal Surrey, a PhD student, working with a colleague in Canada discovered this amazing fact, which means that, of course, treatment of men who have advanced prostate cancer, it can now be much more effective. Because now what they know is that if you actually have metastasised prostate cancer, they'll test to see if it responds to normal treatment. If it doesn't, they biopsy it and find out what the real cancer is that's in that particular location. Clare Delmar: OK. Colin Stokes: That doesn't sound a lot, but, you know, that's a huge step. Clare Delmar: Absolutely. Colin Stokes: A whole range of those steps have taken place in the 14 years that they've been operating. But the other important thing about that, when we put our money in, we said the one thing we don't want is a separated research group. So the research group, always the top guys, Professor Pandha and his top team, all do clinics in the Royal Surrey St Luke's Cancer Centre. Now, what this means is they are day to day dealing with men with advanced prostate cancer, so that links research into reality. Clare Delmar: Absolutely, yeah. Colin Stokes: That was part of our money when we put our money and we said, look, that's what you got to do. So Professor Pandha, every week, is an oncologist working in Royal Surrey Cancer Center, St Luke's it's called, and that means he's constantly up to date. Clare Delmar: But does it also mean that the patients themselves are sort of given some sort of aspect of hope because they might be involved in research, whether it's a full fledged trial or just a new innovation? Colin Stokes: Of course, endlessly. I can remember being involved, talking to him and we were helping to fund an investment into a new trial of a new particular drug for advanced prostate cancer. I remember saying, you better get on with this because you never know I might need it one day. I did, in the middle of the pandemic, find that I needed that extra boost to my treatment and there it is. So now we had two hospitals, all the consultants at the Royal Surrey, part of the Prostate Project, because one of the things we said right from the start, it's got to have in its trusteeship, it's got to have an equal number of medics to patients. So the trustees are balanced when they're looking at what we should do and how we should spend our money between people who are heavily involved in the medical side, and are heavily involved in patient side. And we have that constant debate and discussion as to what is the way we should best next proceed using the money we've got and using our effectiveness and bringing messages to other medical people, to doctors. Clare Delmar: Well, the other thing that I know about it is that the appreciation clearly goes both ways. So can you talk a little bit about that? Colin Stokes: Yeah, well, the university awarded me the doctorate because it was a recognition for the charity of what we'd done with the university and yeah, you're quite right, the hospital for services to The Royal Surrey, I got an MBE. I mean, the reality of the team in the Prostate Project, right from the start, they have been an amazing group of people working together, focusing on the next ambition. Ninety six percent of the money we get given gets used in what we declare as giving men a better chance. Clare Delmar: That's very impressive. So, Colin, I just want to shift the conversation really quickly before we

conclude that something else I think our listeners will be interested to know is, is that you were one of the first in the country to receive the Covid vaccine recently? Colin Stokes: I was. I go into the Urology Centre and meet men and their families who are being diagnosed, have been diagnosed. And the urology centre is obviously at a high spot now because it is an absolute centre of excellence. It's a great centre, I don't know if you've ever been there, I'd be happy to show you around, it is a brilliantly designed centre designed largely by the medical team, led by Professor Steven Langley. And that centre works brilliantly because it brings all the people together who are involved in the diagnosis and treatment of prostate cancer. So I can assure you that is now, a brilliant centre and it's a centre that ought to be replicated elsewhere because it's so... Clare Delmar: That's an interesting idea, so it's like a template. But just to finish on the Covid vaccine, I wanted to ask you about how that's impacted your outlook on health care generally, but more importantly, prostate cancer support in the UK. And how do you see where we stand? Colin Stokes: Well, right now, I think the vaccine is going to be the resolution of this pandemic. Can I just say one other thing... Clare Delmar: Of course. Colin Stokes: One thing about prostate cancer, which is never quite presented and we are in the process. Well, we're going to present prostate cancer in a slightly different way because prostate cancer has no symptoms. This is a symptom-less disease and it only has symptoms when it spreads. Clare Delmar: Yeah. Colin Stokes: So the problem is people are encouraged, men are encouraged to wait until they have symptoms. Then what are you worrying about? Clare Delmar: Yeah. Colin Stokes: What we should be worrying about is the fact that more men are being diagnosed with it, but they're being diagnosed when they have symptoms. That means it's spread. Clare Delmar: Absolutely. Colin Stokes: So we're starting a raging war campaign on getting men to understand it's a symptom-less disease when it can be treated. Ninety four percent of the men who come to the urology centre at the Royal Surrey, and it's in the capsule are cured. So the answer is to men and particularly to black men, because they get it ... Clare Delmar: More than twice the rate, yes. Colin Stokes: So black men should, particularly from the age of 45 and certainly from 50 up to 70, have PSA tests as a guidance to see whether they've got a problem. If they have, get themselves diagnosed because these days with the MRI and the ultrasound and now the fusion of this, the diagnosis is so much more accurate, so much more effective, so the treatment is so much more powerful. Clare Delmar: So how are you going to get that message out there, Colin? Colin Stokes: Well, what we're doing is we were in the process of running training programs with doctors in their surgery. We were going to buy lunches for doctors and explain the reasons why things have changed, because things have changed. So we've got to make sure that every doctor who meets a man for whatever reason between the ages of 50 and 70, offers the PSA test as part of the normal process. Clare Delmar: So you're referring to GPs specifically here? Colin Stokes: Yes, GPs. Because if you think that you've got a lot of GPs who will be worrying about their cholesterol, about their weight, about their eating habits. We've just had an example, a man, a very close friend of mine who knew he should have had a test, didn't. When we realized that his back was in a terrible state, we eventually got him to go to a spinal guy. If at any of those times when he was having his cholesterol done. Clare Delmar: He could of been doing a PSA test. Colin Stokes: Precisely, and it would have cost minimal amount of money. What it's now cost the NHS is two weeks in hospital, injections, support at home, all that, the money we spend and it's right we do it. But if we'd have tested him when we were just doing other things, we'd have found that he'd got it, and they would have treated it and it would have been cured. Clare Delmar: Colin, do you see a time when the PSA test can be self-administered and the campaign becomes something that's taken up not just governments and public health organisations, but even companies offering tests. Colin Stokes: I mean, we get a lot of men coming to use. Because he had been giving all his staff health checks, which includes a PSA, so we should be doing it anyway, testing. What we did... One of the early things we found, we have got a urine test that was developed at the Royal Surrey. They just couldn't do it commercially. Clare Delmar: Right. Colin Stokes: So you can't get yourself a blood test. I mean, you're right about the urine test because it gives you an absolute cancer indication, whereas the PSA does not, as you say, it's only an indicator. What's changed is the diagnostic process is so precise that if only we could get men to have the early test. Colin Stokes: It is true what you just said. But, you know, I'm worried about this sense that the PSA is not a good test for prostate cancer. We're all very excited today about the vaccine that's going to give 90 percent protection. Clare Delmar: True. Very good point. Colin Stokes: Now, if you had a PSA test that is actually ninety five percent, it occasionally gives you too low a result. A PSA will give you 90 percent. Clare Delmar: Correct. Colin Stokes: Most of the people will be all right. And we could use PSA if we used it routinely with men between the ages of 50 and 70, we would have a dramatic difference. Clare Delmar: You're right. And I will certainly endeavour to make sure all our listeners support that and come

to your site to help you do that. Colin, thank you so much for speaking today with me. Colin Stokes: Thank you. Clare Delmar: It's been such a pleasure. Learned a lot and really want to help support what's an incredible project and an incredible team. Colin Stokes: I actually had to resign as chairman, I didn't have to, I chose to. Because at 82, I felt if something happened now, I needed to make sure there was a very good follow up. A guy called Alf Turner and he is now chairman, but I'm still obviously heavily involved. Clare Delmar: So for our listeners, a transcript of this interview is available on our website with a link to The Prostate Project so you can learn more and hopefully find a way to support its great work. Visit www.thefocaltherapyclinic.co.uk, where you can also learn about alternative treatments for prostate cancer and how we approach patient care at The Focal Therapy Clinic and access additional interviews with both patients and clinicians about their experiences with prostate cancer. Small, Local Charities who are Delivering Big, National Impact for Men with Prostate Cancer Happy new year! Our first blog of 2021 is inspired by four small and local charities that are making a real impact on prostate cancer research and practice well beyond their size and locality. In a time of uncertainty and stretched resources, it's organisations like these that make the difference in what's available to both doctors and patients. The Prostate Project Founded in 1998 by the inspiring and now legendary Colin Stokes MBE, the Prostate Project is based at the University of Surrey and the Royal Surrey Hospital NHS Trust. Stokes founded it along with the Urologist who treated him for prostate cancer, John Davies. Since its establishment the Prostate Project has raised over £10 million, and recently opened the Stokes Centre for Urology at the University of Surrey to undertake world-class research on diagnostics and treatments for prostate cancer. Currently 25 strong, the Prostate Project research team are producing results of international importance including the development of antibodies against targets on the surface of prostate cancers, the development of vaccines from the patient's own immune cells and the use of a potential new marker (EN2) in urine to identify the presence of prostate cancer; the first breakthrough in diagnosis since the 30-year-old PSA blood test currently used to detect prostate cancer. They are currently investigating new techniques to identify and treat advanced prostate cancer using immunotherapy. With its research draws on global resources and benefits the world, the Prostate Project keeps close ties to the Royal Surrey Hospital and to the local community in its fundraising and celebrates local artists through its annual Art Auction. The Prostate Project www.prostate-project.org.uk twitter: @_ProstateProjec facebook: The Prostate Project Prost8 Prost8 is the newest of our small charities – established in 2018 by Paul Sayer, it is based in Southend-on-Sea and focused on making focal therapy and HIFU treatment available to all men whose prostate cancer diagnosis qualifies. Paul recovered from prostate cancer without sacrificing his quality of life by having HIFU treatment – something he had to search for himself. Prost8 is founded on the principle, borne out of his own personal experience, that there are some “remarkable medical developments happening in prostate cancer right now and as a result 1000's more men with prostate cancer can live longer and have better lifestyle outcomes” – but these are not made available to the vast majority of men. His mission is to provide many more men with earlier screening, better treatments and a much better life after treatment. Prost8 www.prost8.org.uk twitter: @prost8uk PROSTaid Established in 2006, PROSTaid is based in Wigston, Leicestershire and run by prostate cancer patients, families, friends and urological professionals to support men and their families in Leicestershire, Rutland and Northamptonshire. Information and counselling is available to all men with prostate cancer and their families, and delivered by local men who themselves have or have had prostate cancer. Five support groups are actively run and have continued through the Covid pandemic via videolinks provided by the charity. PROSTaid funds two specialist Prostate Cancer Specialist nurses, one diagnostically focused within the Urology Department at Leicester General Hospital, and the second based within the Oncology Department at The Leicester Royal Infirmary and focused on metastatic and palliative prostate cancer care. I also funds the development of cutting edge treatments not available on limited NHS budgets, in partnership with the University of Leicester and the John Van Geest Centre in Nottingham One of its most visible services is to raise awareness and educate local men and local GPs about prostate cancer, and PROSTaid runs master classes for medical professionals early detection. It runs Awareness Days within local workplaces and among local men's community groups, targeting high-risk groups including men of Afro-Caribbean heritage. PROSTaid maintains an active and ambitious fundraising programme which draws local communities together through sport and adventurous pursuits, further reinforcing its impact on the region and serving as a model for other charities. PROSTaid www.prostaid.co.uk twitter: @PROSTaid The Pelican Cancer Foundation Based in Basingstoke, Pelican is committed to improving the lives of men with prostate cancer by funding innovative research projects that investigate precise treatments, such as focal therapy, that are highly

effective and reduce the severity of side effects. Its focus is on developing precise diagnostic and treatment options that, where possible, enable men to retain their quality of life – preserving sexual, bowel and urinary function. Pelican believes that more precise detection and treatment options for prostate cancer should be made available for patients, and that funding for precise prostate cancer detection and treatment is a priority. Pelican's research projects challenge the prevailing assumption that all men need to have their whole gland and the surrounding structures treated, irrespective of the volume and location of their prostate cancer. It has been a significant contributor to research on focal therapy, a form of treatment that ablates only parts of the prostate considered affected by clinically significant cancer. Focal therapy ablates discrete areas of known cancer in the prostate and can offer men a treatment option to control disease while preserving maximal amounts of healthy tissue. It has supported four clinical trials at UCLH using High Intensity Ultrasound (HIFU) as a method of focal therapy. While supporting world-class research, Pelican is firmly based in its local community and combines fundraising and cultural programmes through the Pelican Film Society which screens monthly films in Basingstoke. The Pelican Cancer Foundation www.pelicancancer.org twitter: @Pelican_Cancer facebook: Pelican Cancer Foundation

Keep an eye on these organisations, as they provide excellent and up-to-date sources of information and ongoing events. Share their links with your friends and colleagues, and, above all, please consider supporting them.

Prostate Cancer in 2020: From Crisis To Opportunity

What a year this has been; like a never-ending emotional roller coaster, as fear and despair give way to opportunity and insight, back and forth. We've learned so much by listening to our patients' experiences as they've navigated prostate cancer diagnoses amidst a raging pandemic and a restricted health service. Out of crisis comes opportunity, and as we review some of the insights gained over the year, we reinforce our commitment to improving the diagnostic and treatment experience for men with prostate cancer. While Covid19 has dominated the healthcare system, it has generated reductions in cancer screening and compromises in diagnostics and treatment. Many of our patients have been severely affected; as described in one of our blogs, men have been put on treatment programmes that are inappropriate for their age and circumstance. Without the support expected from the health system, more and more men took the initiative to seek out treatment options for their prostate cancer diagnosis. In doing so they became informed and determined advocates for their own healthcare, and many of them who received treatment from the Focal Therapy Clinic are now keen ambassadors for focal therapy. As our doctors couldn't meet in person for their regular MDT reviews, we developed a digital solution that is delivering an improved, better service to our doctors and ultimately our patients. Men over 70 who have come to the Focal Therapy Clinic tell us they feel ignored and abandoned in their prostate cancer journey, often arriving at a dead end as diagnosis and treatments offered are limited and depersonalised. Another disproportionately affected group, in terms of both Covid19 and prostate cancer, has been black men. The pattern of Covid19 infection, hospitalisation and death revealed undeniable health inequalities between white and non-white communities, and the rise of the Black Lives Matter movement has ensured that racial discrimination and inequality is understood by all and discussed and addressed by many. Those of us involved with prostate cancer have long known that the burden of the disease is twice that for black men than for white men -- 1 in 4 v 1 in 8. Fortunately, Prostate Cancer UK recently announced a new study called PROFILE aimed at black and Afro-Caribbean men - it's currently recruiting participants. We've learned this year about the importance of data in giving our patients better care, both in the operation of our clinic and in clinical research. Engaging with the global research consortium Prostate Pioneer has shown us how "big data" is being used to answer some unsolved questions about prostate cancer. Next time you're asked to give consent for your medical data to be used, you'll understand why. Covid has spotlighted the importance of good mental health in our collective wellbeing, as the isolation forced by lockdowns led to depression and anxiety for many people. This was exacerbated for those with cancer, as waiting became an unwelcome element in their journey, almost everyone had to endure delays in hospital appointments and procedures, but for those put on Active Surveillance, prolonged waiting became too much to bear. Mental health challenges faced by men with prostate cancer were explored in one of our earliest podcast interviews with Marc Laniado. By far the one issue that has generated the most interest and discussion amongst our patients is the absence of public toilets in our communities. A pre-Covid disinvestment in public facilities was accelerated by Covid restrictions, and while everyone was inconvenienced, older men and men with prostate disease have been hit particularly hard. Many men told us they simply didn't go out, reinforcing the mental health repercussions from isolation. From our many conversations on this topic, we honestly believe that available and accessible public toilets are the one single investment that can give men with prostate disease an immediate improvement to

their quality of life. All of these insights have been garnered through many, many conversations with our patients, some interviewed in our OnFocus podcast and others through patient engagement. Gathering these insights and shared stories over the course of 2020 means that 2021 will be a year of translating them into better care for our patients. Restrictions on Public Toilet access are causing hardship for Prostate Cancer Patients Talking toilets with Tom Riley, founder of Lockdown Loo Our final interview for 2020 is with Tom Riley, aka Sir Caughtshort, founder of Lockdown Loo, who joined OnFocus to discuss the lack of public toilets and how this has caused a public health crisis across the UK. His response was to set up Lockdown Loo, a digital map of available and accessible public toilets. In this interview we discuss how the lack of public toilets discriminates against older folks and, in particular, men with prostate disease. Download the map here, read our blog here and join our Facebook discussion here. Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Mapping public toilets Clare Delmar: Hello and welcome to On Focus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Today, I'm speaking with Tom Riley, also known as Sir Caughtshort and the founder of Lockdown Loo, an interactive digital map of available public toilets across Britain. Tom's here with me to discuss toilets or the lack of them and how this discriminates against older folks and, in particular, men with prostate disease. Tom, thank you so much for joining me today. Tom Riley: Hello, Clare, and thank you very much for inviting me on. Clare Delmar: And should I call you Tom or should I call you Sir Caughtshort? Tom Riley: You can call me Tom. But I seem to have ended up becoming the living embodiment of him. Clare Delmar: Well, you can tell me more about him as we as we move through. So tell me a little bit about the story behind Lockdown Loo and I guess Sir Caughtshort, your embodiment of Lockdown Loo and when and how did you set it up? Tom Riley: We started the map during the summer. Everyone was in the first lockdown, staying at home, and when the government started to ease the restrictions, the hot weather started coming our way and people could start meeting in parks again in groups of six outside. And we were at a park near Hammersmith and we went probably a little bit too far away from home and didn't really think about needing to go to the toilet. And a few drinks later in the heat and suddenly the urge to go to the loo arrived and there was nowhere to go. And I guess certainly I think a lot of younger men would normally pop behind a bush or something, but that was out of the out of the question there. So in the end we had to run all the way across what felt like most of west London in order to use our toilet at home. And I think we both were just sort of sat on the sofa afterwards thinking there's got to be a better way. The next morning, almost within an hour, we set up a website and a map and just went with the how hard can this be sort of approach. And my brother, he's the younger brother so he had to do a lot of the grunt work, which at the beginning was cycling around London, visiting toilets to see whether they were open or not, which was... And I was back at base, I guess, logging the bogs as they were coming in. So I was getting texts saying no throne at Buckingham Palace and things like that. Clare Delmar: Even Sir Caughtshort was refused entry. Tom Riley: Yeah. And within the first couple of days we have 30 and that's and I think about 50 or 100 people had used the map and that felt like everything in the world then and then it just started pouring in as the days went ahead. Clare Delmar: So what's the purpose of the Lockdown Loo map? What is this service you're offering? Tom Riley: It's to help people find and share locations of open toilets in the UK. During the lockdown, with everything being closed, a lot of councils shut their public toilets. A lot of hospitality industry had to shut toilets, which might have normally been on community schemes or just been available to customers. And retail sector as well has also had to shut off toilets because, you know, the pandemic, it's all been about hygiene. At the beginning, a lot of people thought, well, we must shut down the places where there's potential for spread so that meant we had a country during the summer where there were very few toilets at all. Clare Delmar: So it helps people find a toilet. It's been used millions of times. Clare Delmar: Is it updated like daily or weekly or in some regularity? Tom Riley: The way we update it is, people can send us... And it's great when people do send us sort of information, whether it be tips or an actual new location of an open toilet. Every single one of those, we had to check on Google Street View to check they were actually there and pinpoint the locations so we weren't sending people off down strange streets and into forests. We also check and we're checking with councils, businesses and other organisations like the National Trust, say, that a lot of car parks and we do keep it updated almost daily. Clare Delmar: OK, so it is current and it's being refreshed, so to speak. Does it include those types of publicly available toilets? Tom Riley: Yeah, we set out to log all those which were publicly

accessible so they could be in a supermarket. And these are ones where you didn't have to necessarily buy something to actually go and use it. And if there are those properties, so we do have some cafes and pubs I know of which are mapped. And people have told us because people can send us and we do ask that people send us comments and there are always reviews of their locations they've been to. And they'll say, you know, you need to speak to Mark behind the counter in order to use it. And it's those reviews actually from people which I think made the map so valuable to people because it's other people. Clare Delmar: Yeah. Tom Riley: Neighbours almost that have used them. Clare Delmar: And obviously they all share a bond for this being an issue that's really important. And it's kind of like a TripAdvisor for toilets, it sounds like, with reviews and locations. So just to get to a final point on how people use it, so, you know, you're an older man, you know, maybe a bit reticent about going out specifically because you don't want to be caught short, to quote a pun. And you can have this app on your phone and you can say, OK, if I'm going to go X, Y, Z place today, I can see that there is a public toilet open and available nearby. Tom Riley: Absolutely. And if you've got on your mobile phone, if you have the Google Maps app, it will actually open in that. So if you're somewhere without signal, you can kind of reach it and it's all there and kind of integrates well with people's phones. Clare Delmar: OK, so I will make our listeners able to access this when I put this on our website. Like as of today? Tom Riley: Today's a special day today because we've just gone over 8 million people having used the map, which is now a mighty achievement. Clare Delmar: Wow! And when we started our aim, our top ambition, which feels very naive now, our ambition was to reach and help twenty thousand people. Clare Delmar: Wow. Tom Riley: 8 million is absolutely amazing. Clare Delmar: That is astonishing, but it just shows the scale of the opportunity, you know. Tom Riley: Well exactly. But even at the moment someone uses Lockdown Loo to find a toilet every five seconds, which is a statistic which I struggle to comprehend with really. Clare Delmar: So say it again. Every five seconds, what happens? Tom Riley: Every five seconds, someone uses our map to find an open toilet. Clare Delmar: Wow, that is incredible. And do you have an idea of, you know, the different circumstances and needs of your users, maybe age groups or gender, anything, anything like that? Tom Riley: We get some, but not loads. What we do know is that we're very popular with people who are maybe a bit older, people who might need to know before you go almost, and also those with medical conditions and young families. Couriers, for example, but, yeah, those are the strongest, certainly we get a lot of comments from people who do use it. We had actually one which was really, really heartfelt, someone that... So they'd recently been diagnosed and they thought they were going to be very much stuck away from their family, being able to go and see their family outside. And the fact that they could know where they were going, where toilets were, which were open, meant that they could they could go out and they could see family rather than being alone. Clare Delmar: The link between mental health and isolation, which can be very much driven by this, this fear of going out because you're going to be cut short once again and keeping you inside. It's you know, it doesn't it's not a stretch to say this is a real health problem for a lot of these people. And this week I posted a blog I wrote where I actually I mentioned you and the Lockdown Loo. And so it's interesting to hear the comments you're getting because this is something that I've never seen so many people take such an active interest in one issue. Tom Riley: That's something that we didn't know really as well. When we started, I guess we set out quite selfishly to try and help ourselves go out and have a drink in the park. So we get people going, oh, I had stopped going running. Clare Delmar: Yeah. Tom Riley: But now I can actually go on my run because I know which places I can stop on my routes. Clare Delmar: Exactly. Tom Riley: It is such an issue that we're passionate for. We've obviously read every single one and some people write, oh, you know, just one toilet, disabled access. One of the things that I've noticed are these comments that I've just referred to is that there are certain people who are very intent on debating and discussing and arguing why there is a scarcity and who's to blame and is it the politicians or is it who? But then there's another sort of population, if you will, that are actually kind of saying, well, let's not worry about that. Because we need to look to the future and let's not worry about why they're not there now, what can we do to get more available? I mean, given what you've been up to for the last six months, you know, how would you advise people to get involved in campaigning for more access? Tom Riley: I feel I've been on a baptism of fire with this journey. We started to work together on how we can solve this kind of issue, because I feel from what I've learned doing Lockdown Loo is fragmentation of ownership and talking about the issue of public toilets is probably one of the biggest reasons why they fall away, because we all have an opinion about them. Every council says, oh, you know, we've got to keep them going, but, you know, there's costs and whatnot. But there are lots of councils in the UK and it's very easy because of the fragmented ownership of toilets, our fragmented opinions, you know, there are lots of different charities

who want and need and fight for more public toilets. So we started doing this work with my colleagues at Cisterniser and we've been meeting other groups and charities like the British Toilet Association. I think the fact that if we start we're starting to talk in groups more and bring influencers together is a start. Obviously, they're the top of the food chain in terms of politics, even though it's local authorities that largely own these. And maybe I'd say that for someone listening if they wanted to get involved, it's reminding your politician whether that be your MP or whether that be your councillor, especially with... There are local elections coming up, I believe, next year. It takes probably a few minutes, but I reckon there are a very few number of people who actually say what is useful. And if we don't do that and maybe remind people that toilets are extremely useful, then that's when they all disappear and it's harder to get something back when it's gone.

Clare Delmar: Absolutely. And can you just remind us how they will do that?

Tom Riley: To download it or to use it, all you need to do is go to lockdownloo.com and on there is our map and if there are any problems you can tweet us @LockdownLoo. And hopefully this will just be the start of a campaign for better public toilets.

Tom Riley: I hope so. Please visit our Facebook page to join the lively discussion there about the public toilet crisis and visit our website at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with both patients and clinicians about their experiences with prostate cancer. I'll be taking a break over Christmas and will be back with more illuminating interviews early in 2021.

When a Personalised Approach to Prostate Cancer Care Makes All the Difference In discussion with HIFU focal therapy patient Ray Braithwaite

Focal Therapy patient Ray Braithwaite joins OnFocus to discuss the difficult and impersonal experience of care he underwent immediately following his prostate cancer diagnosis which felt to him like being on a conveyor belt. He ultimately went on to undergo HIFU with The Focal Therapy Clinic consultant urologist Tim Dudderidge and felt so strongly about this experience that he published an article in his local newspaper on the Isle of Wight. He's also just published a children's book in time for Christmas, called "A Rather Strange Christmas Day". Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities.

Ray is 70 years old, a retired social worker, and is now enjoying a new career as a children's author. But he's here now to talk with me about how important personalised treatment is when diagnosed with prostate cancer, having experienced something that felt more like being on a conveyor belt. Thanks for having me.

Clare Delmar: So let's start by if you can just tell me a little bit about when you were diagnosed with prostate cancer and what happened then?

Ray Braithwaite: It's a bit of a story. Neither of the conditions I thought were associated with prostate cancer, but the GP wanted to do an internal examination. And he actually told me that there was an abnormality around my prostate and he actually said not to worry, I don't think it's cancer. But I'd like to refer you to the oncology department just in case.

Clare Delmar: OK.

Ray Braithwaite: So he did. And then in February, the oncology department, they told me that they'd like me to have an MRI scan, but I did explain that I was claustrophobic, but they said it should be OK. I went along and the MRI scan for February was good because they accepted that I had claustrophobia and they allowed me to go in feet first, which was fine. And then I finally got to see the consultant surgeon.

Clare Delmar: The urological surgeon?

Ray Braithwaite: The urological surgeon, yes. He was mid European guy, really nice guy, very ardent about his job and very interested in his work. And he didn't want to tell me anything about my condition at this time until he had the biopsy.

Clare Delmar: So, Ray, had you had a PSA test and then what were the results of the MRI?

Ray Braithwaite: Those magic words were never used and I wish I'd have known them. These are magic words that I would recommend people actually use around the physicians they see, but no, he didn't.

Clare Delmar: So Ray, he immediately advised a biopsy without you knowing those crucial elements as you described them.

Ray Braithwaite: Yeah, I said yes. And then I had the biopsy, and that was in April.

Clare Delmar: OK.

Ray Braithwaite: And was quite painful. I didn't enjoy that experience at all.

Clare Delmar: No.

Ray Braithwaite: The nurses were very, very pleasant. And then on the Friday evening of the 24th of April, and it was about four o'clock, I received a telephone call and it was from one of the oncology nurses. And now that's the first time I'd been told that I had a cancer.

Clare Delmar: Yeah.

Ray Braithwaite: And I found that really shocking. At that time, quite late evening, I was by myself, I was alone and literally I was given this information to do nothing with for the weekend, except worry.

Clare Delmar: Yeah, that's tough.

Ray Braithwaite: I did ask if I could talk to her about possible treatments and she said she'd phone me back on the Monday and we could discuss everything then. So

there's a bit of a convoluted story, but that's how I got to know I had cancer. Clare Delmar: So Ray we spoke a little bit before. Can you talk a little bit about those and how they affected your experience? Ray Braithwaite: Yeah, I mean, my wife died in December, the previous December. Basically on my own, I just kind of worry about things rather than take action and do things. Having said that, I had good support from the hospice staff and the hospice staff I've been having counselling there with a member of their staff and I was able to talk things over with them. Clare Delmar: So this was the hospice where your wife had been? Ray Braithwaite: Yes. Right. Ray Braithwaite: My wife was diagnosed in 2016 and she, I'm glad to say, lived on for nearly four years after that. And I was looking after her and making sure that everything was all right around her. Clare Delmar: Did you feel that the health care team that you were engaged with for your own personal prostate cancer diagnosis was sensitive to this? Ray Braithwaite: No, not at all. I mean, you don't phone someone at four o'clock on a Friday if you know their circumstances and tell them that they've got prostate cancer. It's just something that I wouldn't do. Clare Delmar: And you've really been going through a tough time. And this was, of course, happening all during covid as well. Ray Braithwaite: Yeah, that's right. And basically, the nurse on the Monday when she phoned me, she said she didn't want to give me any information at this time, but she wanted me to have some more tests and she wanted me to have another MRI scan. But she insisted and it sounded to me very much as if it was just a process, a tick box situation. The MRI scan was unfortunately arranged for the 6th of May, which is my dead wife's birthday. I went believing that it should be OK because my wife would be with me. Clare Delmar: Yes. Ray Braithwaite: But, of course it wasn't OK. They had the music playing, but then unfortunately the music stopped and then the machine itself stopped. After I panicked and kind of climbed out and they were trying to get me out at the same time. Clare Delmar: Ow, how tough. Ray Braithwaite: Asked if I'd like to try it again. And then I took another walk around and tried it for a third time and it didn't work, so it wasn't completed. And the following week I was asked if I could go for a nuclear medical scan, bone scan, and I was told that the machine is much bigger. I turned up four hours later and that new machine was being used, but they said, no worries, we have another one here and the other one was an old MRI scanner that had been converted with a camera stuck on it. Did you ultimately get recommended treatment for the prostate cancer despite these problems with the imaging? Ray Braithwaite: Well, the imaging, we agreed that I could go in up to my shoulder and we'd sort something out. After all of that, I was then contacted by the nurse, again another telephone conversation and that would have been May the twenty fifth. Clare Delmar: OK. Ray Braithwaite: And basically, the hospital team had had a meeting about me. And at that meeting they were discussing my case and my prognosis and suggestions that were being made for treatment. I phoned up at about 1:30 because I was waiting around and I couldn't wait for too long, I was really quite anxious. Clare Delmar: Sure. Ray Braithwaite: Phoned at about 1:30 and then about 3:30, the nurse phoned me back and she said, yes, there are two possible options. It wasn't given to me. Clare Delmar: And so what did they recommend? Ray Braithwaite: They recommended a radical prostatectomy. Or they recommended radiation therapy, which would have been five weeks going in on a daily occasion throughout the week with time off with the weekends. Yes. Ray Braithwaite: And basically, I was asking about any other alternatives. Clare Delmar: OK. Ray Braithwaite: The nurse said, well, she'd put these sheets of paper in the post to me and they will have all the information that's available. So I then said, but what about HIFU? Clare Delmar: And how did you know about HIFU at that point? Ray Braithwaite: Because I'd done my research at that stage. Clare Delmar: Indeed. OK, well, so then what happened when you suggested that to the nurse? Ray Braithwaite: Unfortunately, this is the way I heard it. What she said to me was we didn't recommend that because we think one of the cancers is too big for that. And that's exactly what I did that evening. Clare Delmar: OK, so you found and that's where you went to Tim Dudderidge? Ray Braithwaite: Yeah. Clare Delmar: OK, and because you knew about HIFU and then you went to see him and you ultimately had the procedure with him. How did that go? Ray Braithwaite: First thing was that we had a Zoom consultation. Clare Delmar: OK. Ray Braithwaite: And that took place in, I think it was early June, and that was absolutely fantastic. The consultation I had with Tim was the consultation I had expected to have with the urology surgeon at the hospital. Clare Delmar: Yes. And what was different with the consultation with Tim this time? Ray Braithwaite: He listened. And we spent about 20 or 30 minutes and Tim went through all of the potential alternatives, including the surgery and the radiotherapy and the HIFU. And he was also able to tell me about Gleason and PSA and the stuff that I should have been told about months earlier, I think. Clare Delmar: Because that was all on your referral notes and your records. But unfortunately, the anaesthetics actually had an effect and they caused me to be very groggy. And so the good thing was that the Spire kept me in overnight. Clare Delmar: OK, that's good. Ray Braithwaite: Took about a week or

so for the anaesthetics to wear off. Clare Delmar: Oh, wow, OK. But they did eventually and the procedure went well? Ray Braithwaite: Yeah. Clare Delmar: So, Ray, I mean, that's quite a story. Can you tell us about these and what you'd like to say to policymakers and other men with prostate cancer? Ray Braithwaite: I'd like to say to the MP and to my own local MP, please answer. Well, it didn't happen, and what I said in the email and in the story was I think that HIFU should be one of the primary treatments that's offered and it shouldn't be left as a trial arrangement. The treatment I believe should be made free, made available on the NHS, and it should be one of the primary treatments that is offered to all men. Clare Delmar: Did you get a response from either the MP or the PM? Ray Braithwaite: No, but the local newspaper did publish it because I remember reading it. Clare Delmar: And I'll certainly make sure our listeners can access that. Did anybody write in or did anybody contact you as a result of that? Ray Braithwaite: A couple of men wrote in and a couple of men contacted me and said how valuable it was. And I was talking to one of the local farmers and he'll make sure that his father asks for the treatment if it becomes necessary. And speaking of which, and picking up from the writing in the local paper, I'm aware that you've recently published a children's story called 'A Rather Strange Christmas Day'. And can you tell us a little bit about that? Ray Braithwaite: Well, on his way to return to home after delivering the presents Father Christmas falls out of his sleigh, and basically he lands up with a family and the family's task is to reunite him with his reindeer and his sleigh before the end of Christmas Day. That's the story. Clare Delmar: That sounds wonderful. Ray Braithwaite: I won't tell you whether it's a good ending or bad ending. Clare Delmar: I think I can guess. Is there a way to purchase it, so they can share it with any of their grandchildren, for example. Ray Braithwaite: Thank you, it's available on Amazon as a paperback. If you buy two copies, you get free postage. Clare Delmar: I will put that on our website so our listeners can, in the build up to Christmas, decide that they might want to purchase that. Congratulations on getting it published. Ray Braithwaite: Thank you, cheers Clare. Clare Delmar: So, Ray, thanks so much for speaking with me. It's been a real pleasure and I'm really glad that you've had a good experience and I hope you have a really nice holiday season. Ray Braithwaite: Thank you. And what level of cancer do I have? Clare Delmar: Indeed, we'll make sure that that gets out there. If you're interested in learning more about HIFU and how we approach it at The Focal Therapy Clinic, visit our web site at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with both patients and clinicians about their experiences with prostate cancer. There's a common theme to many of their comments and questions, often centring around "things I didn't know then but glad I know now", and by far the most dominant is "Why don't more people know about HIFU or NanoKnife Focal Therapy for prostate cancer.?" The vast majority of men who come to the Focal Therapy Clinic have learned about HIFU – and us – through their own initiative and going online. In the case of Barry Reubin, his wife Jackie was so determined to find an alternative to the treatments he was offered that she contacted us directly. "We just didn't know which way to turn initially," Jackie told us, "and when we were faced with the treatments he could have, we were never told about HIFU. I found it by sheer determination and research, and that's how I overcome all the things that we have to do is by research. Thank goodness for the internet." This is concerning when all patients have the right to information on all treatment options, enshrined in the Montgomery ruling. This legal position ensures that when seeking consent to treatment, the question of whether the information given to a patient is adequate is judged from the perspective of a reasonable person in the patient's position. Doctors have a duty to take reasonable care to ensure that patients are aware of 'material risks' or any treatment offering. TFTC Consultant Urologist Tim Dudderidge believes the Montgomery ruling has particular relevance to men with prostate cancer: "We are obliged as clinicians to make sure in every case that the patient's individual circumstances are taken into account when describing the options available. There may be multiple favoured options, but there may also be options that perhaps are second best, but certain patients may favour that as their first choice. And certainly patients who go searching for information definitely understand that because they look at things that might make the grade from a point of view of one outcome like cancer effectiveness. But other people may value other things more strongly and may be prepared to take their chances on cancer effectiveness. Particularly with prostate cancer, because we know that even if you do nothing, at 10 years, there's not a whole lot of difference in survival." The lack of information on HIFU is also surprising given that the UK has been a centre of innovation and application of Focal Therapy technology, even though the technology itself was invented in the USA. So what's going on? Some patients are told that HIFU is experimental, and NICE guidance approves HIFU as part of a clinical trial. On this point it is worth referencing a recent summary of clinical trials by Prof Hashim Ahmed of Imperial College, one of the leading innovators in focal therapy for prostate cancer. According to Prof Ahmed: "We now better understand the drivers of metastatic disease

caused by an 'index lesion' in most cases of non-metastatic prostate cancer, which can be targeted with focal ablative treatment, whilst monitoring untreated areas of clinically insignificant cancer; it is estimated that 8000-10,000 men every year are suitable for focal therapy in the UK. Indeed, patients are willing to trade a small reduction in cancer control and survival for better functional outcomes and improved quality of life; from large cohort studies of focal therapy, it does not seem necessary that they would need to compromise on survival." He concludes: "Whilst feasibility of randomised trials is still in question and further tests of their delivery are awaited, longitudinal evaluation of cancer control following focal therapy using HIFU and cryotherapy continue to support their role as a standard option during counselling for patients with eligible disease." Certain communities are information deserts on HIFU. Delroy Wright is a black man from South London who feels strongly about the lack of information on HIFU in the Afro-Caribbean community. He told us: "I believe there is not enough information out there about it – especially for black guys. If we didn't look into these alternative treatments ourselves, we wouldn't know anything about it. You put a lot of trust into your doctor but many of them do not know much about HIFU – so they are stuck in their ways. My friend, Marcus, and I were both on Active Surveillance and left it for a year and a half before looking into HIFU but so much can change in this time. I feel fortunate that I could still have the HIFU treatment, but Marcus found out he couldn't as his cancer had advanced. I now advise everyone to get their prostate checked and act as soon as possible – the earlier you catch it the more treatment options are open to you." Older men also feel excluded from the HIFU treatment option. Peter Hall is 87 and, following his treatment, he told us: "It never occurred to me that my age would be an obstacle. It was only later when I realised that once you got to the age of 70 and I was 82, when you got to the age of 70, as far as the NHS was concerned, life could be very difficult." When asked how he would advise older men like himself with a localised prostate cancer diagnosis, Peter said: "There are new treatments for prostate cancer. It's not just a matter of having surgery... having your prostate removed or cut away or whatever. You can avoid that because the advances that have been made in the treatment of prostate cancer are huge. And you should really seek out a practitioner who will actually discuss with you whether HIFU is suitable. I said, at the end of the day, if you've got cancer and you're going to have treatment for it, you need to know what kind of cancer you've got and how extensive it is, and then discuss with the expert what kind of treatment would suit you best. And if you're comfortable with that, go for it." So what you can do to raise awareness and help other men learn about HIFU? Here are a few suggestions: Support Prost8, a newish charity established to make HIFU available to more men. Listen to our OnFocus interview with Prost8 founder Paul Sayer here Tell your friends Share info on HIFU with your sports club, choir, AmDram society Own your healthcare – become an advocate on social media – start by following us on twitter (@thefocalTC) and Facebook (The Focal Therapy Clinic) Do you have ideas on how to tell more men about HIFU? HIFU Focal Therapy Prostate Cancer Treatment in Older Men A discussion with focal therapy patient Peter Hall on enjoying life at 87 Peter Hall is 87 years young, and joins OnFocus to share his experiences with focal therapy for prostate cancer and to encourage older men to seek PSA testing. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Today, I'm speaking with Peter Hall, a recent HIFU patient, about his experience with prostate cancer. In particular, we're going to talk about how his age played a role in the treatments offered to him and what his experience suggests for older men. Peter, thank you so much for joining me today. Peter Hall: It's a great pleasure, Clare. Clare Delmar: Wonderful. So and Peter, to tell us a little bit about your lifestyle, are you fit and active and what sort of things do you enjoy doing? Peter Hall: Well, fortunately through the treatments that I have had, I'm extremely fit. In the winter, my wife and I enjoy the great outdoors because we live in a small market town in the Black Down hills of Somerset, and it's great to get outside. Clare Delmar: So, Peter, tell us a little bit about what happened when you were initially diagnosed with prostate cancer. Peter Hall: Well, it was in 2015 and I was then 82. And I suddenly experienced a surge in my PSA figures cause I have an annual PSA and they went 4, 6, 8. There's a vast amount of information and knowledge, and I was referred to a urological surgeon who was a specialist in something that was very new at the time, which was Focal therapy, which is HIFU. And after examination, he confirmed that I had an early diagnosis of prostate cancer, which... that's a bit of a setback. He sat me down and we discussed options and he explained to me, what HIFU focal therapy was. I had the treatments during the morning or late afternoon, I stayed overnight in

hospital to demonstrate that I could actually urinate, and then I came home with a catheter and a bag strapped to a leg. Clare Delmar: Yeah. Peter Hall: It was uncomfortable but irrelevant. Clare Delmar: Indeed. Peter Hall: And this was removed after about three days. Now this is what it really is unbelievable. Clare Delmar: Okay. Peter Hall: But this is what happened. So we're talking about five days in total, having had the procedure, a friend and I played seven holes of golf using a buggy to get around. And who was that? Peter Hall: Yeah, uh, me. Clare Delmar: Right. Peter Hall: So I paid for lunch. Then the unbelievable thing happened. Clare Delmar: Which was? Peter Hall: The cancer returned. Clare Delmar: Okay. Peter Hall: It was a small cluster of cells. And Tim said to me, they're in a difficult place to access and therefore I can't do HIFU again. He said there is another focal therapy treatment available too which I'm recommending and it's called cryotherapy. What the hell is that? Clare Delmar: Yeah, indeed. Peter Hall: He said, well, cryotherapy focuses on each cell and freezes it solid, without damaging the surrounding tissue. And my current PSA reading, which was done, you know, a few months ago, is a staggering 1. Clare Delmar: Wow. Peter Hall: I mean, a newborn baby is probably 1. So these new treatments for prostate cancer are extremely effective and they have extraordinary success rates. Availability and access to them is another matter. Clare Delmar: So that's what I wanted to ask you. I mean, before you went to explore and ultimately receive both of these different focal therapy treatments, did you have other recommended treatments offered to you? Peter Hall: The answer is as far as the NHS is concerned, because, I mean, my GP works for the NHS and he said to me, the NHS will offer you treatment, of course it will, and it will be surgery, he said, and there are other options available. Now the package for a director and senior management on retirement, was as well as getting a pension, you got private health care. Clare Delmar: Right. Peter Hall: So I was able to say to my doctor, I'm very lucky. He said, well, with that in mind, I said, I'm going to refer you to Tim Dudderidge. Clare Delmar: Right, right. Well, boy, you were fortunate in that. Peter Hall: Very, very lucky boy. Clare Delmar: Yeah, and when you first engaged with him, you never felt that your age was in any way an obstacle or a hindrance in any kind of treatment. Peter Hall: It never occurred to me that my age would be an obstacle. It was only later when I realised that once you got to the age of 70 and I was 82, when you got to the age of 70, as far as the NHS was concerned, life could be very difficult. Clare Delmar: How do you mean? Peter Hall: Getting any kind of treatment. Clare Delmar: Yeah. Is that something that you picked up...? Peter Hall: It's a watershed. Clare Delmar: Did you pick that up from your own experience or from...? Peter Hall: I only picked it up fairly recently, to be truthful. My age never, ever occurred to me and Tim never mentioned it. Clare Delmar: So how did you pick it up recently? Peter Hall: On the Internet. Clare Delmar: Right. OK, and what about any friends or any of your golfing colleagues? Peter Hall: Well, all golf clubs are filled with people like me. They really are. Clare Delmar: Maybe not as lucky as you... Peter Hall: Elderly people, elderly males, who've played golf probably most of their life. And once they retire, they can play three or four times a week and they can escape the winter by going overseas and Spain, particularly, and Portugal and go for three months of the winter and, you know, have a really nice time. Clare Delmar: And have you talked with them about their own experiences. Peter Hall: The answer is yes, but in a guarded way. It's a sensitive subject, you know, as far as men are concerned, particularly as they get older. Clare Delmar: Yeah. Peter Hall: But if in conversation, you know, in the club somebody casually mentions that their PSA has going a bit wobbly, I've taken the opportunity to say, look, go on the Internet, look at HIFU, look at people who are offering it. Well, it's equally shocking in my view, is that the government for years and years and years have put into place and quite rightly, circumstances where women can have tests to make sure that they pre-empt cancer. Clare Delmar: Yeah. There's a three or four very serious cancers which are killers of women. Clare Delmar: Yeah, ovarian, cervical and breast cancer. And there are screening processes for them. Clare Delmar: Yes. Peter Hall: And that's very helpful. Clare Delmar: Yes. Peter Hall: There is zero screening processes for male cancers and particularly prostate cancer. No, you are entitled, as you know, to request a PSA test and clearly, as you stated earlier, you've been doing that anyway. I mean, you have an entitlement to ask, but many men don't know or choose not to ask. Peter Hall: That entitlement has reappeared recently. So I turned up one day when I'm 82, or something like that, to my doctor and say I've come to my annual PSA test. You're quite right. Peter Hall: The argument for the PSA as far as the General Medical Council is concerned, is that there was no solid medical evidence of it actually having efficacy, that it actually worked, but at the same time, they didn't have anything else to put it in place. Clare Delmar: Yeah, yeah. Peter Hall: And so to this day, if you have any form of cancer as a male. The first signal that they look for, that the treatment has worked, is they give you a test and that's it. Clare Delmar: So you had a quite a fortunate experience and that you actually had your PSA test and that's what led you ultimately to your successful treatment both times? Peter Hall: When I had

the PSA test that revealed that I had early signs of prostate cancer, that was, as I was concerned, purely routine. Eventually it would have killed me. Clare Delmar: So what then, Peter, do you suggest if you were to give some advice to older men like yourself who are diagnosed with prostate cancer, how would you advise them to seek the best advice and the best treatment? Peter Hall: I have these conversations quite frequently with men in my age group, you know, cause it's not a taboo subject by any means. And I say, look, the first thing you've got to do is to establish a regular PSA test in your life. I say now if then you're unlucky or lucky, which ever way you want to put it... Clare Delmar: Yeah. Peter Hall: ...is that there are new treatments for prostate cancer. You can avoid that because the advances that have been made in the treatment of prostate cancer are huge. And you should really seek out a practitioner who will actually discuss with you whether HIFU is suitable. I said, at the end of the day, if you've got cancer and you're going to have treatment for it, you need to know what kind of cancer you've got and how extensive it is, and then discuss with the expert what kind of treatment would suit you best. And if you're comfortable with that, go for it. Clare Delmar: Yeah, another question you mentioned earlier when you were discussing how this has come up with some of your friends, and you mentioned that this conversation often happened on the golf course or at the golf club. Peter Hall: Yeah. Clare Delmar: Do you think that golf clubs like yours are places where there can be more of, I don't mean to say official, but, you know, a more of a scaleable information campaign to actually help men understand exactly the kinds of things that you're suggesting? Peter Hall: The answer is yes. At least 10 years ago in the men's toilets, official posters appeared advising them in fairly straightforward English, cause this is men only, about the dangers of ignoring the first signs of a problem of urinating because that can be an early indicator that there's something wrong. And the poster said do something about it because you may have prostate cancer and they're still there to this day. The subject to now is more open as far as men are concerned. Clare Delmar: I think you're right, but it's interesting to hear you say that, and especially within, you know, groups of older men like yourself, that it's not something to be afraid of. Yeah, well, you've had a really good experience. Peter Hall: I've been very, very, very, very lucky all the way through. Clare Delmar: Yeah, I can hear that. Well, I just want to thank you for joining me today and speaking with me very openly about your experience. I mean, you really are quite an inspiration for other men and very keen for older men to understand that they do have options and those are very real. So thank you very much, Peter. Peter Hall: Well, I'm very grateful to have had the opportunity, and I hope my tiny contribution just helps some poor guy down the road who doesn't quite know what to do. Clare Delmar: Wonderful. If you're interested in learning more about HIFU in older men and how we approach it at The Focal Therapy Clinic, visit our Web site at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with both patients and clinicians about their experiences with prostate cancer.

An Inconvenient Truth: Public Toilets & Health

An inconvenient truth: public toilets and health Toilets – no one likes the word, few can look you in the eye when saying it, some even associate its use with one's place in society. All this hate for something each and every one of us uses multiple times daily. Except when one isn't available. And when this is the case, as it is on a public basis across the country, it can change behaviour and health for the worse. This week's blog is about toilets – or the lack of them. In case you are not aware, The UK is currently experiencing a public toilet crisis, caused by the perfect storm of Covid19 restrictions, reduced local Council budgets, and economic hard times. It is an inconvenient truth for everyone, but for older folks and men with prostate disease, it hits particularly hard, creating a major disincentive to leave the house. The Health Editor of The Daily Mail recently took the unusual step of recounting his own personal experience to highlight the issue. According to Tom Riley of the wonderfully named organisation Lockdown Loo, a lack of loos is bad for the economy, mental well-being, and our nation's health. He set up Lockdown Loo to provide an updated, interactive map of public toilets throughout the UK. Writing in The Telegraph recently (in celebration of World Toilet Day – yes, it is a thing) he described the spike in use of his Lockdown Loo app during Covid, and cited comments from users: "It's an issue. I walk miles photographing in urban spaces, and the increasing lack of public loos in London over the last 10 years has become noticeable." "It's a basic human right that a toilet can be accessed when required in towns and out and about. I totally agree, that having an underlying health condition has stopped me being able to go out independently. N Ireland is particularly bad." The eminent health think tank Kings Fund examined the problem from a public health and health inequalities perspective and was disappointed to find that little is being done to change the situation: "there appears to be very little activity on a national level from the relevant departments. There does not seem to be a coordinated approach to addressing the reduction in public toilet facilities across the country. This seems like a missed opportunity to address an issue with a significant health impact." It appealed for people to come

forward and share their concerns and stories to build a case they can bring to government. So what can you do in a world with inadequate public toilets? The Urology Foundation provides a card to use in restaurants and other public places to reduce embarrassment². Prostate Cancer UK also provides a card but, given its stature and influence on all things to do with prostate cancer, it is disappointingly silent on the issue.³ Positive Ageing London has issued a "Toilet Manifesto" which you can support and share amongst your community⁴. Write to your MP and leader of your local council asking why public toilet provision is inadequate and point out how it discriminates against older people and men with prostate disease⁵. Support the British Toilet Association Where Can I Go campaign. The Focal Therapy Clinic is keen to lobby on this issue.

The Focal Therapy Clinic Multidisciplinary Team Goes Digital

The multidisciplinary team (MDT) review of patient cases is indisputably a critical part of patient care for men with prostate cancer. Bringing urological, radiological, oncological and histological expertise together is in patients' best interest and can significantly affect outcomes. Like many processes and procedures in healthcare, the MDT has had a push to go digital by the Covid pandemic. At the Focal Therapy Clinic, we've innovated and adapted to this new reality in a way that has benefited both doctors and patients. Out of crisis has come opportunity. Now, possibly more than ever, healthcare collaboration tools are needed not just to allow doctors and specialists to meet remotely and discuss patient care, but also to improve efficiency within clinical teams experiencing backlogs of cases. TFTC has put together a digital collaboration platform, designed expressly for an optimal prostate MDT. The technology supports imaging, real-time contouring and reporting, patient record review, voice, messaging, and recording of all proceedings. TFTC Consultant Urologist Tim Dudderidge believes the approach has significantly improved the MDT process: "Going online has really made it much more flexible. The people who are involved in any particular discussion are totally in the room and those people don't need to be can just go on mute and wait for their turn to come around. We can be in whatever clinic room we're more comfortable in or where we've been working in the morning. And that flexibility allows people who are on holiday but really want to discuss a special patient to be able to dial in or people on conferences and so on can just join the meeting from where they are. And it's certainly also facilitated our focal therapy meeting, which has brought together experts from completely different parts of the country. There's actually no way that we'd have been able to hold that, given how busy we all are, if we all had to physically meet in person. And to have Dr Clare Allen join us for our focal therapy meeting is a real pleasure and we're so lucky to have her input. And that makes that focal therapy meeting so effective in helping identify those men who've approached us to see if they're suitable." Each case is discussed around real-time imaging, integrating detailed patient history and assessments of a patient's current circumstances including lifestyle, fitness, family, and treatment preferences and priorities. A screen shot of a recent TFTC MDT is below: Imaging and radiological input, critical pieces of diagnostic information within a prostate MDT, is now presented and reviewed in a more detailed and effective way. And I think the advantage of having such a subspecialist radiologist involved in this is that the images can be contoured and we use those contours for our clinical work for biopsy and for treatment. But being able to, if you like, process the amount of information in a meeting, to have the lesions contoured on the screen really helps you to quickly see. And it sort of takes away a whole level of discussion because you can immediately see what the radiologist is talking about and we can then quickly correlate that with the biopsy information and then we can start to form treatment plans in our head and discuss them. But now being able to combine that with the sort of expertise we get from Clare Allen and the contouring, it's creating an ecosystem where patients who come in at the beginning of the pathway with us can have really good quality scan performed, have that scan contoured and marked so that we can see the lesions. To discuss that in our group, to be able to plan the treatment and then to be able to deliver the treatment using that same image which has been contoured, and it just it creates this flow which is bound to improve the quality of the treatments." You can hear more about Tim's views on the MDT in a recent OnFocus interview [here](#). In many ways, the digital approach delivers enhanced benefits for patients who, while not in attendance and unable to advocate for themselves, can access images and recorded content from the meeting. Tim adds: "if you're in an MDT and all of those (patient specific) issues are clearly recorded, then the MDT has a chance to be aware of that. Otherwise, there's a danger that people make assumptions about a patient's longevity, about activity, about what the patient's interests are. And then the MDT might come out with a recommendation, which is too focused, and doesn't allow the breadth of discussion that should happen for every patient, regardless of their age or what assumptions we might make about their lifestyle." Our doctors take an entirely holistic approach to each patient, seeking to understand and advocate for the physical, mental and behavioural aspects of our patients' health, and the digital MDT gives them more space and time to do this. Covid

has presented unprecedented challenges to our healthcare system, and it is very satisfying to see the innovation it has spawned delivering real and lasting benefits to both doctors and patients. The Importance of Best MDT Practice in Treating Prostate Cancer Tim Dudderidge explains what an MDT is and what it means for patients The Focal Therapy Clinic Consultant Urologist Tim Dudderidge joins OnFocus to discuss the importance of the multidisciplinary team meeting (MDT) in informing diagnostic and treatment decision for men with prostate cancer. Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

MDT meetings & prostate cancer

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. I'm Clare Delmar. Today I'm speaking with Tim Dudderidge, consultant urologist at Southampton University NHS Trust and The Focal Therapy Clinic and a pioneer in non-invasive treatments for prostate cancer. We're going to discuss how the multidisciplinary team meeting, or MDT, is crucial to patient care. So the last time we spoke, which is a few months ago, and that was a conversation we had about sort of changes in the diagnostic pathway. And we were chatting about how this is important for patients to understand that and what sort of nodes in that process they might want to question their care. And you talked a bit about something called the MDT, the multidisciplinary team meeting, as a really important point in that diagnostic pathway. moment. So I guess we're at that moment and I think it is a really important issue, not only because covid has presented some real challenges to having these MDTs which will pick up on in a few minutes. But before we get into the specifics, I'd just love for you to talk in your own sort of frame of mind. Why should patients even care about it?

Tim Dudderidge: So the MDT really took shape in its current form some years ago when there was a process of what we call improving outcomes guidance. And it was really trying to look at the whole system that led to the change in cancer services in the UK, which effectively led to sub-specialisation and a clear distinction of who was providing cancer services and who wasn't. And that led to increases in individual surgeon volumes and a whole lot of other things which improve the quality of care. I think that the objectives of today's MDT are perhaps slightly more focused than the more broader objectives that existed at the time. And actually things like the recent covid pandemic has forced us to really rapidly change how we go about it. So you said it's crucial and I think overall I would say it is crucial. But actually in an individual patient's case, the MDT, like anything else, can get it wrong. And so I think it's really important to recognise how the MDT works and how to get the best out of it. And also, one thing we're not very good at is making sure that the patient's voice is heard. And so I think it's important to think about how that is delivered.

Clare Delmar: So you obviously agree that patients should care about it. How does it make a difference in diagnosis and treatment?

Tim Dudderidge: At the moment, well, I guess it's been the same for a while, we gather all the information about the patient's case and it all comes together in the MDT for assimilation. Now, very often this will happen before anyone has seen the patient with all of those bits of information available. And often that's done because the cancer pathways mandate that we're constantly making progress through the pathway. And the MDT is a way of making sure that that progress is being made and the follow up appointments will often be triggered after that MDT. And we'll look at the imaging, the history, the biopsy results, and basically work out what the diagnosis is. And sometimes you get a sort of recommendation, you know, this is what the treatment should be. But I think it's really important that actually the MDT convey sort of the range of options, because especially in prostate cancer, it's very rare that there's one recommended treatment and nothing else should be considered at all. It does sometimes happen, but mostly what we should be saying is this is the range of recommended treatment options. But we may also include, and this is important in focal therapy, treatments that the body of doctors present may not necessarily recommend, but they might accept is within the range of reasonable discussion. And I think this is where we get into the issue of how does the MDT cope when there are controversial treatment options on the table. And I think, generally speaking, the MDT fails patients in that people's biased opinions might say, we recommend surgery and be pretty bold about that. But actually, of course, the other options get squeezed out. You know, particularly important that we therefore have all the specialties represented in this MDT, oncologists in particular, so that radiotherapy is properly explored. And I think increasingly we need to have surgeons who are in the MDT who are aware of which cases are suitable for focal therapy so that the patient's interests can be advocated for in that MDT, and these options can be listed as reasonable options. So this is just not happening in many MDTs and which is why we've had to develop our own focal therapy MDT.

Clare Delmar: So, I

mean, ultimately, it's the patient's choice, how he gets treated. So who actually then recommends or actually communicates the outcome of the MDT? Tim Dudderidge: So the clinic appointment that follows the MDT will ideally involve the surgeon reviewing all of the primary information, the imaging reports, the original history, the biopsy report, and assimilating that themselves. And then if you like, checking with the MDT outcome that everything tallies because there is a serious danger with these MDT meetings being under such pressure that actually sometimes mistakes can happen. And I've been involved as an expert witness, actually, in cases where somebody simply conveyed the MDT outcome without checking any of that and things got completely mistaken. So I think whoever is explaining the outcome of investigations, I think it's really important that patients check with the nurse who is doing this or the doctor who is doing this. Are they checking the reports, checking the MDT outcome, making sure everything tallies and explaining it? Because I think that's the first thing that mistakes can happen. The other thing is, is that it's really important that before just conveying the MDT outcome, that the people discussing things with the patient sort of find out, obviously you've got to explain the cancer diagnosis and that's a whole other discussion. But once that's been done and the various treatments have been explained, it's really important that the doctor doing this or the nurse doing this because very often in the NHS is being done by specialist nurses, is that the patient's priorities are identified because it's very easy for an MDT, which might, and I think MDT do perceive their job as trying to explain the best cancer treatment and by that I mean the treatment which eradicates the disease most effectively. And actually what patients mostly want is a balanced discussion about getting rid of the disease, of course, but also doing that in an acceptable way. And it's very clear that patients are very prepared to accept a reduction, even a modest reduction perhaps in the long term success rate in order to have a more acceptable treatment. And a really good example of one of the early examples of this was when in breast cancer surgery, instead of removing the whole breast they looked into, could we just remove the lump and a margin? And of course, wide local excision of breast cancer is now by far and away the most frequently undertaken procedure and radical mastectomy is really reserved for special cases. So I think if you imagine the same context in the prostate, we really should be thinking about reducing the impact of treatments. It went from radical prostatectomy to nerve sparing prostatectomy and then it went from an open operation to a keyhole operation. So the same pressures are at work, even with surgery. But I think we can take it further and use focal therapy in those selected cases to give a better balance of benefit and risk. Clare Delmar: I agree. I mean, when we speak to patients, particularly the breast cancer analogy really resonates for lots of reasons, because often their mothers or their partners have experience with breast cancer and the emotional and other aspects as you say. Tim Dudderidge: Just getting back to the MDT, I mean, once we've explained these options, we contextualise the options both in terms of the success, the side effects, the long term functional impacts. We then leave the patients in this position where they are dizzy with information and it's really difficult to process that. So it's then important that they have time to think it over. This disease does not usually necessitate a decision there and then. It's also important to share with the patients a sort of written summary of that discussion. And so the clinic letter being copied to the patient, I think, is a really important aspect of that. Providing them with sort of standardised written information about the different procedures can be very helpful. But it's important to sort of, again, contextualise those information sheets with the patient's individual circumstances. So some patients, when I'm reviewing their scans for radical prostatectomy, I'll measure their prostatic urethral length and I'll be able to say, oh, you've got a good or less good chance of early continence recovery. Again, with erectile dysfunction recovery, depends on the treatment plan, both with focal therapy or with surgery. What degree of nerve damage is going to be caused by the treatment that's being designed for you? So patients can then come away with the explanation, the written information, their clinic letter, and then they need some chance to follow up and that might be with a cancer nurse specialist or might be another appointment with the surgeon. And of course, visiting an oncologist can be very useful and is certainly recommended if people have got radiotherapy as an option that they want to consider. Clare Delmar: So communication is clearly important. Does it vary across clinical groups and hospitals and disciplines in terms of approach? Tim Dudderidge: I think it does. And the first thing is in terms of the discussion, there are some cases that probably don't require a full discussion with ten people, which is what the MDT is. And so some places are reserving the discussion for the more important cases that may be involving a big treatment, like a radical treatment and some of the follow up cases or the more routine things which have a more procedural element to them, perhaps they can be dealt with in a paper exercise. The major cases that get discussed require the presence of obviously the coordinator who manages the information, the surgeon, maybe several surgeons, clinical oncologists. With localised prostate cancer,

we don't need a medical oncologist, but a medical oncologist is really useful when we've got any case of metastatic disease. So we actually have two parts of our meeting so that we can bring them in just for the section that they're needed for. And a histopathologist is very useful, so they can sort of describe the histological features. The pressure on these meetings means that we don't review the path of every single case. But nowadays the histologist is really there to help us to, I guess, orientate the pathology with respect to the imaging. So help to understand where the disease is and so on. So those are the, I guess, the key people in the meeting. What's useful in our meeting as well, we often have the specialist nurses join us because it gives them an insight into what we're thinking. So when they're speaking with patients, they have that sort of insight. Clare Delmar: So how has covid impacted this? I mean, you've done these online now, and can you talk a little bit about how effective that's been? Tim

Dudderidge: Well, I actually prefer the new set up. In the summer it was stifling, it was really always difficult to sort of keep your concentration for the whole meeting. And there are times when they're discussing perhaps other tumour types or things that are not so relevant to your individual circumstances. So at any single point in time in this big room, there would be people not really sort of paying attention, maybe checking their emails, doing some paperwork, even having little conversations on the side, which is natural. We're all human, we get only so much concentration span. And it was not a great environment for such a kind of challenging meeting with up to 100 people in it. The people who are involved in any particular discussion are totally in the room and those people don't need to be can just go on mute and wait for their turn to come around. People can be getting on with their other activities on the side if they need to be. And it doesn't then cause disturbance to the main flow of the meeting. We can be in whatever clinic room we're more comfortable in or where we've been working in the morning. And that flexibility allows people who are on holiday but really want to discuss a special patient to be able to dial in or people on conferences and so on can just join the meeting from where they are. So I think the technology has really helped. And it's certainly also facilitated our focal therapy meeting, which has brought together experts from completely different parts of the country. There's actually no way that we'd have been to hold that, given how busy we all are, if we all had to physically meet in person. And to have Dr Clare Allen join us for our focal therapy meeting is a real pleasure and we're so lucky to have her input. And that makes that focal therapy meeting so effective in helping identify those men who've approached us to see if they're suitable. Clare Delmar: Yes, I've seen that. And what's also impressed me is how the images can be shared in such an incredibly powerful way in this online setting. I mean, do you think that's actually superior to the previous setting? Tim

Dudderidge: Absolutely. And I think the advantage of having such a subspecialist radiologist involved in this is that the images can be contoured and we use those contours for our clinical work for biopsy and for treatment. But being able to have, if you like, process the amount of information in a meeting, to have the lesions contoured on the screen really helps you to quickly see. And it sort of takes away a whole level of discussion because you can immediately see what the radiologist is talking about and we can then quickly correlate that with the biopsy information and then we can start to form treatment plans in our head and discuss them. So I think that having digital imaging has been around for a while and very useful. But now being able to combine that with the sort of expertise we get from Clare Allen and the contouring, it's creating an ecosystem where patients who come in at the beginning of the pathway with us can have really good quality scan performed, have that scan contoured and marked so that we can see the lesions. To discuss that in our group, to be able to plan the treatment and then to be able to deliver the treatment using that same image which has been contoured, and it just it creates this flow which is bound to improve the quality of the treatments. Clare Delmar: Yeah, that's a good word for it. How can a patient ensure that they're getting the benefit of the MDT and particularly in light of the fact that they're not present to advocate for themselves? Tim Dudderidge: Well, I think at the beginning of any person's cancer pathway, the surgeons seeing the patient, but also the patient themselves should be sort of projecting a bit to the future. And sometimes I have people coming in with a high PSA and they start saying, well, what treatments are available for this? Let's not jump the gun. But actually, in many ways, I take my hat off to those patients who are trying to imagine what they need to know, what they need to be thinking about. And I guess in the first meeting, if someone's got prostate trouble, we really should be asking ourselves, are you sexually active? Just things that might be important down the line, because it might turn out that a whole load of discussions are unnecessary if the person has no interest in active sex life. If that's how it is, then it really sort of simplifies the discussion because you don't have to weigh up the pros and cons of maintaining their sexual function because you can just confirm with them that that's the case and then say, well, we'll just focus on the other functional outcomes. But on the other hand, if they say that they do have an active sex life and many men in their

70s and even 80s, you know, there's no age determination on this issue. And you need to know that because you can't just assume that someone's eighty two, they're not interested. And I think, if you're in an MDT and all of those issues are clearly recorded, then the MDT has a chance to be aware of that. Otherwise, there's a danger that people make assumptions about longevity, about activity, about what the patient's interests are. And then the MDT might come out with a recommendation, which is too focused, and doesn't allow the breadth of discussion that should happen for every patient, regardless of their age or what assumptions we might make about their lifestyle.

Clare Delmar: Tim, thank you so much for speaking with me today. If you're interested in contacting Tim or learning more about the MDT and how we approach it at The Focal Therapy Clinic. Visit our website at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with both patients and clinicians about their experiences with prostate cancer.

Big Data seems to be the solution to many of the world's problems, if you believe the media stories that abound asserting its potential to address just about any problem out there. So, as our interest at the Focal Therapy Clinic is prostate cancer, we wanted to know if it is helping scientists and clinicians to better understand and treat prostate cancer, and if so how? And before we even go there, we wanted to know what exactly is big data? Google tells us that Big Data is a term that describes the large volume of data – both structured and unstructured – that inundates a business on a day-to-day basis. It's what organizations do with the data that matters. So what kind of large datasets do healthcare organisations generate, and what do they do with them? Big data in healthcare describes massive volumes of information created by the adoption of digital technologies that collect patient information and help in managing hospital performance. Sources for big data include hospital records, medical records of patients, and results of medical tests. Clinical trials and biomedical research also generate a significant portion of big data relevant to public healthcare. Combined with large datasets on demography, for example, these health datasets can be analysed to give deep and evidence-based insight into a multitude of health-related questions. In terms of questions related to prostate cancer, big data is helping to identify aggressive cancer, match the right treatment to the right man, and understand how cancer cells develop, leading to better diagnosis, better treatment and better prevention.

Prostate Cancer UK, with funding from the Movember Foundation is supporting research using big data – some examples of its application are: Building a database of genetic data from biopsy and blood samples Predict how gene activity is affected by prostate cancer treatments Develop computer models to understand why multiple prostate cancers appear together

Another organisation dedicated to using big data in prostate cancer research is Prostate Pioneer. PIONEER is a European Network for Big Data in Prostate Cancer, consisting of 32 partners across 9 countries. Its goal is to ensure the optimal care for all European men living with prostate cancer by unlocking the potential of Big Data and Big Data analytics. By applying advanced data analytics, and developing a data-driven platform of unparalleled scale, quality and diversity, PIONEER aims to deliver meaningful improvement in clinical practice, prostate cancer disease-related outcomes, and health-economic outcomes across the European healthcare landscape. PIONEER will assemble, standardise, harmonise and analyse high-quality big data from diverse populations of prostate cancer patients across different stages of the disease, aiming to provide evidence-based data for improved decision-making to clinicians, healthcare providers and policy makers. According to Pioneer, there are a number of critical questions that remain unresolved regarding the screening, diagnosis and treatment of prostate cancer patients, which big data can help to investigate. These questions relate to: Disparities in the incidence of prostate cancer between different countries as well as unacceptable inequalities in prostate cancer survival rates across the EU. There is insufficient knowledge on risk factors for prostate cancer and on patient characteristics. This lack of knowledge means that prediction of which patients will have the best outcomes with specific treatments remains poor. A lack of meaningful engagement of all key stakeholders (including patients) in the processes which define the most important prostate cancer research questions that urgently need answering. Lack of effective implementation of knowledge gained in clinical practice (including knowledge informed by real-life data), with variability within and across European countries. This results in inequality in prostate cancer care, increased risk of short- and long-term harms to patients, as well as excess costs related to inappropriate management. PIONEER's approach is to firstly identify critical evidence gaps in prostate cancer care and then standardise and integrate existing big data from high quality, multidisciplinary data sources from prostate cancer patients across different stages of the disease into a single innovative data platform. Based on a unique set of methodologies and advanced analytical methods, PIONEER will attempt to transform the field of prostate cancer care with particular focus on improving prostate cancer-related outcomes, health system efficiency and the quality of health and social care delivered to

all prostate cancer patients and their families. In addition, PIONEER will aim to provide standardised care pathways for all clinical centres across Europe. An excellent video on Pioneer's work is [here](#). Pioneer's clinical coordinator, who is responsible for assembling the datasets for research, joined OnFocus for an interview [here](#). Next time you are asked to give consent for your health data to be used in research, think about the work of these organisations and the many others that are using your data in combination with millions of other patients to investigate, and hopefully resolve, the gaps in knowledge about prostate cancer.

How Big Data is Helping to Answer Questions About Prostate Cancer

An Interview with Susan Evans Axelsson from Prostate Pioneer

Susan Evans Axelsson, Clinical Coordinator joins OnFocus from Prostate Pioneer, a European consortium aiming to transform prostate cancer care by maximising the potential of Big Data. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Enhancing diagnosis and treatment for better outcomes for prostate cancer

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we engage with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Susan Evans Axelsson, clinical coordinator for Prostate Pioneer, the European Network of Excellence for Big Data in Prostate Cancer. It's part of a European mission to improve health outcomes in health care systems in Europe by maximising the potential of big data. And it's tasked with transforming the field of prostate cancer care by focusing on improving prostate cancer outcomes, health system efficiency and equality of health and social care across Europe. Thank you very much for inviting me on to speak about the Pioneer project.

Clare Delmar: You know, it sounds incredibly complex and intimidating, and I think you are just the perfect person to try and demystify and to get people excited about it. Because, you know, you and I have obviously been working together and I've become extremely excited about it. And I think this is an opportunity to share that and to really communicate to our listeners how big data is really a big, important part of the future of prostate cancer. So on that note, maybe we can open with you just telling me, what is the Pioneer project and what's your role in it?

Susan Evans Axelsson: So that kind of sets the context. First, I think I should let you know what Pioneer stands for. So it's "Prostate cancer diagnosis and treatment enhancement through the power of big data in Europe". The mission of Big Data for Better Outcomes is to improve health care outcomes in health care systems in Europe by maximising the potential of big data. There's a few other programs within this mission, its Roadmap, which focuses on Alzheimer's disease, Harmony for haematological malignancies and Big data for cardiovascular disease. And I know that your listeners, we really need to understand what big data is in order for you to understand why we need it and how we can use it.

Clare Delmar: Exactly. Well, first of all, just before we dig into that, just tell us really quickly what your role is. So for our listeners, you're based in southern Sweden and you're coordinating a group really across Europe, correct?

Susan Evans Axelsson: Well, it's all over the world, actually. What we do within work package three is we identify these high quality data sets and then we start a dialogue with data holders. So, for instance, if your patients are part of a clinical trial, a hospital that's collecting the data, we go to this data holder and we say you have this great data set we think would fit very nicely in with the Pioneer platform. You know, you work for years to collect this data and you want to make sure that it's used for the benefit of the patient. So my role is to start this dialogue and to help the data holders understand the importance of their data when collected with other data sets, and also to feel comfortable with sharing the data and know how it's shared and how it's used.

Clare Delmar: So that's pretty clear, I think. Can you give us some examples of what kind of data we're talking about?

Susan Evans Axelsson: Well, it's all sorts of data. For instance, we collected from a company, a small biotech company here in Sweden, and it was them holding the data and collecting the data. So we have worldwide sets that have worldwide data and we have sets that are specific to an area. So it's that type of data.

Clare Delmar: OK, so you've defined...

Susan Evans Axelsson: Imaging data, genomics data.

Clare Delmar: OK, so that gives me a bit more so it's obviously specific to areas, but more important, specific to types of let's see how you actually gather information on an individual patient, whether it's from an image or from a drug.

Susan Evans Axelsson: Yes. Quality of life is very important.

Clare Delmar: The ultimate source of it is the individual patient who has to give consent for his. Has that....

Susan Evans Axelsson: Absolutely.

Clare Delmar: Has that been a problem or an opportunity?

Susan Evans Axelsson: Well, when we collect the data now, we have to make sure that everything was approved before. And that is extremely important that when you are going in for surgery or when you're diagnosed with prostate cancer, if they say maybe you have a cancer that does not need a therapy right now, you're going to do watchful waiting or active surveillance that can also be set

in a database and that can help us to understand how cancer evolves over time. And so your doctor may ask you, can we use your data for this type of project or can we use it to incorporate with other data to help build and get a picture of how the cancer evolves? So we can use big data, we can use data from this clinic, and this clinic, and this clinic and put them together to be able to improve diagnosis and the treatment of prostate cancer and to better understand the disease.

Clare Delmar: OK, that's interesting. So the big actually refers to the size of these datasets, as you said, and you're doing something slightly unusual by putting these all together.

Susan Evans Axelsson: Yes, it's important not to base a clinical recommendation on one data set because you have different populations. A drug could affect African-American men, different from white men, different from Asian men. It might not be apparent, but if we set and we can harmonise and we can put three different data sets, four different data sets, five different data sets together, we'll be able to focus what we're doing. We'll be able to really contribute to overcome the differences of treatment for men with prostate cancer. We need to stop the current underuse of effective drugs and overuse of ineffective treatments. And we can do this by using big data to really get the bigger picture of what's going on in men.

Clare Delmar: So your work actually complements the clinical trials that are already out there for drugs or devices or technologies?

Susan Evans Axelsson: Big data is similar to real world populations, whereas when you have clinical trials, they report on streamlined cohorts. And we need this from men across Europe, not just in Sweden where I am, because we really need to standardize how men are treated. Even here in Malmö, a man is treated, can be given a different treatment therapy than a man in Gothenburg. And you have doctors that say "this has been working for years and this is what I'm going to stick with". We need to be able to guide guidelines and help give the best therapy for men.

Clare Delmar: So let's look at the concept of evidence, which is what clinical trials obviously seek to produce. I mean, are you suggesting that by using these big data sets, you can take some evidence that's been generated from, as you say, a cohort, a carefully selected cohort, and then use that to actually standardize treatment or standardise the outcome of that trial?

Susan Evans Axelsson: We can help to guide, help to dig through the crap. Within the Pioneer platform already we have data sets from academic and from industry, which is quite nice because we can really see what's going on. But you know that, you especially, you have this podcast, you really try to give the men the information they need. And prostate cancer is something that can be cured if caught early enough, if caught while it's still confined within the prostate. However, unfortunately, it's taboo to talk about prostate cancer, and it's still the second leading cause of death among men. We know that there is insufficient knowledge on the risk factors and patient characteristics. We know that we really need to integrate real world clinical data into how men's disease is classified and their care pathways. We're missing the standardisation of the outcomes.

Clare Delmar: OK, so and this is where you think by building up these large, voluminous data sets that will help address that?

Susan Evans Axelsson: Very much.

Clare Delmar: Yeah. Can you give us an example of some of the research questions or some of the actual clinical questions that the Pioneer teams are addressing and using the big data to help them understand better?

Susan Evans Axelsson: What we did within the Pioneer, we identified a number of questions covering all stages of prostate cancer, focused on... We were focusing on the various conditions, including screening, diagnosis, risk stratification, which includes like genomic profile, treatment and the complications of treatment. So, and when I say we identified, that means that it was members of the EAU Prostate Cancer Guideline Panel, that's the European Association of Urology prostate cancer guideline panel and other prostate cancer key opinion leaders. They were contacted to determine the most important questions that they felt were in the field of prostate cancer.

Clare Delmar: OK, and can you just give us an example of one or two on that list?

Susan Evans Axelsson: Yeah, well, we have 57 that were identified, but I need to say that once we had these questions identified, then we performed a prioritisation survey among two stakeholder groups and these groups, they were health care professionals, which included pharmaceutical companies, but also, most importantly, were patients with prostate cancer.

Clare Delmar: OK.

Susan Evans Axelsson: So we know that by involving the patients and all of the relevant stakeholders is key. Helping the patient to be actively involved in designing and prioritizing the research questions so the patients help us to know what they feel is most important with their care of prostate cancer. So it was actually a prioritisation exercise.

Clare Delmar: And very ground up I can see.

Susan Evans Axelsson: Yes, we have, like I said it was like fifty seven questions we've identified. We have a top five that we're working to address within Pioneer right now to say let's test the platform and make sure they work. And we have one that's focused on what are the relevant tumor specific and patient specific variables that affect prognosis of prostate cancer patients suitable for active surveillance. Another one we're wanting to look at is what is the clinical benefit for determining patient's genetic risk profile

regarding prostate cancer management, especially in the screening setting? And can we look at the natural history of prostate cancer undergoing conservative management like watchful waiting, you know, or the side effects and local problems or looking between the treatments. Clare Delmar: So quite a range, really... Susan Evans Axelsson: It's very much a range. Clare Delmar: And I'm beginning to get a sense of how you could use large sets of data to begin to understand that. I mean, is then the actual acquisition of these data sets one of your biggest challenges or are there other challenges as well that you're facing in making it all happen? Susan Evans Axelsson: Yeah, well, I mean, it is a big effort to convert and harmonise large cohorts. Within work package three, my main focus and our main challenge is motivating contributors to participate. When they do clinical trials to make sure they get the right approvals from the patients, so that they can use them and can share their data. We also have to make sure that we satisfy all GDPR and privacy regulations while we have these meaningful research collaborations, we need this to be a useful platform. As a whole, the issue of big data in medical research and in health care systems, it's a complex ethical issue. Clare Delmar: Indeed. Susan Evans Axelsson: Yeah, it's complex. We have to make sure we have data privacy, cybersecurity, the social aspects of patient data being used. And for that we have a work package dedicated to ethics, legal and government of data sharing. We're not interested in a patient's name when we do this big data, we do allow data to be shared from the data holder in two ways. So we keep the data with the data holder and we harmonize it behind their firewall so nothing ever leaves. So we do not want to have patients that are scared to share data because we need this data to be able to improve how the patient is being treated. Clare Delmar: OK, so what's your message then, to like if you could get in front of large patient groups, you know, like a case of the prostate cancer communities, what would you say to them in terms of why it's so imperative that they sign these consent forms and why they should possibly advocate this to their colleagues? Susan Evans Axelsson: Well, first, I would have to say, you know, early diagnosis saves lives, so guys stop with the taboo. And when you do talk about your health, you know, when you talk to your doctor, get as much information as you can and tell your doctor you are willing to share the results of what's happening. You are willing to put your data in a large data platform because these platforms, we have to make sure that this is safe. And it's the only way that we're going to be able to standardize and that we're going to be able to get consensus on what is the most important prostate cancer outcomes. We need to identify critical evidence gaps, and for that, we need the men to give us the data to help us. Clare Delmar: So, I mean, basically, there's almost like the beginnings of a movement here. Like patients can actually help each other... Susan Evans Axelsson: Absolutely, and that's why we have patient advocates. We very much listen to them. Clare Delmar: And second quick question, I guess really final question. I mean, so to the extent that patients then understand that sharing their data is more than an altruistic thing, it's actually something that's in their interest in terms of their health and the health of their brothers and their friends or whatever. But that is fundamental to, I guess, your whole mission, which is that you honestly believe that by accumulating these large datasets, that is the key to really beginning to understand some of the key issues facing prostate cancer researchers. And you think big data is actually something that's going to really sort of accelerate that? It's the only way that we're going to be able to give each individual man the treatment that's best for him. It's the only way that we're going to meaningfully improve clinical practice. Clare Delmar: OK. Susan Evans Axelsson: Health, economic outcomes. I mean, think of the money saved from a man treated early, than a man who is treated later on in the disease. Clare Delmar: Absolutely, I don't think anybody disagrees with that. I think the issue here is, you know, how your project can really contribute to improving that. And you've got I mean... Susan Evans Axelsson: It's evidence, it's evidence-based data and that's what we need. Clare Delmar: That's the word that everybody likes. And if each individual understood why their data was important and gave consent and then sort of advocated this to others, and you'd be sort of over some of the initial challenges here. Susan Evans Axelsson: So, I mean, men need to ask questions. They need to know it's possible that they can share their data and can help other people because prostate cancer, a diagnosis doesn't just affect the man, it affects their whole family. Clare Delmar: I think a lot of them do understand that. I mean, I certainly talk to many patients who actively take the initiative and say we really would like to share our experience, you know, whether it's about a certain diagnostic pathway they went through or particularly if it's around a treatment. Susan Evans Axelsson: That's so nice to hear. Clare Delmar: So this just adds another element to that, that are you aware that by contributing your data, you're actually doing yourself a favor and contributing to the research? So, yeah. Susan Evans Axelsson: And that's why I really appreciate you taking the time to get this out. Clare Delmar: You know, it's an important project and, you know, the fact that it's so collaborative for one thing. Susan Evans Axelsson: Yeah, very much. Clare Delmar: And I

think I mean, that's interesting. I mean, if you look at some of the recent events, either the vaccine that was announced last week is a really good example of international collaboration... Susan Evans Axelsson: Absolutely. Clare Delmar: ... and research. And I want to thank you so much for chatting to us. Susan Evans Axelsson: Thank you very much, Clare. Clare Delmar: Maybe we'll have another chance to do it again with a more specific set of questions. But for the moment, I think you've given us some real insight to what big data means and how you can actually use the term big data and prostate cancer at the same time. So, anyway, thank you so much for speaking. Susan Evans Axelsson: Thank you, Clare. Clare Delmar: It's been fascinating and a real pleasure. Links to the Prostate Pioneer Project and a transcript of this interview is available on our website, where you can also access information and insights on living with prostate cancer. BAUS 2020: Reasons For Men To Be Cheerful This week was the annual meeting of BAUS, the British Association of Urological Surgeons. But that didn't detract from the presentation of and discussion around multiple innovations that will have real impact on men with prostate cancer. Medical conferences like this are an important way for clinical, research, academic, and medical industry (eg drug, device & supply) people to learn and share, both formally and informally. They contribute to the adoption of new technologies and techniques, the shifting of attitudes, and, ultimately, improvements in patient care. Two presentations stood out in their focus on how technology is being used to improve both the performance of clinicians and the outcomes for prostate cancer patients. In a session on the evolution of minimally invasive surgery in UK Urology, Prof Prokar Dasgupta of Kings College London spoke on how advances in digital technology and Artificial Intelligence are helping surgeons to improve their surgical performance, and to increase precision in prostate surgery. In terms of performance, Prof Gupta has been using AI to analyse videos of surgical procedures, resulting in metrics to improve surgeons' performance, such as accuracy, consistency and efficiency. He also demonstrated how he's using AI to "volumise" images on a prostate MRI scan and create 3D printed models of individual prostates, which are then used for surgical improvement. The photo below shows a 3D model of a prostate with tumour, and the actual prostate which had been surgically removed with a significantly improved level of precision. Professor Hashim Ahmed of Imperial College presented his view on the future of Urological Cancer Management, which he described as "rosy". Prof Ahmed is one of the world's leading innovators in the development of imaging-led diagnostics for prostate cancer and minimally invasive treatments like focal therapy. He predicted some big advances in screening, early diagnosis and minimally invasive therapies for prostate cancer over the next ten years, starting with the sobering context of an increasing health burden – 60-65k men per annum will be diagnosed with prostate cancer by 2030. As his graph shows, diagnoses are growing but so are the required MRI scans and biopsies, and at a faster rate, making the clinical burden fall largely on radiology and pathology. Expertise in these areas is already experiencing shortages and expected to continue, increasing the possibility of diagnostic errors and inappropriate treatments. Prof Ahmed believes that AI and machine learning will play a role in addressing this problem, and sees evidence of this already. He described how AI tools will help in screening, diagnostic imaging and histopathology, and showed how in some cases, particularly histopathology, AI tools are already bettering the performance of humans in "seeing" significant cancers. In terms of minimally invasive therapies, Prof Ahmed pointed to a prediction from an American colleague, who suggested that "if the past 25 years brought minimally invasive procedures, the next 25 will see the elimination of invasion". This may not be entirely accurate on the outcome but it certainly describes the direction of travel, as Prof Ahmed confirmed that "Focal Therapy is now coming into its own with more data on recurrence and mortality, all looking very favourable and improving all the time." With the commitment to improving the outcomes for men with prostate cancer shown this week at BAUS, there is reason for men to be optimistic. Remember, Remember, The Month Of Movember This week began the annual monthlong celebration of moustaches, raising of funds, and high-profile promotion of men's health – also known as Movember. Founded in 2003 by JC Coghlin, Movember is a global community of "Mo Bros and Mo Sisters" making a difference in mental health and suicide prevention, prostate cancer and testicular cancer. Coghlin was recognised this week as one of the 13 most influential men in Men's Health globally by Men's Health magazine. In paying tribute, the magazine described the genesis of Movember: "Like many of the best ideas, the concept for Movember was dreamed up in a pub. Inspired by the work they had seen women doing to raise funds for breast cancer, Travis Garone and Luke Slattery felt that men should be taking similar action on behalf of their own well-being. The following year, they registered as a company and gave Justin "JC" Coghlin a role as campaign manager. But to cut through the stigma, we had to get men having fun together." The risk paid off – generously. Today, Movember has raised more than £598m for men's health causes." This month will see thousands of men growing moustaches in

support of men's health. What is Movember's mission in supporting men with prostate cancer, and how is it going about this? Its aim is to halve the number of men dying from prostate cancer, and halve the number of men facing serious ongoing side effects from treatment by 2030. We unite researchers and experts across the world to chase down breakthroughs in prostate cancer, from early detection through to diagnosis, treatment and support. It's not just about a cure – it's about quality of life." Movember supports a nine-point "plan of attack" which includes specific clinical programmes, informational campaigns and global initiatives. According to Natasha Hill, director of brand and strategic marketing at Cancer Research UK, it has: "I really admire Movember - it is so different and so fresh. They found a way to appeal to men in a way that other campaigns just don't - with banter, and a sort of blokey jokiness." This is no small feat since men are generally reluctant to go to their GP and have been known to boast about how long it has been since they last saw a doctor. Independent research found that Movember has had an impact. More men are talking about health issues specific to them, getting general check-ups and becoming more aware of the health risks they face." Are you or have you been involved with Movember? If so, we'd like to hear about it, and promote you and your initiative on our social platforms. Raj Nigam on Ageism and Prostate Cancer Age Discrimination How the treatment of Covid patients has brought age discrimination and care into focus The Focal Therapy Clinic consultant urologist Raj Nigam joins OnFocus to discuss how the changing narrative of ageing is impacting men's experience with prostate cancer. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options:

020-7036-8870. Changing narratives of ageing Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we engage you with issues facing men diagnosed with prostate cancer that are little known, less understood and often ignored. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Raj Nigam, consulting urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy Clinic. And we're going to discuss how the changing narrative around ageing is impacting men's experience with prostate cancer. Clare Delmar: You're becoming quite the veteran in these discussions, so I'm just going to charge right in and I want to kick off by referencing a very impactful piece that was reported last week by The Times – for our listeners, The Times of London. And it was a big investigative study that basically showed that there was significant age discrimination of covid patients over the last year, which has brought ageism and care of the elderly into focus. I mean, even entering the chambers of parliament and other places where it was really, really talked about. So I want to ask you, do you think that this raised awareness that this investigative study has brought will have an impact on clinical practice? I think the covid pandemic, if anything, has magnified a situation that many of us felt already existed. The concept of ageism, as we have discussed, was effectively made unlawful back in 2012 through the National Health Service in the UK. And this is because there are prevailing attitudes towards increasing age, guiding our medical decisions and management. And it probably has not caught up with the fact that people are living longer lives and healthier lives. And yet we are using chronological age as a surrogate for deciding on even whether we investigate people based upon their age, let alone treat them. So I think you're right that what covid has illustrated rather starkly in my view, that ageism does exist and that this is sanctioned at the highest level. I mean, when the pandemic was in full flow, we had sort of NICE guidelines, which are national bodies on how we should decide whether somebody gets a ventilator and so on. I mean, while the report was focused on covid patients, others have come forward as a response to describe similar practices and attitudes in other areas, including prostate cancer. So I'd like to ask if you can illustrate, if you can describe in some detail some of the patient situations that you've seen where ageism has compromised care. Do you think this is a moment to harness public interest and support around ageism and demand change? So obviously, the field that I'm in of prostate cancer, age or ageism, if you like, has played a significant role over the years in deciding management of such patients. And if you want to break it down, I would describe ageism in this field as a sort of nihilistic approach, really, which ignores the individual circumstances, their state of health, their outlook on life and so on. And we as doctors, we're all guilty of it to some extent, insofar as we have developed a slightly parochial attitude towards elderly patients. And therefore these terms, such as watchful waiting and active surveillance, have come into being, i.e. offering basically no treatment. And of course, I've come across several patient situations like this one, which I only saw last week with a chap of 73 years old, very fit and well, very active, who had been told in his locality, oh, nobody will offer you surgery at your age for prostate cancer. So he was effectively being put down the hormone therapy route, which would give him several side effects, which would limit his activities. He runs huge businesses still and is very active, yet he had been told on the

grounds of his age, his chronological age, that he would be denied curative treatment. Clare Delmar: And I know you've said with regard to hormone therapy that this has been something you've seen, unfortunately, at a large scale during covid. Do you see it in any other ways, whether it's surgical procedures or you mentioned watchful waiting... Raj Nigam: Covid pandemic time was obviously a highly specific time and was very unusual, of course, in that all surgery and all radiation treatments and all chemotherapy treatments were halted at that time, when we knew so little about the virus. And a surrogate for that was, in effect to try and buy time, was to place men on hormonal therapy. And I've come across so many men where the side effects of such treatment were not even discussed. So those patients who would have been suited for a radical treatment without any hormones were denied this. But even now, hormones are still being used as a marker of actually saying, well, all right, if you want treatment, this is what we'll give you because you are elderly. We hear them every day, which many of our patients view differently or in some cases even reject in their own lives. As you've indicated, this gentleman you were just referring to at 73 is thriving, deeply engaged in an active life when their prostate cancer is diagnosed, but yet they are treated as elderly or vulnerable – back to those terms. Raj Nigam: Those three words you've chosen are very interesting: ageing, elderly, vulnerable, but all of them, in my view, sort of carry negative connotations. Raj Nigam: And certainly in the covid era, which we are still in, those would be words that would put fear into a slightly older population because they would fear being treated in a certain way. I think we have to remember that life expectancy has changed and has improved over the years, although less so over the last 10 years or so. And in the UK, for example, a man who lives to the age of 65 can expect to live another 19 years, a man who lives to the age of 75 can expect to live another 12 years. In fact, the greatest number of deaths in the UK, now happen in their 80s rather than in their 70s. Raj Nigam: ... from that point of view and therefore these definitions of ageing, elderly and vulnerable are no longer valid for men and women who reach the age of 70. Raj Nigam: And all covid has done is really magnified this, I think, that this does go on in medical care, either subconsciously or consciously. Clare Delmar: Exactly and that's why I wonder if this is a moment to really bring this out, because it is happening. And by that I mean a collection of both researchers and activists and campaigners who are using the term longevity to show that longer, better lives are possible through advances in medicine as well as shifts in attitudes, behaviours. Do you think something like that has a role to play in supporting men and ensuring that they get appropriate treatment for prostate cancer? And although I've just quoted you some figures regarding life expectancy, we now recognise healthy years of life expectancy as well. Raj Nigam: I mean, there are lots of different measures in terms of measuring quality of life. QALYs are, if you like, a surrogate marker of people living quality, added life years, if you like. There are some geographical variations in that and there are some ethnic and racial variations. And even within the UK, we know that although health equality years are improving in most areas, there are one or two pockets geographically in the UK where that is not so obvious. But yes, you're right, to come back to your point regarding the longevity movement and so on, I agree with you that this is a moment, coming out of covid, whereby we can apply it to other medical conditions such as prostate cancer. There are lots of charities for the elderly, prostate cancer charities, and so on, who should be perhaps harnessing this and advising their men who are over a certain age exactly what is available to them and what should be required of them when they have their consultations following their diagnosis. Clare Delmar: And really trying to address or indeed even cancel out this fear factor and instead giving men positivity that they are likely to live long lives based on certain metrics that you've referenced and that a prostate cancer diagnosis should be considered in that context. Raj Nigam: Totally, totally like several charitable organisations, there are other means of trying to improve this, not least, of course, patient empowerment, empowering patients to ask for certain things, say, look, I might be 70, I might be 71 or whatever, but, you know, why can't I be treated like a 50 year old? I think that there are several factors which may promote this change, not least of which is the extension of the retirement age. And I think as people continue to work for longer, which they will be required to do, well into their 60s and so on, then maybe certain attitudes will change and the definitions of terms like elderly should change. Clare Delmar: So a final question: could you sum that up in a piece of advice you might give to men over 70 about engaging with their doctors? Raj Nigam: I mean, I think the first thing that such men need to recognize that there are long held cultural attitudes within the medical profession and beyond regarding aging and so on, and some of the words that you've used will resonate with the medical profession, unfortunately, rather than with patients themselves. You can speed that up through legislation sometimes, but I think patient empowerment is the big key and patient knowledge. So if patients are aware that actually because I've reached 70, I may not be offered certain treatments, I may not be offered the opportunities for modern day diagnostics and

so on, that a) I should learn about this and find out information about them and then absolutely demand say, look, I really do want to undergo investigation. And sure if I do have the type of cancer that I'm just going to live with and die from, then I can make my judgment at that point in time. And then, of course, if I'm in treatment, then I should be aware of all the treatment options, not just those which are widely available, which are often radical treatments, which is why certain doctors parochially sort of try and "protect", in inverted commas, their patients from such radical treatments because they are deemed to be older than other patients. So I think that as long as they are given all that information, which does take time and it's true that the NHS doesn't always have that much time. A lot of my second opinions that I see, it's just a case of going over all of the information that I have, but that nobody has actually sat down with them to explain exactly what is available. So I think that the quickest win is, if you like, patient empowerment and patient information and knowledge and being able to engage with their doctors appropriately. And I hope that we will be a force in bringing it out there and working in partnership with some of these organisations that you mentioned.

Clare Delmar: A transcript of this interview is available on our website, where you can also access information and insight on living with prostate cancer.

Age Discrimination a real issue for Prostate Cancer Patients This week saw a major investigation from The Times describing how the NHS overwhelmingly neglected and, worse, outright discriminated against older people during COVID. The Guardian weighed in citing this as an amplification of something that has been happening for a while. Both reports generated widespread condemnation across many quarters, and stepped up advocacy amongst elderly and age support organisations. It's interesting to juxtapose these reports on age discrimination with what we're hearing from our patients, because while they are most definitely feeling the impact of age discrimination, it's playing out in some very specific ways. Many of our patients come to us because they have felt dismissed, abandoned and even actively discriminated against in their treatment for prostate cancer within the NHS, all of which they perceive as being due to their age. But second, there is a more nuanced version of events that emerges – and that is a picture looking like two parallel universes, one in which men are fit and active when they are diagnosed with prostate cancer, with expectations of many more years of fitness and health – and another one in which men over 70 are seen as not worth treating at all. These men are living full, active lives – engaged in sport, travel, family & community, and not willing to compromise on their level of commitment to any of these, despite their prostate cancer diagnosis. Some tell us they are fitter and more focused now than they have ever been, and others embrace a new narrative of ageing which espouses that "70 is the new 50" Yet they are consistently denied the treatment they deserve. In some cases this is due to COVID, which has very clearly restricted what's available to them, but not always. These men are experiencing both undertreatment – eg active surveillance – and overtreatment – eg hormone therapy – relative to their personal circumstances and intentions. There is a significant disconnect between the expectations these men and their partners have for the quality of their lives and how the NHS engages with them around a disease like prostate cancer, which affects lots of men and is something they may have to live with for some time. On the one hand, there's messaging on a theme of "old, frail and vulnerable", which is amplified and reinforced by COVID (quite reasonably in many cases, but not all). On the other hand, there is powerful messaging around the importance of exercise, social engagement and prevention. Indeed, we are learning more and more about living longer, healthier lives and the "enhanced longevity" approach is, appropriately, gaining steam. It would behave the NHS to regard all men with a prostate cancer diagnosis, including those over 70, as having expectations of a full life and a willingness to commit, sacrifice even, to achieving that. If you have thoughts, insights, stories and experiences around ageing and perceptions if it, get in touch -- we'd love to hear from you.

Prostate Cancer Scotland : Men need to be aware of Prostate Focal Therapy as an alternative to Radical Treatment A discussion with HIFU focal therapy patient, Graham Ogilvy Journalist and publisher Graham Ogilvy joins OnFocus to discuss his recent experience with a prostate cancer screening and diagnosis in Scotland that ultimately led him to seek treatment in England, and offers strong advice for men in Scotland to question the "blunt instruments" that are the default diagnostic and treatment offer there. Press play in the audio player below to hear the interview, and speak to The Focal Therapy Clinic at 020-7036-8870 to learn more how focal therapy can help treat your prostate cancer. Please find below a written transcript of the interview.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Graham Ogilvy, a former journalist from Dundee, who's here to discuss his experience with initial diagnosis of prostate

cancer in Scotland and how this led him to undergo HIFU treatment with Raj Nigam at The Focal Therapy Clinic at Mount Alvernia Hospital, Guilford. Graham, welcome and thanks so much for joining me today. Graham Ogilvy: Thanks Clare, pleased to join you on our Zoom technology. Clare Delmar: Absolutely. So, Graham, we've been chatting a little bit before this interview, but for the benefit of our listeners, I'm just going to start off our conversation by picking up on your journey to southeast England to Guildford to see Raj earlier this year from Scotland for the HIFU treatment that we're here to talk about. How did this come about? How did you start off in Scotland and wind up down in Guildford? Graham Ogilvy: I was diagnosed with prostate cancer last October at the age of 62. Quite a slick conveyor belt operating. And I got the sort of the good news that the cancer was curable, at which point, you know, I was pretty happy about that, obviously. And that's when I think it got really quite interesting. Clare Delmar: Interesting how? Graham Ogilvy: Probably because I haven't had that much to do with doctors, I kind of imagined that there would be a consultant and he would present the choices and make a recommendation. Doesn't quite work like that. There is a third, brachytherapy which I asked to be considered for, but there was a sort of inexplicable delay in getting to that. And so we were really focusing on the two choices, which was the removal of the prostate gland or its destruction with radiation, hormone treatment and radiation, which seems to be something of an Ottoman choice. They could either have their testicles crushed between two silk pillows or smashed between two bricks. Clare Delmar: But the outcome was the same. Graham Ogilvy: A bit of a blunt instrument, I think. And the next day I saw somebody who was a consultant to do with the hormone treatment and radiation, and he told me what he did. And then you have to make your mind up. I didn't feel terrible... I'm not really a medical expert, so that was a bit of a surprise. There was then this attempt to get in touch with brachytherapy people who were based in Edinburgh. There was a bit of a delay, a bit of an interregnum during which I was obviously reading online about things. I was aware of the HIFU option, but it wasn't something that I pursued, firstly because I didn't know anybody who had it, I think. Secondly, I didn't really know how to go about accessing it. It seems to me, you know, I mean, without going on Amazon to get prostate treatment, you know, that's what it felt like. I mean, it's not the way we've been brought up. Clare Delmar: You mentioned in a previous conversation that your diagnosis was initially confirmed by a TRUS biopsy. Is that correct? Graham Ogilvy: Yes, yes. Clare Delmar: Were you offered another option, how did the TRUS biopsy affect your diagnosis and ultimate treatments? Graham Ogilvy: This was actually very interesting and putting my journalistic hat on, I must say, if I wasn't retired, it would be rather a good story. The TRUS biopsy, which is a transrectal biopsy, is, as the name suggests, inherently slightly dangerous in that the chances of infection are elevated. So the risks are self-evident. You're given a piece of paper alerting you to the fact that one man in 200 will die as a result of this and you're given two antibiotic tablets to take a couple of hours beforehand. And luckily for me, unlike a friend of mine, I didn't get an infection. I was duly phoned with the results, which was that I had "a wee bit of cancer on one side, but nothing on the other side". And this was graded on the Gleason score four plus three, which I understand that three plus four, is pretty much better than four plus three. Four denoting that it's got an ambition to travel. So armed with that information, the next step is what to do about it. Clare Delmar: Yep. Graham Ogilvy: And neither of the options looked fantastic because I didn't get up in the night as lots of guys have to do and I still don't. If I had the surgery, I was going to have these problems. Clare Delmar: Yes. Graham Ogilvy: And but then when it came to the radiation and hormone, first of all, the hormone treatment I gathered was pretty devastating. But possibly what I would have gone for, because the side effects are less dramatic than the removal. I also happen to live close to the hospital. So it wouldn't be a problem for me to go up there every day, but it certainly would be for a lot of guys who live further away. So I was tempted to take that route. But what was a big thing for me that concerned me about radiation was that after you've had radiation, they say that surgery is not generally possible if it comes back because the tissues are gunged up. They weren't sure if I would be suitable for that, but that was a decision to be made in Edinburgh. There was quite a delay. During that delay I was reading about HIFU, as I had done already, but then a friend called and put me in touch with his brother in law who had successfully been treated with HIFU three or four years ago. And he's a partner at an international law firm and pretty astute, and pretty forensic in his analysis. I tried to... I got online and was spurred into action with this. And also I'm not sure if I was impatient or disenchanted or both, but not hearing anything about this brachytherapy because I hadn't had any information for about five or six weeks. I was standing waiting for the bloody letter to arrive every day, you know, twenty past one. It's never arriving. And then of course, by this time you sense that perhaps it's never going to arrive unless you make an intervention. So I went online and there was a few things and I tried to get this guy, but it wasn't easy to find this guy who's one of the top men in the field. But I

saw that he was part of a group who had been working on this in terms of having it assessed for the NHS. And then I noticed that when I saw the focal therapy clinic, I saw that one of the people, one of his collaborators was Mr Nigam who was at The Focal Therapy Clinic and who also had collaborated with this guy and was cited on the papers that I had looked at. And then they got in touch and then I jumped on a plane, went down and saw Mr. Nigam. Clare Delmar: Did he request another biopsy or did he work with your...? Graham Ogilvy: Yes. First of all, the NHS were very good about giving me the records and the MRI scan I had so that Mr Nigam could see that. The MRI scan he thought was of a very high quality, etc., but did require to be another biopsy. And this was very interesting because this was a different biopsy from that that is performed in Scotland. It's more exact, it's a transperineal, I think they call it. Clare Delmar: MRI fusion, ultrasound fusion. Graham Ogilvy: And it's more accurate to begin with. Unlike the one that you get in Scotland, there is a general anaesthetic, but you're given intravenously antibiotic during this. It struck me that here I was getting an inherently safer procedure because it is safer with less chance of infection, with greater protection. Then I was horrified to subsequently learn that, in fact, in large parts of England, the biopsy that we get in Scotland is not allowed because it's regarded as being dangerous. And I understand it's banned in certain parts of Europe as well. Now, the other thing about this rather disappointing thing about this biopsy that I had in Scotland was that. The wee bit of cancer on the one side and the no cancer on the other side turned out to be not quite the picture. I'm only imagining because I don't have any medical knowledge that it may be that they don't require so much accuracy, if all you're doing is applying the blunt instruments of surgical removal or radiation, basically destroying the thing so they don't need to know. But what did emerge was that from this safer but more accurate procedure was that in fact I had quite a bit of cancer on one side and a little bit on the other side. So the picture was rather different. So I think there's an issue there to be addressed in Scotland. I mean, I presume it's costly to knock people out and all that, but I do think that part of the problem with prostate cancer is that it affects old guys who, you know, are not sexy, not high up in the political agenda, although I think obviously prostate cancer is gaining traction in the political agenda and it is becoming more important. But I ask the question: if one woman, one mother, one grandmother, one daughter, one sister in two hundred was dying needlessly from a breast cancer biopsy. My question is, why are these men dying? Clare Delmar: Yeah, no, it's a pretty critical question. I mean, there's a few things you've mentioned here that, you know, I just want to probe a little bit more about, you know, particularly the Scottish experience. I mean, again, this use of blunt instruments, as you describe them, seems to be common and persistent. And as you then you know, was shown to be quite evident in England. Not only was it not, but it was actually seen, as you said, dangerous and inaccurate was kind of secondary. And then the second thing you talked a bit about was that Scottish men are potentially affected by ageist attitudes or even gender based ones. You know, the sort of old guys are effectively ignored. I mean, do you feel that other people share that view? Graham Ogilvy: Yeah, I have spoken to other guys who have been in this situation and they feel that way as well. I think it's UK wide, I think that because it affects older guys, I really can't understand why they're not screening for it. I know the argument about everybody's going to get it sooner or later. And, you know, most people can live with it and all this kind of thing, but there are men turning up and it's too late. There's the cry. It seems to me that you might save yourself a lot of heartache and money by earlier intervention, you know? I know people who've turned 60 and gone to the doctor and asked for a blood test because they're concerned about this, just as a matter of routine, and they are told, no, presumably they don't have any symptoms. So maybe... I understand the health service is under pressure and I certainly support it most avidly. But the biopsy I know about and if the NHS is one part of the country says it's dangerous, and won't do it, why is it being done elsewhere? Clare Delmar: So that's the question. So Graham, in your experience, how would you advise men in Scotland who've recently been diagnosed with prostate cancer? Graham Ogilvy: Well, first of all, I think that they have questions to ask and all the rest of it, and I think I had some experience of the expert nurses at the prostate cancer charity, Prostate Cancer UK, really excellent. They are very reassuring. But they also tell you what the scores are on the doors, the questions to ask, the buttons to press, et cetera. My experience was, you know, I was deemed by Mr. Nigam to be suitable for this HIFU procedure, which is ultrasound where it meets and generates heat and basically they burn out the cancer. They've been doing it for quite a long time, 30 years on the continent, coming up for 10 years here, I think possibly. But my PSA had gone down slightly from 12 and a half to ten and a half. I got the operation done at Guildford, which was a very nice hospital, very friendly people, very straightforward procedure, no real discomfort afterwards. I had a catheter, which you could do without, but it wasn't as horrendous as I imagined it to be. And I liaised with the NHS up here, when I came back and the district nurse came around and removed the

thing I never felt it at all and it was back to business as usual, I'm delighted to see. So it was all pretty amazing, actually, because I had the operation on the Thursday night, Thursday during the day, rather, and was out having an Indian meal and a glass of red wine on Friday night. Clare Delmar: That's really good to hear. Well then subsequently I had two... You're always reluctant to jump up and down in celebration with cancer, but I subsequently had two blood tests. The blood tests are done at the local doctor's surgery and she sees them and we have a phone chat. Mr Nigam was very pleased with the results coming down to two. So to get down to two is really good. Clare Delmar: That's really good. Graham Ogilvy: And certainly as far as side effects go, I mean, I just think about what might have happened. I just think I've been so lucky. Clare Delmar: Now, clearly you have you know, it's been really interesting to have you share this, because I think a lot of men need to understand how to take the steps you have and exactly what went through your head, what you encountered. So Graham I really want to thank you for sharing this. And I think your comments about some of the blunt instruments, as we said earlier, are quite telling. But I want to thank you so much for speaking with me today, it's been a real pleasure. Graham Ogilvy: OK, Clare, thanks very much. Clare Delmar: A transcript of this interview is available on our website, where you can also access information and insight on living with prostate cancer. As Black History Month draws to a close, it's appropriate to focus on recent developments in understanding why black men in the UK bear twice the burden of prostate cancer as white men – 1 in 4 versus 1 in 8. Earlier this month, Jonathan Oloyede, leader of City Chapel in east London, joined OnFocus to discuss the challenges that men in his community face regarding their health and how he is playing a key role in supporting them. He emphasised the theoretically simple but practically complex role of raising awareness: "There's not much awareness that is being made available and money being spent equally sometimes on what I would call a black man's issue with prostate cancer compared to something like breast cancer or cervical cancer." He has specific suggestions for improving this: "I think this kind of information should be available at every clinic. They tell us that men find it difficult to go to the clinic or go and see the doctor, it's known. There should be more effort made by government and made, by the NHS to reaching black men in particular with regards to prostate cancer, because like you rightly said, one in four men will get prostate cancer. And if that is a known stat and I don't see any reason why much more is not being done to reach us as black men." Prostate Cancer UK is rising to the challenge on raising awareness in the black community with a media campaign and first UK prostate cancer clinical trial focusing on black men. This video is particularly moving and will hopefully be shared amongst communities like Jonathan's. <https://www.youtube.com/watch?v=A1AsqKS6g30> This week the charity announced the "first-of-its-kind study in the UK ...aiming to solve the mystery of why black men develop prostate cancer at twice the rate of other men in the UK." The PROFILE study will look at the genes of men of African and Caribbean descent to see if they can learn to predict prostate cancer risk, and find better ways of diagnosing and treating the disease. The study is currently open to men aged 40-69, who are of African or Caribbean descent and haven't previously had prostate cancer. Communities like Jonathan's will be key to recruitment, and Jonathan is keen to work in partnership with organisations like Prostate Cancer UK. "If we have organisations that want to engage with the black community and with churches, I definitely would love to get in touch with them. And if they if they have the right attitude and the right personnel to connect with the black community, we would love, I would really, really love to do that very open to do that." Running into Cancer – Tony Collier's Story Spreading awareness about PSA screening for prostate cancer Tony Collier, ambassador, awareness speaker and fundraiser for Prostate Cancer UK joins Clare to discuss his campaigns and the messages he wants every man and his loved ones to hear regarding prostate cancer. In May 2017, while training for an ultra marathon, Tony was told that a groin strain was in fact prostate cancer that had spread to the pelvic bone and was working its way throughout his skeletal system. In his words, "a worst case prognosis of two years was a real shock but I was even more shocked when I discovered that if I'd requested a PSA blood test every year from age 50 I could have had curative treatment. Now it's my mission to make sure other men know." Engage further with Tony via his blog and on Twitter @ethansgrumps Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Joining me today is Tony Collier, ambassador, awareness speaker and fundraiser for Prostate Cancer UK. In May 2017 while training for an ultramarathon, Tony was told that a groin strain was in fact prostate cancer that had spread to the pelvic bone and was working its way throughout his skeletal system. But I was even more shocked

when I discovered that if I had requested a PSA blood test every year from age 50, I could have had curative treatment if only I'd known. Now it's my mission to make sure other men know." Tony is here to discuss his campaigns and the messages he wants all men and their loved ones to hear regarding prostate cancer. From a rather dull, overcast, wet Manchester, UK. Clare Delmar: Yes, actually pouring rain here in London. I mean, I introduced a little bit about who you are, obviously, and some real highlights about the fact that you were (still are?) I mean, earlier on, you've actually been an ultra marathoner and then you received this diagnosis and now you've become a campaigner. So can we start this conversation by sharing with us what you would say were the key events in your journey with prostate cancer thus far. Tony Collier: Yeah, sure, Clare. I ran my first marathon when I was 50. Clare Delmar: Which one was that? Tony Collier: I think it was Brussels in Belgium. And then I went on to do another 18 marathons, having said never again 18 times. Clare Delmar: 18? Tony Collier: I ran 19 in total before the age of 59. Clare Delmar: Wow. Tony Collier: From 50 to 59, 19 marathons. Clare Delmar: What was your PB? Tony Collier: PB was 3hr23 so I was a pretty decent sub elite runner. Clare Delmar: Wow. Tony Collier: I've done one marathon since my diagnosis which was London and strangely it's the one I'm most proud of. I ran it in five hours and seven but I'd been on hormone therapy for a year which had a massive effect on my running ability. But I raised thirteen thousand pounds for Prostate Cancer UK. Clare Delmar: Well done. Tony Collier: So I'm actually most proud of that one. My running career sort of took a step up when I heard about this incredible race called Comrades Ultramarathon in South Africa. It's often 28 centigrade and quite a challenging race. Clare Delmar: Wow. Tony Collier: So I turned up in 2015 but I picked up an injury six weeks before and basically had to bail out after 17 miles and then the following year, 2017, I completed it – one of the proudest moments in my life. But then the relevance of Comrades is that I was training to run it again in 2017 and in April 2017 I ran two marathons a week apart. I could barely get my right leg out of the car and that became a bit of an issue because obviously Comrades was on the horizon and I still wanted to do it. The MRI scan obviously showed up something untoward, and he sent me there and then for a chest x ray and blood tests. And then he said to me, just because I want to rule out anything untoward, tomorrow, I need you to go and have a full body CT scan. Of course you can imagine that evening my wife and I were just struck with fear and terror... Clare Delmar: Of course. Tony Collier: ...absolute terror, sleepless night, horrendous. I went to my running club that evening and the doctor phoned me as I was leaving at about eight o'clock and said, I'm really sorry, but I'm ninety five percent certain you've got prostate cancer and you'll need some more tests. So we had more tests, bone scans, biopsies, all the usual stuff and I was told about 10 days later, that I'd got stage four prostate cancer. And then the most scary thing is my wife asked the urologist at the first meeting with him. It also meant I'd run 19 marathons and one ultramarathon with cancer inside me. Clare Delmar: So no symptoms? Tony Collier: Absolutely symptomless, completely symptomless. If I think back to the months before my diagnosis, the only thing I can think of is that my ejaculations were weaker. And it turned out it was actually stress fractures of the pelvic bone where the cancer had eaten into the pelvic bone. And so that was what was causing the pain. Clare Delmar: So your first PSA test ever was during this time? Tony Collier: First PSA test ever was on the 8th of May 2017 when the sports injury doctor sent me to have one. And I remember seeing the bloods form for the blood test and he'd written a PSA because we don't do PSA test as standard in the UK. Started Bicalutamide for 28 days, first injection of Prostaglandin part way through that 14 days and then three monthly Prostaglandin injections after that. And I was due to have docetaxel chemotherapy on the 23rd August, about three months after diagnosis. Lots of people contacted me and told me about this new wonder drug that had been announced at the cancer conference in Chicago in June of 2017 called Abiraterone. Clare Delmar: Yes. Tony Collier: And I basically talked to my oncologist about it and he decided that my private medical insurers might fund it for me and they did. My PSA at diagnosis was 129. Clare Delmar: Wow. Tony Collier: And it has stayed at zero for the best part of three years now. But I think the biggest shock for me was that I'd had it for ten years. Clare Delmar: Yes, of course. Tony Collier: And then moving on from that, that basically leads to why I became an advocate. Clare Delmar: Yes, exactly. How has this led to this role as an advocate and campaigner? Tony Collier: Well, to be honest, I started off I was absolutely furious that if I'd known that I could ask for the PSA test from age 50. If I'd known about it and actually done something about it because, of course I may not have done something about it. If I had a PSA test every year from age 50 I could have had curative treatment and I wanted to make sure that other men knew they would end up like me if they didn't go and have a PSA test. Until we have a screening programme for prostate cancer, we are not going to catch men until they're too late like I was. And I want to make sure as many men as possible are diagnosed early because early diagnosis equals curative treatment – most of the time. My family were the faces of the

2018 Christmas appeal, which raised probably near a million pound. And I've done some television interviews, radio interviews, I've written articles, and basically I make as much noise as possible. Clare Delmar: Yeah, you're quite a social media star. Tony Collier: Well, I try my best to be out there as much as possible. I didn't want her to be in a difficult position. Clare Delmar: Indeed. Tony Collier: So we both agreed that it was the right thing for us to do. Clare Delmar: It's interesting because that's one of several themes that I've been particularly interested in and we've seen with the patients who come to us. You know, the wife or the partner is often the advocate and is affected clearly in multiple ways as well. So I just want to pick up on something you said a minute ago about some of the changes you've seen in this sort of three year period. So in addition to that, and maybe the PSA is a place to start, but what changes have you seen in that short time that might even give hope or give caution to other people, whether they're medical changes or you mentioned attitudinal changes or behavioural changes? I'd be really interested to hear what you think about that. Tony Collier: I think Prostate Cancer UK has been very effective in raising the profile of prostate cancer and using celebrities to do so. So when Bill Turnbull, the newscaster, and Stephen Fry, the actor, were open about their illnesses, we ended up with something called the Turnbull-Fry effect. The other impact that Turnbull and Fry had is our job as awareness speakers became much easier. We met obstructions, we met, I think, situations where people were not very comfortable about it, but because it was now much more in the public domain, we were pushing against open doors. And I think that's been really, really important. Clare Delmar: And what have you seen as some of the most open doors in terms of channels? Where have you found these doors to be particularly open for you? Tony Collier: I think in my own case, because I was a runner, I wanted to tell my story to running clubs and that was a bit of an issue because obviously running clubs are all fit young men. The story about my running life, about running all six of the world marathon majors, running Comrades, some funny anecdotes about running life, but then link it into my diagnosis, which was basically brought about by running. If I weren't a runner, I'd still probably wouldn't know to this day that I had this thing inside me. And I approached loads and loads of running clubs in my area of England and we basically managed to get in front of as many people as possible. But I think the other issue is when I spoke to people about telling them to go and get a PSA test, initially I was meeting obstructions to that. But the Turnbull-Fry effect had a massive impact because people actually knew that they should, in fact, be having these tests. So it made my story easier. Clare Delmar: Just to shift a little bit about some of the changes you've seen in behaviours, and there's some good news there about getting out there. I think you're probably aware that one of the outcomes of that effect was, I think, the first ever interview in The Lancet or the BMJ, where Stephen Fry actually was interviewed by his urologist. Tony Collier: Yeah, I saw that. Clare Delmar: So I think it really penetrated lots of spaces. But just want to shift a little bit to... and the fact that you've seen so many different groups of men and I hear what you're saying about running community, but obviously you've even gone broader than that. And what I'm wondering is how many health inequalities you've noticed within these groups, because one of the things that we're certainly seeing are some very significant health inequalities, particularly for men over 70. And I'm interested in what your experiences with these groups and what thoughts you have on empowering them. Tony Collier: Well, I think the first thing is that my perfect audience to speak to doing an awareness talk is a group of women, and that's mainly because they are very influential and they go home and make sure their men go and have a PSA test. So a group of women is definitely worthwhile speaking to. Clare Delmar: And do you do that very often? Tony Collier: I try my best. I'm particularly interested in seeing new drugs come on stream because I think new drugs are something that will hopefully prolong my life. And the big issue at the moment in England is that it's not available as a first line treatment for men newly diagnosed with castration sensitive metastatic prostate cancer. And that means basically men in the UK diagnosed stage four with metastases go on to docetaxel chemotherapy. And the big problem is that the older the man, the greater the chance of having comorbidities and the less likely they are to tolerate docetaxel chemotherapy and its toxicity. And it's interesting to see that Prostate Cancer UK, when they appealed to NICE about the prescribing of Abiraterone for first line treatment, basically looked at the elder population particularly, with a view to saying, you know, these men can't tolerate docetaxel to the same extent and we are therefore denying them the treatment that will prolong their life. I mean, whether that's the partner of a gay man or a trans woman or whether it's a heterosexual partnership, the support for partners is really, really limited. And one of the big issues with a terminal diagnosis of prostate cancer and being on lifelong hormone therapy, is loss of libido and erectile dysfunction. Clare Delmar: Yes. Tony Collier: ...and it's very horrible because it affects both partners in the relationship. Clare Delmar: Of course it does, yes. Tony Collier: I mean, it's just something that's troubled me ever since my diagnosis and it's something that you've got

to be able to talk very openly with your partner about. And we were very fortunate that we actually did have access to a psychosexual therapist, a clinical nurse specialist, and she was fantastic. And one thing that stuck in our mind from our conversations with her – the hormone therapy removed your drive, but it didn't remove your desire. And I don't think that level of care is available for the partners of any patient with cancer in the UK to the same extent it should be. So I think there's a massive inequality there. Clare Delmar: I agree with you and I see lots of evidence of that. I think the other thing I wanted to just pick up on was about the drug access that you talked about a bit earlier. And you know how some is available, some isn't, and what can be tolerated, particularly with older men. And so to the extent that there is this disconnect between what's out there but what's actually accessible or available, how do you see this changing? And do you think campaigns and advocacy like yours is a key part of this? Tony Collier: I think access is still appalling and it's still very much a postcode lottery. The fact that you can get Abiraterone as first-line treatment in Scotland but can't in England is disgraceful. Chemotherapy for many is life changing and Abiraterone and Enzalutamide much less so, in my opinion. People are dying earlier as a result and it is so difficult to get the patient voice heard. They wanted examples of older people who would have done better on Abiraterone than docetaxel. But there is a limited audience for that. Clare Delmar: Yes. Tony Collier: ... And I think this has got to change. But I'm not holding my breath that we're going to see change very quickly. Clare Delmar: Finally, Tony, you have been in very recent times in the so-called covid era, a very strong advocate for the rights of cancer patients and also some of the issues we've talked about for different reasons, like inequalities, like mental health challenges that have just been exacerbated through covid. Do you have any messages that you'd like to share here around that? Tony Collier: I think the big message really is that people are obviously suffering mental health issues because of covid. Whilst living with cancer as well, you can imagine that I don't want to spend my life locked down, not seeing friends or not seeing family when I know that I've got a shorter life expectancy. Clare Delmar: Absolutely. Tony Collier: And it does prey on my mind, inevitably and it must prey on other people's minds, hugely. I was having business problems primarily because I was trying to get out of business, to spend life enjoying myself a bit more. And basically everything got on top of me and I had an absolute total meltdown, and I came back and I was constantly in tears, shaking, anxiety, depression, and I went to seek help. It is not weakness to seek help. Clare Delmar: No. Tony Collier: So I would urge anybody having a really, really tough time with covid and a comorbidity or just with covid and the general mental health issues. Please go and seek help, it's so important. Clare Delmar: So, Tony, how do our listeners find you or do you have lots of things you've referred to? Is there a couple of things you can say just quickly about how people could find you, maybe engage with you or certainly access your campaigns? Tony Collier: Sure. And actually there's one on there that I think is called living with prostate cancer, the good bits, because it's not all been bad. Back in 2018, I was a model in a fashion show and starred on the catwalk underneath Concorde at the Manchester aviation viewing park. Clare Delmar: Oh, wow. And I'm not very used to public speaking, but I remember quite vividly that Rick Astley, the singer, he was actually performing free of charge and like doing the disco at the evening gala ball for free of charge, just to support the charity. And I remember looking down, looking at him and he was in tears and I think it's that profound effect that you can have by telling your story, that's really, really important, and I think that I've been able to do things that I would never have dreamt of doing. So the television interviews, for example, radio interviews, I do those because it's really important to spread the word. I don't want any personal glory from it, but spreading the message about going to get tested is so vital. And I would never have had the soapbox to do that from without my diagnosis. Clare Delmar: Yep, no, indeed. And I hope we can get the message out to more men – go and get that PSA test done. Clare Delmar: Absolutely. A transcript of this interview is available on our website, where you can also access information and insight on living with prostate cancer. Recent stories in the media have highlighted growing backlogs in cancer imaging within the NHS. And there has also been recent announcements from the NHS on a future of "one-stop" diagnostic centres based in local communities where cancer imaging could be made more easily available and accessible. As voices build on how to restore cancer imaging services to stave off a new crisis in cancer care, and to create an opportunity for better and more accessible imaging, it's a good time to assess what is needed in prostate imaging and to build a platform for consistent, high-quality delivery – which will ultimately lead to better care. At its most basic, the prostate MRI scan underpins the decision to biopsy or not to biopsy, and it can eliminate 30% of patients from undergoing biopsy. – a huge step forward from the days when all patients with elevated PSA were biopsied. TFC Consulting Urologist Alan Doherty points out that: "One of the main things I think about an MRI scan is that you can try and avoid doing biopsies. You want a patient to have confidence that the PSA is borderline elevated not because of an

aggressive cancer and therefore doesn't need a biopsy. If you biopsy everyone who has an MRI scan, then there's no point doing the MRI scan because you're going to find out what they got anyway. So it's really important that this concept, and I don't like the term pre-biopsy MRI scan because it suggests that the MRI scan is just a sort of adjunct to the biopsy." At its most sophisticated, the prostate MRI scan confirms location, size and severity of prostate cancer with high levels of accuracy, underpins targeted biopsies and treatments, and monitors progression through active surveillance. "The current best practice is to have a report where they look at what's called the PIRADS scores and something else called the Likert score", says Alan Doherty. "Relatively recently, and even now, you'll get some reports which will say something like there's a slight abnormality on the left hand side. So what sort of evolved was a score where a radiologist will say that they think it's virtually 100 percent likely that there's cancer there and they'll give that a score of five and then there will be a situation where they think it's likely rather than very likely, and in that situation they'll give a score four and then you will get the sort of threes which are equivocal and then twos where they think it's unlikely and one where they think it's very unlikely. Now, within the prostate, I want to know what the score is and I want to know where they think that cancer is likely to be. And so a good radiology report will map the prostate and in different parts of the prostate, will give it different scores. And then what I like to have is a diagrammatic representation of what they're talking about so I can actually see it in a cross-sectional basis. I want to know that there aren't any surrounding abnormalities in the lymph nodes or the bones. And if an MRI is done properly, you can really move forward with the whole management of the patient." In the UK, the NHS performs well on delivering the basic requirement, enabling an informed decision on whether to biopsy. Since 2018 NICE guidelines recommend an MRI before biopsying a patient, and the implementation of this has been good. However, at higher levels of sophistication, there is considerable variability in the quality of imaging and reporting. This can have a significant effect on achieving optimal diagnostic and treatment decisions. According to Alan Doherty: "the quality of reports varies enormously. And I think the diagrams are just so useful because the diagrams reflect what you see when you do the biopsies. But also when you communicate the results to your patient, the visual image is universal, whereas the way the radiologists describe the changes varies enormously and it's really quite complex language. So it's like listening to a foreign language." Alan's full interview can be heard [here](#). At TFTC, all patient cases are brought before a multidisciplinary team (MDT) to agree diagnostic and treatment decisions., and the MRI scan and report is the foundation of this discussion. The Consulting radiologist, Dr Clare Allen, presents each patient's MRI report, and a team of consulting urologists discuss this in the context of the patient's lifestyle and personal circumstances, leading to consensus on diagnosis and what treatment to recommend. It is very much a case of high quality information (the MRI scan and report) leading to highly informed discussion (the MDT) which leads to optimal diagnostics and treatment decisions. If you have any questions about your MRI scan and report, or how and where to access a best-practice prostate MRI, please contact us at the Focal Therapy Clinic. Jonathon Oloyede on How the Black Community is Addressing Health Inequalities in Prostate Cancer Advocating for better prostate cancer awareness, screening and treatment In recognition of Black History Month, this episode of OnFocus builds on the stark fact that Black men are diagnosed with prostate cancer at twice the rate of white men, and invites a leader in London's Black community to explore the reasons why. Jonathan Oloyede is a British Nigerian who trained as a medical doctor and now serves as a full-time missionary and minister in England and Europe. He is founder and leader at City Chapel in East London, which among its many community outreach programmes supports local health initiatives including a man-to-man mentoring project. In this episode, he discusses the challenges that men in his community face regarding their health, and how he is playing a key role in supporting them. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. I'm Clare Delmar; joining me today is Jonathan Oloyede, born in Britain but bred in Nigeria, Dr. Oloyede is a medical doctor by profession and now serving as a full time missionary and minister in England and Europe. He's founder and leader at City Chapel in East London, which among its many community outreach programs, supports local health initiatives, including a man to man mentoring project. We're going to be speaking about the challenges that men in his community face regarding their health and how he is playing a key role in supporting them. And particularly as seeing that this is Black History Month, we really wanted to get a sense of

some of the issues that are facing the Black community in the UK. You've clearly become a catalyst for men seeking access to both information on screening and treatment for many, many health conditions, including prostate cancer. Way back in 1999, I pushed my church, then we were in Plaistow in East London, to do a health programme. And I connected with a number of other organisations, including the local health hospital and the MPs and councillors. And that was just an example of my passion to get people focused on their health and living properly and living well. And so the advocacy for prostate cancer has come about recently because in my church we founded something called the Newham Foodbank. It's become an independent charity and we've handed it over to some other people now to run it. But the passion to get people focused on support for their health locally speaking and in the community is something I've been passionate about for many, many years. We run a monthly programme where we're encouraging men to go do their checkups, go check their blood pressure, check their prostates. But before we do, I wanted to just explore a little bit about through these initiatives, have you seen evidence of health inequality in your community? And by that I mean varying levels of access to diagnostics and treatment for cancer, for example. Jonathan Oloyede: And to be honest with you, inequality always comes down to my opinion in terms of poverty. It also expresses itself in terms of access to either public or private health care, but there are always horror stories of people not being able to have the funds to do certain things. And then people, if you have money and you had better access, you could go and pay for something or sort some diagnosis quicker. One of my young men at the group in the community developed prostate cancer and was being pushed around. And he said to me, you know what, Pastor Jonathan – that's what he calls me or PJ – he said, I'm going to be spending the rest of my days getting black men aware of these treatments, they're not telling us that these things are available. If I knew, I would have done this a long time ago, but I didn't know there was anything called HIFU treatment and he gave me all the information about it. So this is one of the things that I can see inequalities because there's not much awareness that is being made available and money being spent equally sometimes on what I would call a black man's issue with prostate cancer compared to something like breast cancer or cervical cancer. Why do you think there isn't more being done to address the inequality of information dissemination and, you know, compulsory checks in men for prostate cancer like there is for women with regard to breast cancer and cervical cancer? Jonathan Oloyede: To be honest with you, I don't know why, but I suspect it all comes down to money. And somebody needs to explain to me why the NHS doesn't make it compulsory for men at a particular age, 35, 40, to have their regular checks and just like women would with regards to breast cancer and that it would come down to money, it would come down to funds being made available. If they were female and white or if they were white men, you know, more awareness would be made about what they're going through. Clare Delmar: Wow, I mean, the thing that makes it even more important is that the figures for prostate cancer now are that one in eight men will get it. They tell us that men find it difficult to go to the clinic or go and see the doctor, it's known. There should be more effort made by government and made, by the NHS to reaching Black men in particular with regards to prostate cancer, because like you rightly said, one in four men will get prostate cancer. And if that is a known stat and I don't see any reason why much more is not being done to reach us as Black men. Clare Delmar: So are you open to formal or informal relationships with prostate cancer organisations, for example, charities or research institutions, to bring this information and advice to your community? I mean, if we approached, if we're told how to access this, we bring professionals to our churches. And so it's not just about religious stuff or teaching the Bible, but we also present practical stuff to help people with regards to their school, education, their health. So if we have organisations that want to engage with the Black community and with churches, I definitely would love to get in touch with them. And if they have the right attitude and the right personnel to connect with the Black community, we would love, I would really, really love to do that, very open to do that. Clare Delmar: I mean, there is an open invitation and I think there's the making of almost a campaign there, because you're incredibly networked, I mean, not only you individually, but your church is very much part of a network of churches, not only all over this country, but wider, isn't that correct? I mean, I used to in my community, I ran programmes where I used to take Black and white churches to stadiums. We've got about eleven thousand activists and people on our mailing lists, and so we're widely networked not just the Black community, but to the Christian community at large. And so this is something I'm very, very passionate about, and I'm open to engage with anyone who will have the same passion or communicate that they care. Clare Delmar: So how do you think communities like yours can help to reduce the health inequalities that you see? Jonathan Oloyede: I think by advocacy, that's why I'm on this programme with you and talking about it, making the necessary things aware and for us to create a platform for information dissemination so we can be

the churches, the Black churches and Black leaders or majority Black church leaders and communities can be platforms on which the trumpet of information can be blown. And we would have less graphical grave statistics of men dying from cancer or the families being devastated by discovering the cancer when it's too late. Jonathan Oloyede: I would say that there's an opening and there's an invitation for people to get involved with us and connect with us and promote this. I know one or two people who like me are advocates that want to make this happen and would talk about this online. And I think hopefully this conversation will continue as we try to build those relationships. Clare Delmar: I'd just like to say that it's been a real pleasure and a real honour to speak with you today. And as I said, I hope we can continue the conversation and see some partnerships and a real opportunity to work with your community and get Black men much better access to care. Clare Delmar: A transcript of this interview is available on our website, where you can also access information and insight on living with prostate cancer. Alan Doherty on The Crucial Role of MRI Reporting in the Diagnosis and Treatment of Prostate Cancer Alan Doherty, Clinical director of the Birmingham Prostate Clinic, discusses how variation in MRI reporting methods affects diagnostic and treatment decisions, and offers advice to patients on ensuring that they are getting best practice from their MRI scan. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. How radiologists and diagnosticians work together Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this sombre fact comes a multitude of challenges and opportunities. Joining me today is Alan Doherty, clinical director at the Birmingham Prostate Clinic and recently voted one of the UK's top 10 prostate cancer specialists in the national poll of consultant urologists published in the Daily Mail. Alan has been an innovator, advocate and dedicated practitioner of the MRI diagnostic pathway for prostate cancer, and he's here to talk with me about the importance of MRI reporting in optimising both diagnosis and treatment. Alan, thanks so much for joining me. Alan Doherty: Clare, this is very kind of you to ask me to join you. And this is a huge and important subject which virtually transforms the management of prostate cancer, so pleasure to be here. Clare Delmar: Wonderful. And I think the issue is that most patients, they may not even know and they certainly don't understand exactly how important that is. And I think that's what we're going to try to sort of drill down into in this brief interview today. Alan Doherty: To start this off really, I can give you an anecdotal example of a very well known professor in oncology who has been treating prostate cancer for years. But he was always a sceptic of the use of PSA as a screening test to identify people with early prostate cancer. And he was of the view that the PSA was pretty inaccurate, would pick up early cancers that didn't need treatment. And I could see him change his mind as the MRI scan came along and was able to identify the sort of patients that need to be identified. And so suddenly the advent of this technology has even changed the minds of sceptic people, that you can look for cancer and you don't necessarily have to be over-diagnosed and over-treated. Clare Delmar: That's really encouraging. OK, so then what are the diagnostic decisions that you, as a diagnostician, consulting urologist make with the MRI report? What does it actually inform you to do? Alan Doherty: Well, first of all, they usually go to their GP's first or they've been picked up in some sort of health screening environment and they have had a PSA blood test. And traditionally that patient would go straight on to have a prostate biopsy if the PSA was borderline abnormal. And if the patient is informed, he will say, well, you know, I'm a relatively young man, I want to pick up a cancer if it's present so that I can attempt to be cured. And then I think if the patient is clear in their mind what they want, then it makes it very easy for me to decide what to do next. So sometimes you say to a patient, you've got so many comorbidities, in other words, you've got so many other illnesses that even if you did have prostate cancer, we wouldn't be wanting to treat it anyway because it's not a priority. So sometimes you say, look, you shouldn't be as worried as you are because you've been affected by the media. You say to them, yes, in your case, you know, it would make sense to find an early prostate cancer, but have you thought through what would happen if we did pick it up? What I tend to do in nearly everybody is to arrange an MRI scan and this is before we do a biopsy. And this is now become pretty standard practice now, I don't think you'll find many places in England where they will biopsy you without an MRI scan first. Clare Delmar: It became NICE guidance back in 2018, didn't it? Alan Doherty: Well, that's right. I mean there are patients where, you know, you do an exam, digital rectal examination of the prostate through the rectum and it's obvious that there's a cancer there. And it's obvious that all you need to do is to have a couple of cores, and by cores I mean samples of the prostate to confirm the diagnosis and then you can go on to treatment. But in the vast majority of

patients where the PSA is borderline and by that I mean sort of less than 20, you need the MRI scan to sort of give you an idea of whether you're dealing with an aggressive prostate cancer or not. And as we're going to go on to discuss the issue is how confident are you that the MRI scan is giving you the correct information? Clare Delmar: Exactly. So on that point, let's look at both the form and the substance in the reporting that you use. What is the minimal requirement of information for you to make a diagnostic decision in an MRI report? And I guess what's the current best practice and what would be on your wish list? Alan Doherty: I think the current best practice is to have a report where they look at what's called the PIRADS scores and something else called the Likert score. Relatively recently, and even now, you'll get some reports which will say something like there's a slight abnormality on the left hand side. So what sort of evolved was a score where a radiologist will say that they think it's virtually 100 percent likely that there's cancer there and they'll give that a score of five and then there will be a situation where they think it's likely rather than very likely, and in that situation they'll give a score four and then you will get the sort of threes which are equivocal and then twos where they think it's unlikely and one where they think it's very unlikely. Now, within the prostate, I want to know what the score is and I want to know where they think that cancer is likely to be. And so a good radiology report will map the prostate and in different parts of the prostate, will give it different scores. And then what I like to have is a diagrammatic representation of what they're talking about so I can actually see it in a cross-sectional basis. I want to know that there aren't any surrounding abnormalities in the lymph nodes or the bones. And if an MRI is done properly, you can really move forward with the whole management of the patient. Clare Delmar: That sounds like a lot of information. I mean, what you've just described, how often do you see that done? Alan Doherty: When I have patients referred to me from other centres, in particular the NHS, I find that's not often done. And if they give me a PIRADS score, unfortunately, most radiologists are slightly afraid of reporting a normal scan and they tend to give a Likert 3 lesion or a PIRADS 3 lesion far too often. I can see why they do it, because if they say, well, I think there probably isn't one there, well, they might be right. And if they say, well, I think there probably might be one there, again they might be right. But the knock on effect of that is that if you don't have a radiologist that's giving you information that is essentially saying the prostate looks normal, that means you have to biopsy nearly everybody. And one of the main things I think about an MRI scan is that you can try and avoid doing biopsies. You want a patient to have confidence that the PSA is borderline elevated not because of an aggressive cancer and therefore doesn't need a biopsy. If you biopsy everyone who has an MRI scan, then there's no point doing the MRI scan because you're going to find out what they got anyway. So it's really important that this concept, and I don't like the term pre-biopsy MRI scan because it suggests that the MRI scan is just a sort of adjunct to the biopsy. Clare Delmar: It actually provides the biopsy plan. And then if you do biopsy, it provides the plan for that. Alan Doherty: And that's exactly right, Clare. And you see when you go on to talk about focal therapies, what's really important is that the MRI results match up with the biopsy results because you are going to be treating only part of the prostate. And so if you don't have confidence in the MRI scan, you really find it very difficult to offer focal therapy to any high standard. And that's why, you know why the focal therapy group, we do insist on the highest quality MRI scan reporting we can possibly get hold of. Clare Delmar: So I just want to go back to, before we get onto treatment decisions, the information that you talked about on your wish list, how is it best presented and communicated to you? I mean, so not just what's on it, which you've described in some detail, but sort of the form of it is does that vary? Does that make a difference in how you might understand? Alan Doherty: Yes, it varies enormously. And I think the diagrams are just so useful because the diagrams reflect what you see when you do the biopsies. But also when you communicate the results to your patient, the visual image is universal, whereas the way the radiologists describe the changes varies enormously and it's really quite complex language. So it's like listening to a foreign language. Clare Delmar: Yeah, yeah. Alan Doherty: They're always saying that a picture's worth a thousand words, it's absolutely correct. There is complicated systems which collect MRI data and then transmits it around the place, don't allow you to tag on the images. Some units seem to manage it, but very few. Clare Delmar: So it sounds like there's a lot of variation amongst hospitals and radiological practices. I mean, is there out of this variation, is there any kind of gold standard that you can point to? Alan Doherty: I think a measure of how good an MRI scan is has not really been established. I don't think those sort of standards are out there so that you can judge whether a unit is up to it or not. So one of the things which I think they should look at is how does a radiologist report the PIRADS 3 lesions? You can imagine if there was a difference between an average of five percent in one group and 50 percent in another group. And in my experience, the units that don't report a lot have a very high number of PIRADS 3s reported and the top centres, have a very low level. It's far too easy to say, well,

I'm not sure, so I'll call it PIRADS 3, and that makes it a useless MRI scan. Clare Delmar: It's actually really important for patients to understand that because, I mean, that can presumably have a big influence on the treatment decision? Alan Doherty: Well, it means that virtually everyone gets a biopsy then. Clare Delmar: And then possibly the wrong treatment? Alan Doherty: Sort of. Alan Doherty: But secondly, you could be picking up the cancers which maybe didn't need to be picked up. But I think I suppose an MRI scan, if it's well done, will help the biopsies, even if they're done through the transrectal route, which, as we've discussed before, is not the best way of doing it. Clare Delmar: So, I mean, in your experience, the specialist radiologist is crucial to this indication? And is it your view that specialist radiologists are limited in supply? Alan Doherty: Yes. Clare Delmar: And why do you think this is? Alan Doherty: First of all, it probably takes many thousands of reports to do, but also you need to have regular feedback from the people who are doing the biopsies, then finding the cancers and then doing the treatments. And I think the people who are part of multidisciplinary groups where they are always getting feedback on what they have reported is probably the most important thing of the lot. So in any NHS unit there will be quite a few people who report prostate MRI scans and they may not even be part of the hospital where the MDT occurs. And I think also perhaps a lot of radiologists don't know that people are taking their opinions seriously enough even to go to the extent of not biopsying them, because I suppose there's a medical legal aspect to this where they're scared that if they don't biopsy and they miss a cancer, that they will be potentially in trouble with litigation. So I think the future might be where the guidelines allow you to not take a biopsy if you are confident in the MRI scan. Clare Delmar: OK, so just going to pick up on the MDT because I'm not sure many patients certainly don't participate in them, but they don't understand exactly how the radiologist plays a role in that and that the actual scan and the radiologist report is in fact what the MDT is discussing, correct? Alan Doherty: Yes, that's right. So the MDT will be looking at the cancer in the MRI scan, but they're not doing it that often from the point of view that if the biopsies are negative, then they don't get discussed. If an MRI scan is negative and we don't biopsy them, it's only with further follow up that, you know, whether that MRI scan got it wrong or not. So you might find two years down the line that the PSA continues to go up, you do a biopsy and there was a cancer there. I mean, there was a time when I wasn't confident in the MRI scans that I would do these urine gene tests. So there's one called PCA3, and that's when I realized just how variable reporting was, because in some radiologists they would be saying it's normal and then the gene test would come back positive. So it wasn't until I started gaining confidence in a radiologist who got it reliably right that I stopped in the urine gene test. But there is definitely variation out there. Clare Delmar: So I'm going to ask you a slightly controversial question. I mean, do you think that one way of addressing both the shortage that we talked a little bit about and this variation, which has come up a couple of times, do you think that something like artificial intelligence might seek to somehow address that and improve that. Alan Doherty: Well, for sure, because all the radiologist is looking at is various grey scales and patterns and that's really relatively easy for a computer to work out. And then the feedback is not that difficult to put back in the computer system to work out what's happening because they can log what happens over a long period of time and remember to put that feedback. So the whole screening program will probably be transformed on the basis that if you have confidence in the PSA blood test and then an MRI scan is readily available and accurate, well, you know, that's going to transform the whole thing. Clare Delmar: Absolutely. So what would you advise a patient to ask if there could be one question that a patient should be asking and should need to know to give him confidence in his diagnostic and treatment procedures about the MRI? I mean, the other interesting question, I think, is if you report PIRADS 4, which if you remember I said that was that it's likely to have prostate cancer, but that likely is a percentage, if you think about it. Well, of course, that also it's not just the radiologists when it comes to percentage, it's also how good I am at hitting the target. As a combo between me and my radiologists, if it's PIRADS 4, I know that that's a 70 percent likelihood of hitting a cancer. Clare Delmar: Interesting. Well, I think you've demonstrated exactly that special relationship between the radiologist and the diagnostician in your case. It's been really informative and insightful, and I know patients will benefit from understanding this key element in their prostate cancer journey. Alan Doherty: Always a pleasure, Clare. Clare Delmar: Wonderful. For a transcript of this interview and to learn more about how technology is improving diagnostics and treatment for prostate cancer please visit thefocaltherapyclinic.co.uk. Prostate Cancer and Covid-19: Widening Impact and Stronger Voices Over the last few weeks, a double whammy of anxiety has hit the NHS as fears of a Covid second wave build and more evidence of the delays to cancer patients were revealed. This has generated a surge in influential voices advocating for cancer patients and putting forward demands that cancer patients are not forgotten as Covid restrictions continue and, in many

areas, deepen. The Daily Mail reported in September that prostate cancer referrals from GPs to specialists had dropped by half during lockdown, and that they were at their lowest in ten years. In total 27,000 fewer men have been referred to a specialist with suspected cases compared to the same period last year, according to analysis of official NHS data by Prostate Cancer UK. Prostate Cancer UK pointed out that "there is significant variation across the country in terms of delays to treatment, with many men contacting us concerned that they have been 'forgotten about'". This week the Express reported on severe hit in funding to cancer research charities, citing a likely 46% cut to cancer research. It referenced an analysis by the National Cancer Research Institute (NCRI) which found that in 2018-2019 charities accounted for more than half of publicly funded cancer research, pumping in £362million. The predicted fall in provision would see overall public investment in cancer research drop by a quarter. The greatest impact would be on research focused on tackling specific cancers, for which charities provide 70 percent of the funding, the NCRI said. Covid 19 has revealed deep health inequalities in the UK, and has made many in the medical, media and political community more aware of differences in disease impact based on race, age, socioeconomic status and geographic location. This week Cancer Research UK highlighted how these inequalities manifest in the incidence of cancer. The good news is that some powerful voices in government, medicine and media have begun to cut through the negative news stories and advocate for action in addressing the growing, widespread and urgent needs of cancer patients. These voices have been getting louder each week, and we will continue to join them. In Parliament, the Health Select Committee delivered its report on the impact of Covid19 on essential NHS services, stating: "We've heard of severe disruption to services, especially cancer, and here we could be looking at tens of thousands avoidable deaths within a year. If we're to avoid this going forward it is time to give as much priority to avoiding harm and death caused by the interruption of normal NHS services and introduce mass testing for all NHS staff. Today we set out these and other steps the government and NHS leaders must take to manage services through a second wave." On Monday, The Labour Party demanded that government ministers outline a plan to tackle the growing backlog of non Covid care, especially for cancer treatment, and provide enhanced cancer screening, citing the number of people getting treatment for cancer following a national screening programme is at an all time low, with just 319 people getting treatment in July 2020. The number of people starting treatment following screening has dropped by two-thirds, compared to the same time last year. And in the medical community, cancer patients have a champion in the form of Professor Karol Sikora, former head of Cancer programmes at the WHO, and a powerful voice in mainstream and social media on the need to give cancer patients care during the pandemic. "We must do everything within our power to reduce the overall waiting list. That would be a disaster that will take many years to recover from, and potentially costing thousands of lives.", he said this week. Here at The Focal Therapy Clinic, we are picking up three key trends that have developed in the Covid era from our conversations with prospective patients. First is a significant increase in the use of Hormone therapy for men with relatively low-risk prostate cancer. As a Consultant Urologist Raj Nigam pointed out in a recent OnFocus interview, this is happening with astonishing frequency and compromising the quality of life for too many men. Second is what is becoming known as "age apartheid", where men 70 and over are not given access to innovative treatments that can maintain their (often very high) quality of life. Third is the number of men on Active Surveillance who are struggling to sustain regular monitoring as appointments are cancelled and diagnostic procedures delayed. We are advocating for our patients and actively joining the voices that are calling on government and the NHS to provide the services that they deserve. If you have a concern about your prostate cancer diagnosis, get in touch -- we're here to help. Alex González on the Origins of HIFU Technology for Prostate Cancer Alex González from Sonacare Medical, leading developers of HIFU systems for prostate cancer, explains the origins of HIFU technology and how it has developed to become a powerful non-invasive treatment for prostate cancer. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. How image guidance led to the development of a non-invasive life sparing treatment Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Alex Gonzales, global director of sales and operations for Sonacare Medical, based in Charlotte, North Carolina. Sonacare is a leading developer of high intensity focused ultrasound – HIFU – technology that's used in the management of prostate cancer. Alex and Sonacare have been closely involved with several clinical trials that have

demonstrated the effectiveness of HIFU in treating men with early stage prostate cancer. And we're going to discuss how this technology developed, where it's going and what this means for patients. And to really put some meat on the on the framework of what is HIFU and what does this mean for patients? I think a lot of patients have a lot of questions about this, and you are probably just the person to address them. I'm going to start off our conversation, if I may, by just picking up on the point that Sonacare was one of the earliest adopters of HIFU technology, I believe. We were one of the original really commercialisers of the technology. Clare Delmar: Yeah, commercialisation. So can you tell us how and where HIFU technology developed and then how Sonacare was established around that? Alex Gonzales: It's a wonderful sequence of events and people think that the concept of ultrasound with focalisation, with image guidance is something new. But in all reality, this started in as far back as 1972 with Professor Frank Fry and Professor Narendra Sanghvi in Indianapolis, Indiana, who had taken this concept of using ultrasound imaging, ultrasound guidance, focusing in ultrasound to treat glioblastomas – cancer in the brain. That of course developed and later spun out of Indiana University in the early nineties with the concept of why don't we image, why don't we focus this beam of ultrasound energy and why don't we treat only a very discrete, precise amount of tissue, very similar to how you would focus in the sun's energy with a magnifying glass, they found a way to do that with ultrasound. So now we're able to see the target that we want to see with ultrasound, something non-invasive, something not harmful. And we're able to treat using that same energy source, just hyperfocus over an area of pinpoint energy. Clare Delmar: That's a really interesting way of describing it, because I think most people are familiar with ultrasound from a purely imaging perspective. And certainly every woman who has a child will have experienced ultrasound in utero, as you well know. So it's a pretty familiar technology for imaging, but I don't think anybody normally imagines that you can focus it and I'm using your word in the way that you've just described to actually effectively kill bad cells. Is that what you're actually saying? Alex Gonzales: To very discreetly destroy tissue while simultaneously imaging the tissue? Women's cancer, the concept of let's find the disease by investigating it, let's image it, let's include imaging in the diagnostics. Clare Delmar: So are you referring specifically to mammography here? Alex Gonzales: Mammography, later on mammography and incorporation of MRI and CT, but the new concept in general of being able to use image guidance, let's use that to also target the biopsy and then let's use that to have a non-toxic, minimally invasive quality of life sparing technology. That initial group that founded what was US HIFU 15 years ago, which is what led us to partnering up with Professor Narendra Sanghvi, remember that pioneer from the early 70s that was trying to find a way to use this to treat brain cancer. We partnered up with his spinout that came out of Indiana University in the early nineties called Focus Surgery and US HIFU was born - US HIFU now being Sonacare Medical. We've rebranded along the way, as we've entered many, many markets and received approval to use this technology commercially in over 30 countries since. Clare Delmar: OK, all right. So is it true that Sonacare, as you now are, uses HIFU exclusively for prostate cancer? Alex Gonzales: We use it exclusively for prostate tissue ablation is our formal approval by the FDA here in the United States. In some countries, it's even used for the benign prostatic hyperplasia, that benign overgrowth of the prostate that leads a man to get up and have to urinate quite frequently and with significant urgency. So our approvals will vary depending on the market. Clare Delmar: But in the U.K. and the rest of Europe, it's for treatment of cancer. Alex Gonzales: In the U.K. specifically, it's used exclusively for the treatment of prostate cancer. Clare Delmar: Yes, OK, so that the regulatory environment has a big call on how HIFU is actually being used. And I guess that's beyond not just prostate, but in the other areas, because it's true to say that you're using HIFU for other organs or other tissue masses, not just the prostate? Alex Gonzales: There are other companies that use HIFU to treat everything from uterine fibroids, liver tumours, some experimenting even in pancreatic cancer, rectal cancer. So, yes, yes, the ability to focus that ultrasound beam over a precision, a pinpoint area is being explored in multiple tissue states. So just to focus it on the on the prostate cancer, but again, to look at HIFU amongst a range of focal therapies. And here I'm referring specifically to prostate cancer. Alex Gonzales: When you look at any technology or any procedure, surgical or non surgical procedure, you want to look at a couple of things. But number two, what does it do with respect to side effects and how do those side effects affect the patient's quality of life, the patient's family's quality of life? You can treat a man with prostate cancer, with radiation, with open surgery, with laparoscopic surgery, with robotic surgery, with freezing therapy and with high intensity focused ultrasound, with HIFU. What really differentiates itself is that it allows for cancer control while preserving quality of life because we're able to incorporate precision guided biopsy into our planning, because we've got this millimetric precision and all this being done in a minimally invasive environment where there's no cutting, no open surgery. We're talking about

a transrectal probe delivering this ultrasound energy not only to help us visualise, but also help us treat the tissue. You just reminded everyone that the same type of ultrasound is what's used to view babies in utero, to view a kidney, to view a prostate before it's biopsied. We're able to focus it over a very pinpointed area of precision, thus achieving the same level, very comparable level of cancer control, but while maintaining quality of life with the least amount of side effects. All prostate cancer treatments have a certain degree of incontinence, the man's inability to control their urine flow. The veins, the arteries, the nerves run really close to the prostate, almost like the veins on an onion, on that skin. And any form of energy or any teasing with a scalpel or any dosing with radiation makes those nerves very susceptible to damage. So although HIFU does have side effects associated with it, they are the same type of side effects as with the conventional, quote unquote, gold standard therapies. You will find that it has less degree, less percentage of a chance of impotence and incontinence while still maintaining good cancer control.

Clare Delmar: And the product you use is called Sonacare, is that correct?

Alex Gonzales: The product we use is called the Sonablate.

Clare Delmar: OK.

Alex Gonzales: Third generation of the Sonablate, that's a device that's manufactured here in the United States.

Clare Delmar: And so everything you've just said about proving its efficacy in terms of both cancer control and reduction of side effects, that's all come through over a series of clinical trials to prove this, correct?

Alex Gonzales: That's come through over a series of clinical trials, as well as over 45000 patients that have been treated with transrectal, HIFU prostate tissue ablation in over 33 different countries and with currently well over 80 peer reviewed publications showing its safety and efficacy. So tell us a little bit about these trials, because ultimately that's the evidence base that's going to convince any sceptics and invite anybody who's already ready to go.

Alex Gonzales: Sure. There have been a variety of trials, trials in which they try to randomise subjects into two groups, one that would get HIFU one that would get surgery. There have been trials that are single arm comparative, meaning you're comparing someone that has failed radiation therapy and is receiving HIFU as a secondary treatment, as a salvage treatment. You've got trials to where you're performing HIFU as a whole gland treatment, meaning we're treating the entire thing regardless of where we found the disease. There have been trials where we're only treating the side that is affected and further yet, there's trials to where they've treated only where the significant portion, the significant disease has been found. So you've gone the gamut of the trials in the European community as well as the Asian community and here in the United States. What we received clearance for here in the United States in October of 2015 was a prostate tissue ablation indication, I like to think of it or explain it as it's an acoustic knife. It is a tool that the physician can use for whatever tissue the physician would like to use it for, is my layman's interpretation of that clearance.

Clare Delmar: And back to the trials, it's striking to me that the UK has been a world leader in adopting and implementing HIFU for prostate cancer patients? But why do you think this is?

Alex Gonzales: The United Kingdom has been at the tip of the spear and has pushed the envelope with respect to men's health, specifically prostate cancer diagnosis and prostate cancer treatment for many, many years. You can look up the history, the long, very positive history of Professor Mark Emberton, Professor Caroline Moore, Professor Ahmed, Richard Henley, Tim Dudderidge. These individuals have not been afraid to push the envelope and explore how to better serve their patients in the UK. And because of the dedication of institutions like University College Hospital and Imperial College and so many amazing institutions that you have access to in the United Kingdom, they've explored and compelled the use of better imaging in order to better diagnose, in order to more accurately treat. They have pioneered not only the way we treat, but they have changed the entire paradigm all together.

Clare Delmar: Let me ask you a question, because when you said HIFU as a technology mode really, was introduced back in Indianapolis. That was before the advent of this precise imaging and particularly the new sequencing through multi parametric. So how did HIFU work then?

Alex Gonzales: Back in the 70s, this is what led to this huge hurdle, because as it was being developed for glioblastoma, they literally had to remove parts of the patient's skull and the computer to drive the ultrasound imaging and to create the amount of high intensity focused ultrasound energy literally took up an entire room. Fast forward into the 90s with the development of technology, the progression of computing power, the incorporation of CT and MRI in the early 90s, and the proximity of the prostate to a mucosal opening – the prostate as it sits right on the other side of the rectum, it was easy to get to. So it almost lent itself to the modality it was about.

Clare Delmar: Oh, that's interesting. So just because of what you said, the access and the fact that you already had this as a way of seeing where the cancer was, it was ready made for this. But then the MRI has just given you that level of precision that has made this a far more powerful and effective treatment option, correct?

Alex Gonzales: Correct. In the past, they had to put in that transrectal ultrasound, introduce that into the

rectum. On average, there was a statistic a few years back that indicated that a man would have to undergo that moderate level of discomfort, having six, twelve, twenty four needles through his rectum on at least two different occasions before they actually found any cancer. That's what I always tell people, that prostate specific antigen or PSA is it's not an indicator of whether you have cancer. It's an indicator that your prostate is sick somehow and you need to do some investigation. So you have a simple five minute painless blood test, the PSA – canary in the coal mine – that says let's investigate this further. Investigation further no longer means I've got to subject myself to this session and introduction of multiple needles in through my rectum, through the prostate, and wait for those results to come back just so that they can give us some potentially nebulous news of, well, we didn't find anything, let's check you out for another six months and then come back. Now we've got the ability to send someone for a basic MRI, this sequence that's going to give us these images of abnormal looking tissue that now have a strong correlation to the disease state of the prostate, still not a one hundred percent confirmation, but we've got very strong indications that a good MRI read will tell you what areas of high suspicion you should investigate further. Take that one step further with technology that we now have that can precisely guide the physicians needle into those areas, we can still do randomized biopsies on the prostate, but now we've actually got some targets we can see in real time. And once we get confirmation on the patient's disease state, you can transfer that MRI data to the Sonablate HIFU platform and use it as a map. So now we have a map to the targets to be used on the Sonablate HIFU device that can precisely lay a deposit of energy on those targets. You see the tissue on the screen and you hit a couple of clicks on the screen and then you don't. Clare Delmar: That's a really good way of putting it. Where do you think this is going? Alex Gonzales: I think what we're seeing is this revolution where patients every year become more and more aware. They're doing a lot of research and we all joke that my wife says that I'm a WebMD kind of person, right. Most of the patients that I've come in contact with, there's thousands and thousands over the past 15 years since I helped found Sonacare, are very well educated, very well researched patients. There is a specific candidate and HIFU's not here to necessarily replace insert your other technology name here. You're looking at a future in which technology will play more and more of a role in diagnosis. We will be able to recommend less toxic, less invasive, more discreet treatments for these patients. And we'll end up with these patients that were diagnosed early, treated with minimal harm and have allowed them to be productive, happy citizens for the rest of their lives. In the event that the cancer returns, you can treat it again with another HIFU. Clare Delmar: Well, that's something I hope we can all look forward to. I really look forward to hearing more from you and from Sonacare Medical about developments with HIFU. If you'd like to learn more about HIFU technology and Sonacare Medical, please visit for sonacaremedical.com. For a transcript of this interview and to learn more about how technology is improving diagnostics and treatment for prostate cancer, visit The Focal Therapy Clinic at www.thefocaltherapyclinic.co.uk. HIFU Focal Therapy For Prostate Cancer – Born In The USA, Coming Of Age In The UK The “special relationship” between the USA and UK, currently watched closely as the former prepares for a general election and the latter for its exit from the EU, has delivered particular benefits to patients with early-stage prostate cancer. Focal therapy, and HIFU in particular, have their scientific and technological roots in the USA, and their clinical and institutional success led here in the UK. In the 1970s, scientists at Indiana University were combining ultrasound physics and medical engineering to ablate, or remove, targeted tissue in the human body with high levels of precision. The result of these experiments was the development of HIFU - high intensity focused ultrasound technology. The first human HIFU trials were in patients with terminal brain cancer, which demonstrated encouraging improvement in patient symptoms. Following those early experiments and trials, recognition of HIFU's potential broadened. By the 1990s, a small team was established at Indiana University School of Medicine, and in 1998 that team formed Focus Surgery, Inc to commercialise HIFU technology. With a dedicated laboratory, a handful of patents and a number of government grants, the team developed the capacity to manufacture the first system for prostate HIFU ablation, known as Sonablate. In 2004, USHIFU, LLC was established in Charlotte, NC to implement a clinical trial with an early version of the Sonablate system. Four years later, USHIFU purchased Focus Surgery and a new subsidiary, International HIFU, was created to expand the use and sales of Sonablate globally. According to Alex Gonzalez, founder of what became SonaCare Medical, “we were watching what was happening in the UK and knew this would be key to the success of Sonablate”. What was happening in the UK was no less than a revolution in diagnosing prostate cancer. Led by Professor Mark Emberton and his team at University College London, a new approach to sequencing MRI scans, known as multiparametric MRI was proving to image cancerous lesions on the prostate with increasing levels of precision and accuracy. This has led to both a significant reduction in biopsies and a vast

improvement in the accuracy and efficacy of required biopsies. In 2018, NICE incorporated mpMRI into its guidelines for prostate cancer, advising all men to undergo an mpMRI prior to biopsy. Accurate imaging and targeted biopsies underpin the success of focal therapy, and following these developments in imaging, SonaCare Medical began to work with the UCL clinicians to conduct trials on focal therapy. These have enabled a body of evidence to build around the efficacy of HIFU in treating early-stage prostate cancer: A Multicentre Study of 5-year Outcomes Following Focal Therapy in Treating Clinically Significant Nonmetastatic Prostate Cancer, Partial ablation versus radical prostatectomy in intermediate-risk prostate cancer: the PART feasibility RCT, Focal Ablation Targeted to the Index Lesion in Multifocal Localised Prostate Cancer: a Prospective Development Study. The success of these trials have led to others, and excitement has built around a current trial, CHRONOS, led by Professor Hashim Ahmed of Imperial College London, which is investigating the outcomes of new prostate preserving surgery against whole prostate treatment. Alex Gonzalez of SonaCare Medical is very optimistic about the future of HIFU in prostate cancer and credits his UK colleagues with the pivotal role they have played in building up the evidence base. "This has vastly improved the success of focal therapy, because as more men are diagnosed with early-stage disease through mpMRI, this gives us the opportunity to offer focal therapy and to provide access to this non-invasive approach to treating prostate cancer", he says. "Early, accurate diagnosis and focal therapy work hand in glove." The special relationship continues.

Chris Lewis on the Growing Influence of Cancer Support Communities

Chris Lewis, founder of one of the UK's largest and most influential online cancer communities, joins Clare to discuss how cancer communities are evolving to support many cancer patients, not just as a source of communal solace but as a powerful political and media advocate for patient rights and improved services. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

How patients are organising for change

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK, and with this somber fact comes a multitude of challenges and opportunities. Joining me today is Chris Lewis, award winning global cancer campaigner and creator of Chris's Cancer Community, where thousands of members engage regularly with Chris's insightful blogs and take inspiration for their own cancer journeys. So wherever people are listening to this, I hope they can imagine this beautiful Indian summer day in the UK.

Chris Lewis: It certainly is one of the rare ones.

Clare Delmar: I'll agree with you on that. I think overall, I really want to hear about the community and how you can help people who are diagnosed with cancer and specifically for most of our listeners, men and their families who have been diagnosed with prostate cancer. So I'd like to start off by asking you, when you set up Chris's Cancer Community, when was that and what were the issues that drove you and, of course, the challenges you faced at that time?

Chris Lewis: So it was way back in 2012, I set up Chris's Cancer Community. Then I had a stem cell transplant and lots of very, very complex treatment and that introduced me to the world of cancer. But I realised once I had my own personal cancer experience that actually things weren't as advertised. And it was a great upset to me, not just for myself because I'm quite a forward guy and I don't have any problems finding things that I need. But actually for other vulnerable people, and I use that word vulnerable because that's what people tend to become once they hear the word cancer.

Clare Delmar: Yes, indeed.

Chris Lewis: So I was very upset that I saw cancer patients, you know, once you hear the word cancer, I saw discrimination against people with cancer, things like insurance, all sorts of things, jobs, mortgages, banks don't want to lend to you once you've got cancer. And I said to my wife, look, I know I have a very poor prognosis, but this is something I need to do something about. They need to hear from the horse's mouth what actually is going on, fancy TV adverts by charities and the like, are just not cutting it anymore. It took me a few years to get back on my feet, if you like, from the cancer treatment and everything that had gone on in my life because of that. You know, I'm really from the dinosaur days of if I want to speak to somebody I picked up the phone and this was all new to me. And friends of mine said, oh, you know, if you really want to be a voice, it's not just in the UK. And Chris's Cancer Community was born.

Clare Delmar: Wow.

Chris Lewis: So the issues are quite common when you enter social media. So first of all, we all start with no followers and everyone looks at my social media following and laughs. But actually people started to engage with and the longer I went on, I found I had an audience, crazy as it might seem, and it certainly was to me anyway. And actually it gave me a lot of information and gave me some data, you know, some really early data about what other people were feeling...

Clare Delmar: And experiencing...

Chris Lewis: Yeah, exactly. When you're going through cancer, you think you're the only one that's going

through those issues. So the Internet has been a great medium for us to join, like minds if you like, across the world. The challenges I faced was getting out there, really, because all the big charities, all the big organisations of health care, drug companies, they've all got all these internets and they've got people working on the website, all fancy stuff. So one of the issues I faced was getting my stuff recognised, but I never found it really any different to my normal life. So I just stuck to the honesty, and I wrote all the posts really from my heart and other people shared it. And we just had a really great, really human community, nothing to do with charities or any of those things. It was very sort of independent of anything else, really.

Clare Delmar: So how big is the community today? Chris Lewis: Well, that's always a difficult one to judge. So on my social media, I suppose across my platforms, I have about 50000 followers.

Clare Delmar: Wow.

Chris Lewis: Which, I don't know how you judge that, to be honest, because when you look at footballers and pop stars, you know, they're into the millions.

Clare Delmar: Yeah, yeah.

Chris Lewis: But I do know when I look around on the cancer platforms, there aren't many individual players, not like big organisations, but individuals that have that sort of following. And I suppose, you know, I'm only talking about cancer day in and day out, so it's not fashion, it's not food.

Clare Delmar: Do you find the issues change? Do you find that you're responding as much from hearing what your members say to each other as to what you're picking up because you have links to various policy makers and health providers? Chris Lewis: Yeah, very much so, Clare. That's what really stimulates me about social media and my website and everything else is the fact that every single day I get up, there is a different issue, whether it's my own issues or issues that other people have raised. It's vast work, Clare, as I'm sure you're very much aware.

Clare Delmar: I mean, I'm well aware that – you've just mentioned covid – so I wanted to ask you about that. I mean, you've been a particularly strong voice for the cancer patients that have been delayed or compromised in any way by covid-19. And every now and again I look back for some old content and every few years I'm seeing the same things come up, cancer poverty, lack of action, those sort of things. And so for me with covid, the things that have shown up now with covid and cancer that I just couldn't... I've got a bit of a voice, of course, now in the community. And I just couldn't sit back anymore and watch people die unnecessarily because of treatment they're not receiving when they should do. You know, everybody these days, all I want to talk about is money, but that's not what I want to talk about.

Clare Delmar: So let me just ask you quickly, because you're such a global influencer and I will use your term influencer, I can see that. And have you found cancer patients delayed everywhere or is there some kind of ranking or how do you help people in systems that you're less familiar with because you're based in the UK? Chris Lewis: Actually, I'm quite well familiar with most of the cancer systems around the world, particularly the US. I have a lot of followers in the US, but all around Europe and pretty much I've travelled across the world. I've spoken in a lot of countries and I have a lot of followers, a lot of clinicians, not only patients, but I have a lot of followers that are clinicians from around the world. You look at the States, you look at Canada, areas that don't have the sort of health service that we have and that we have become reliant on, of course, there are so many different issues from around the world, but the principles are roughly the same. The treatment, for whatever the reason, whether you're paying for it or you're not paying for it, your treatment, is delayed.

Clare Delmar: And you're seeing that everywhere? Chris Lewis: Every single place I look and you know, the real big factor for me, the real one that capped it for me to turn me into action, if you like, is the fact that how covid dominated the world. But actually, there will be a lot more people that die of cancer than will ever die of covid ever. And basically, what frustrated me more than anything was to see everybody come together, which is a positive thing. It's great to see labs and charities and everybody to do their very, very best to get rid of these covid-19. But I don't understand that if we can work together around the world against covid, which we must, why can't we do it with cancer?

Clare Delmar: How are you campaigning to support these patients? This is... We're in a different world now with Internet and Internet, you know, your campaign can be drowned out. There's a lot of naughty things going on on the internet.

Clare Delmar: Absolutely.

Chris Lewis: My principle of the campaign and I've joined together with a lady called Jo Taylor, who's again probably an influencer, she's in the breast cancer sector. Currently they're just in a self survival mode because of covid, they're getting no money and they're not sure how many staff they're going to have, so a bit busy looking after themselves. But that's the fact of life.

Clare Delmar: Yes.

Chris Lewis: They're not in any great position to shout on behalf of patients. It's quite obvious they're not bothered about cancer because there's enough publicity going on about the cancer issues in this country and across the world. So what we decided was the only way that we could make a difference was to give other patients the confidence to share their stories. And because people, let's be honest, if you're feeling very poorly and you're feeling very vulnerable, the last thing you want to do is "fight" the system for the things that you should be entitled

to. But we want to see action and what we've tried to do, Jo and I, we called it Patients Together. And that's because we want to give people the confidence to share their stories, tough as they are, because on the Internet, you know, the Twitter, when people are seeing those stories, we're gathering much more support. When those are public, when you give them to a charity with greatest respect, mostly they use it for their own purposes, for fundraising or something else like that. So by making noise, we hope to shape the government that way.

Clare Delmar: OK, let me just ask a quick question about the charities, because I agree with you there, first of all, there are many and again, globally, of course, but even in the U.K., there are some big ones and then there are some small ones and there's some arguments about why there are so many. I mean, my understanding is that certainly I can name a few of the big ones that actually spend a lot of their money on very important cutting-edge research with the end goal of new discoveries, new drugs, new devices, new diagnostic procedures to reduce the impact of cancer. So, yes, I understand that's been obviously curtailed and compromised during covid, but do you not see a future for them working in alignment with the community you've built so that your community can inform them?

Chris Lewis: I'd love to see that, Clare, but quite frankly... I mean, I know virtually every CEO of every cancer charity in this country, most cancer charities I'm doing some work for in some form or another, whether it's a consulting basis or voluntary. They might not see me as a good advocate, if you know what I'm saying, because I speak out, I speak on behalf of patients. But you know, the charity pound, most of them make that into 30p, if you're lucky and I've got my own little charity, every charity gets is like £100. But they don't work with patients on the whole because they're worried, patients speak out. They're worried about their own brands and their own fundraising seems to come before that. So...

Clare Delmar: Right.

Chris Lewis: I've spoken to two or three major charities here, and all I can do really with them is embarrass them on social media because to try to get any collaboration from them is almost impossible.

Clare Delmar: OK, so if I could just move a little bit towards patients themselves and direct this more around those with prostate cancer. I know we've spoken before about your work with a prostate cancer support group in South London. So I'd like to ask you what you see is the most common theme amongst this group and what advice you would give to someone newly diagnosed with prostate cancer.

Chris Lewis: So I got into the... As you say, I got into the prostate cancer support group, and that was a new world for me. And it's a local group to me, I wanted to give something back to the local community for me that was important. And I thought that's good, I'll learn something from this because I didn't really know much about prostate cancer.

Clare Delmar: OK.

Chris Lewis: But now I do, after ten years working with the guys right. And the answer to your question, the first answer is that, the most common, is confusion on diagnosis and treatment options. As you well know, you're in the sector of prostate cancer and there are many, many different ways of dealing with it.

Clare Delmar: Yes.

Chris Lewis: Of course, there are different degrees of prostate cancer, let's make that clear. And I can understand why that exists, that confusion, because if you... What I find from the experience of talking to these guys is that if they are talking to a surgeon, the surgeon would always want to remove the prostate. But then if you talk to somebody else, they will obviously promote whatever bits they're doing so I don't think it's made clear enough, is my opinion because every new guy we get has got the same issue. So it seems it's not made clear enough, that there are various alternatives to the first offer of treatment. I mean, I'm wondering if part of the confusion is because there are these different stages in the diagnostic process, not to mention different approaches to it. And is it a question of being more joined up or is it something different?

Chris Lewis: Probably a combination of the two, personally speaking. I think the joint thing you talk about, is an issue throughout cancer, by the way, not just prostate cancer, but that's an issue throughout healthcare, I would suggest.

Clare Delmar: Yeah, yeah.

Chris Lewis: But my experience in cancer is that it's not joined up as good as it could be. But also my experience is that anybody who's got diagnosed with cancer, particularly guys, because we're not good in those situations at all, we leave it late generally to go and see the doctor because we're big tough guys, we don't go to the doctors as frequently as we should and we don't talk about it very often. So once you hear that word, cancer, I know for most of these guys, they just want to get it out of them, whether that's the best thing or not. But they just want to get rid of the cancer psychologically.

Clare Delmar: Yes.

Chris Lewis: So a lot of guys go for the operation to have their prostate removed when that might not necessarily be the best thing.

Clare Delmar: So what advice do you do you give to a lot of these men in your groups?

Chris Lewis: And that's easy as well. Take your time, because basically... Everybody thinks that when you've got a diagnosis of cancer that needs removing in the next day or two and thankfully, in a lot of cases, it isn't that at all. That's only the start of a longer process where you do actually... In most cases of prostate cancer, you probably die with it rather than of it.

Clare Delmar: Yes.

Chris Lewis: So, you know, there is a bit more time than I think the

patient perceives when they hear that word cancer. Clare Delmar: Yes. Chris, I'm afraid we're running out of time, but I want to thank you so much for your very, very valuable, very personal insights. And I hope we can speak again soon, maybe more specifically about men and how they perceive their choices with prostate cancer. So thank you. Chris Lewis: Thanks very much. Clare Delmar: If you'd like to engage with Chris and Chris's Cancer Community, visit his website at www.chris-cancercommunity.com, follow him on Twitter, where he is known as @christheaagle using the hashtag #patientstogether or find him on Facebook at Chris's Cancer Community. And to learn more about patients experiences with prostate cancer, visit us at www.thefocaltherapyclinic.co.uk. Online Communities And Support Groups: One Man's Penance Is Another Man's Empowerment For many men, an immediate recommendation following a prostate cancer diagnosis is to join a support group. This will generate a range of responses, from "bring it on" to "run a mile", and much in between. There is certainly a Marmite quality to these groups, whether online, offline, or led by hospitals, charities or sporting organisations. What's impressive is the sheer variety of them, and how they can be defined and experienced so differently. The act of participation, including talking, sharing and "finding a tribe" are powerful drivers. Charities, hospitals, and sporting clubs are all involved and will provide varying levels of access and trust. Interestingly, or perhaps alarmingly, there is very little easily accessible research investigating men's participation in support groups and the benefits derived from them. Googling "research on men's participation in prostate cancer support groups" yields 2 studies, the most recent being a Canadian study from 2014. Its conclusions: "Results showed that PCSGs were positively valued, particularly for information sharing, education and psychosocial support. Poor inclusivity, privacy, and accessibility were identified as potential barriers, and recommendations were made for better marketing and web-based PCSGs to increase engagement with potential attendees." An American study from 2000 explored why men with prostate cancer seldom attended support groups, pointing out that women outnumber men by three to one in cancer support groups, and that prostate cancer support groups are sponsored by churches, hospitals, professional organizations, and community agencies in response to the unique challenges men face in developing coping strategies associated with their illness experience. It concluded that: "Research is needed to identify the efficacy of alternative and complimentary means of support for men with prostate cancer. The developmental and psychologic orientation of "what it means to be a man" needs to be considered. Indeed, a one-to-one support program is consistent with many theories and may be a more acceptable means of support for men when compared with current support groups." I spoke with Chris Lewis founder of Chris's Cancer Community, one of the most global and influential online communities, based here in the UK, about community support for cancer patients. When Chris established the community in 2012, the internet and behaviour of people around it were very different than they are now. He started out with the motivation to help others who, like him, had a cancer diagnosis and were experiencing confusion and disinformation about treatment. Publishing blogs very quickly attracted others who were keen to share their stories, and a community was born. Now Chris has emerged as a powerful voice amongst politicians, policy makers and media in advocating for cancer patients. This is proving important during the Covid era, characterised by some powerful forces: the global nature of the pandemic and scale of people affected; the displacement of cancer patients in respective healthcare systems; and the severe hit that cancer charities have taken in fundraising and service provision. Communities like Chris's are not just comfort or solace in a time of fear and confusion and abandonment, but a vital source of information on diagnostic and treatment options. They are more influential and potentially more beneficial than ever, and so can be seen as powerful advocates for patients in a world dominated by multiple organisations, conflicting information and lots of noise. Whether it's advocacy, solidarity, information, solace or comfort being sought, there is likely a support group out there that can provide any or all of these. Given the vast changes in the cancer treatment landscape during the Covid era, 2020 might be the year to overcome prejudices and check a few out. Chris's Cancer Community Prostate Cancer UK Support Group finder

Discussing Age Discrimination in Prostate Cancer Treatment with Raj Nigam The need for an individualised, holistic approach to treatment The Focal Therapy Clinic consultant urologist Raj Nigam discusses how age discrimination occurs in prostate cancer treatment and shares his thoughts on how older men can address this. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. I'm Clare Delmar; joining me today is Raj Nigam, consulting urologist at the Royal Surrey NHS Foundation Trust and The Focal Therapy

Clinic. We're going to discuss how age plays a role in men's experience with prostate cancer treatment and explore how this is changing for better and for worse. And this time about one of the issues related to health inequalities that we've touched on before and very much launched by a lot of the patients that are approaching us. We're finding more and more patients coming to us with a very common story, they're aged 70 plus, fit and well, living life to its fullest when they're diagnosed with prostate cancer and they're disappointed in what they perceive as a dismissive, sometimes even defeatist approach in their care. And I think this is coming more to the fore as more and more men are living healthier lives well into their 70s and even beyond. It's probably deeply ingrained within the medical culture in terms of our training that one of the first things we look at regarding any patient is their age, their chronological age, and it's only secondarily that we are taught to look at what their biological age actually is. So we always know exactly how old the patient is before we've even met them and started talking to them. And that plays a subconscious role, I think, in the sort of conditions that we might be diagnosing in them or what we are thinking about they may have, and also the possible treatment options that may lead on from such a diagnosis.

Clare Delmar: It sounds like there's essentially a disconnect between the quality of life of older men and the sort of institutionalised approaches to prostate cancer treatment? So if we focus in just on prostate cancer, we know that there are variations firstly around the country in terms of life expectancy. Therefore, there will be different age groups and different numbers in those age groups, in different parts of the country. And we know that life expectancy has been improving up until about 2010 and thereafter it has remained fairly static. And that is also manifest in terms of prostate cancer, that we are seeing increasing incidence of men with prostate cancer. And therefore, the improvements that we have seen in the diagnosis and early management of prostate cancer are probably not being borne out in terms of mortality statistics. We know that this was actually made unlawful back in 2012 and therefore that we should be thinking more of men in terms of their biological age and their physical age as opposed to their chronological age. I mean, I think that there are a number of discriminatory factors that we all know of, but age was not always recognised as one. And within the NHS it was declared that ageism was actually unlawful and that we could not deprive men and women from either access to diagnosis or access to management simply because of their chronological age. The complicating factor in prostate cancer is that there is a well-known adage that, oh, you're much more likely to live with prostate cancer than die from it. And I'll give you a case story which just came to my mind just now of a chap that I've looked after for a number of years. But essentially this is borne out partly in the science in that a lot of elderly men who are diagnosed with prostate cancer do not necessarily die from it. But equally, there are a lot of men who are even denied the opportunity to know what type of cancer they have and are deprived from the lesser invasive treatments that we sort of parochially think that they should not have a radical treatment because of their age. He was 72 years old when I diagnosed him with a high grade, what we call, Gleason eight prostate cancer. He is now 90 years old, he came to me and he said to me, look, he was very educated, sharp and so and he said, look, Mr. Nigam, I've had my three score years and ten, I've had a good life and I really don't want anything to impact upon that. This sort of what one might call defeatist attitude is seen in a lot of men who are scared of having aggressive treatments. In those days, and I'm talking about 2002, we did not have the benefit of the minimally invasive treatments that we have now. And even now, to this day, he is 90 years old and he drives himself to Portugal and back and is very fit and active. So I think it is ignoring that biological age and convincing men that there are minimally invasive treatments around and that we can manage them in this way and that they do not need to hide away from these treatments.

Clare Delmar: I want to pick up on a phrase you mentioned earlier in your comments, which was that many men or more men die with prostate cancer than of it. And that phrase, as you well know, has really come to the fore, even in the popular media, so to speak, during Covid, because we hear the same phrase around Covid, which is generated lots of, I think, variation in data and lots of debate about deaths. But be that as it may be, Covid has raised awareness around the world of, again, health inequalities and including age. And many observers have noted that the various biases and issues that we have in medicine generally have been brought to the fore with Covid and how, for example, the elderly people were managed and treated with this potential diagnosis, particularly in Western countries, and that was sanctioned at the highest level. People who have now begun to think, well, hang on, do these sorts of issues and criteria for diagnosis and management apply in other conditions? And we've known for a while that in cancer management, that age and ageism has played a role. You know, for example, in breast cancer management, there have been several studies which have shown that the outcomes of more elderly women with breast cancer is worse, where ageist attitudes have been brought in. This pervasive notion that you're much more likely to live with it than die from it is one that is actually

influenced even in the earliest stages of diagnosis. They will be denied further investigation to even diagnose what type of cancer they have because they say, look, even if you have it, it won't affect you in your lifetime. And even when it is diagnosed, far more men are given this management term of what we call watchful waiting, which is an old term and it's a little bit parochial and probably has a bit of unconscious bias attached to it. But we have to recognise that the mental effect on a lot of men who are diagnosed with this is quite great no matter what their age. And we know, again, the outcomes are worse in men who are affected mentally by the diagnosis than those that are not. So I think it's something that we all have to take a step back and take on board, that we really must not have our subconscious biases regarding age when we're either trying to diagnose or manage the condition.

Clare Delmar: So the thing that fascinates me is that more men are living longer, healthier lives. So many of the men who come to us are super fit cyclists, marathon runners, mountain climbers. And even if they're not into extreme sports, they're just very passionate about living their lives and they're very conscious of managing their health and their wellness. And as I'm sure you're aware, there's a whole industry developing around that and making men, if not their partners more aware of, you know, longevity, I think is the word that people are using.

Raj Nigam: And I think that there are now new statistics produced which look at not just purely at life expectancy, but also healthy years of life expectancy. How many years are you likely to remain healthy, not just how many years are you likely to live. And these statistics are now available and we're seeing that those numbers are actually increasing. So we know that the number of healthy years, there are regional variations, of course, within the UK, but the number of healthy years that men and women live is getting bigger. And therefore, there's absolutely no reason why they should not be deprived correct and an appropriate treatment for their newly diagnosed prostate cancer, which in a younger man you would treat slightly differently. And I see this in my other subspecialty interest of Andrology that there are a lot of men who come to me in their 70s who have, like you say, are very fit and active, exercise regularly and have difficulties with erectile function. And for some reason they are told, oh, you've had your time, you don't need to worry about things like that and therefore are denied the referrals and the appropriate treatments for that particular condition.

Clare Delmar: So, Raj, as we've talked about before, you're an incredibly strong advocate of, I guess, what we call a holistic approach in engaging with and treating your patients, and can you discuss how this plays out with older men? How do you approach them in a holistic way that's going to help them live that quality of life that you refer to?

Raj Nigam: Obviously, we will note the age of the individual, but then once you start talking to the individual, once you start experiencing exactly what their way of life is and what they are thinking and also what their comorbidities are and so on, and realise that actually these chaps are pretty healthy then the actual chronological age goes out of the window. And you really have to start treating the man as though he was in his 50s or in his 60s and thinking, right, how far do we need to go with the diagnostic algorithm that we have and therefore the management thereafter? Once he and I have that diagnosis, then we can discuss exactly what is the most appropriate treatment for him. And it may well be that the radical treatments will not be appropriate, but that does not mean that he should not be treated, and given this watchful waiting tag and waiting for what? Waiting for it to metastasise, waiting for it to spread, waiting for him to develop severe symptoms from it. So within the context of prostate cancer, that is the way that I would manage the patient, that it would not be on the basis of chronological age. And I think I touched on my Andrology field as well, that I see a lot of more older men, shall we say, you know, with erectile function. And I'm sure not the first of conversations around this because I know it's something that's extremely important to our patients and to the wider public as well as we age as a society. So thank you so much for talking to me and I look forward to continuing the conversation again soon.

Clare Delmar: If you'd like to learn more about Raj's work and about The Focal Therapy Clinic, please visit www.thefocaltherapyclinic.co.uk. When Active Surveillance Becomes Anxious Surveillance For many men, Active Surveillance is an ideal approach to managing an early-stage prostate cancer diagnosis. They understand the obligations on both patient and care provider to monitor their prostate through regular PSA testing, MRI, and biopsy, and are confident this can be managed effectively. For these men, the trade-off between invasive treatment and its side-effects and regular visits to a clinic tips favourably to the latter. They struggle with the obligation of regular monitoring, and sometimes this is exacerbated by constraints in the healthcare system, resulting in delays or missed appointments. But far more importantly, it's the "not knowing" that compromises the well-being of these men. "Having gone through the process of diagnosis, and then being told he doesn't need to do anything and yet he has cancer, is too much for some men. In a recent On Focus interview, TFTC patient Perry Letcher talked openly about his short-lived experience with AS. Initially he was positive about it, "at the time I was relieved because I had been worried that I had a

life threatening illness”, he told us. And at the time, you know, when I was told active surveillance, that seemed perfectly logical and I was perfectly happy about it”. Perry was on AS for a little over a year, and found his feelings about it shift considerably. And I think that it’s very easy for the NHS to say, you know, he’s on active surveillance and that’s OK and we’ll just leave it. Not realising that that person can have massive changes in their own feelings about how it goes”. “When I had this MRI, I was expecting the results in a week because that was what I’ve been told when I had them. I then phoned up the urology clinic and was told, no, there’s no way we can have them now, that it would be two weeks. I phoned them after two weeks and I said, oh, yes, well, of course, I don’t know whether they’ve come in yet, but in any event, the multidisciplinary team would have to review them before we could do anything and say anything. And I was fully aware that it was affecting my mental sobriety and, you know, my mind can take me to some fairly dark places. And I truly believe that because when I was an active alcoholic, my mind took me to some very, very dark places to the point where I was seriously contemplating ending everything.”

A recent study in the US explored how AS was experienced by men with low-grade prostate cancer. “For roughly one-third of the patients, it is more like “anxious surveillance”; they drop out of AS because they find they can’t handle the uncertainties of living with cancer. One-third drop out because surveillance has shown they have more advanced cancers requiring intervention. The remaining third go on to live out their lives and die from something other than prostate cancer”

The authors point out that non-surgical alternatives, such as focal therapy, are building evidence fast. “Men on active surveillance for low-risk or intermediate-risk (Gleason 3+4) disease aren’t just waiting for their cancers to advance so they can undergo treatment. Patients may forget that AS can buy us time as new strategies and new technologies emerge.”

Focal therapy is a viable alternative for many men on AS. If you are an AS patient and interested in learning more about focal therapy, contact us for an informal discussion.

Prostate Cancer – A Second Opinion Can Change Everything

Prostatectomy patient Mark Stubbs shares his story

The Focal Therapy Clinic patient Mark Stubbs discusses how seeking a second opinion for his prostate cancer diagnosis and treatment led to an unforeseen approach and better outcome.

Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Prostate cancer is now the most commonly diagnosed cancer in the UK and with this somber fact comes a multitude of challenges and opportunities. I’m Clare Delmar; today I’m speaking with Mark Stubbs, who came to The Focal Therapy Clinic earlier this year after his prostate cancer diagnosis and just as Covid-19 was accelerating and his windows for further investigation were closing. Mark, thank you so much for joining me today.

Mark Stubbs: Hi Clare, good afternoon.

Clare Delmar: Let’s start at the very beginning, as we say. Can you summarise for our listeners what happened to you at the time of your diagnosis?

Mark Stubbs: Well, what happened was I had a very, very slight raised PSA. Basically trying to cut a long story short, after that, I had a rectal exam followed by another PSA test and then a multi parametric MRI scan. I was previously hoping to have HIFU focal therapy treatment, hoping that the cancer was of such a grade that it would be treatable. But as it happened, the cancer was quite aggressive, although I was told it was contained within the prostate, which eventually led me to have a robotic prostatectomy which was performed in the middle of June.

Clare Delmar: So, Mark, what compelled you to pursue the extensive research you did on the treatment options for prostate cancer?

Mark Stubbs: Well, what happened was I got a letter through the post basically giving me the results of the multi parametric MRI scan, and it freaked me out, to be honest. It said that the scan had revealed an extensive abnormality in the right hand side of my prostate, which suggested prostate cancer. So basically I decided that I wasn’t just going to sort of sit around and be depressed about it. And I quickly found out about focal therapy with it being less invasive than other treatments. But basically I thought, well, if it’s going to cure it and the side effects are minimal, then it’s worth pursuing.

Clare Delmar: OK, and then what happened with the existing consultant and the existing care team you were working with?

Mark Stubbs: What happened was they’d actually proposed a TRUS biopsy, a transrectal biopsy. But I found out through my own research that to have the HIFU, I needed a template biopsy or a transperineal biopsy. So what happened was then I was put on the waiting list with the NHS to have a template biopsy. I was told at the time the wait was between eight, possibly eight, maybe 10 weeks.

Clare Delmar: OK, this was when?

Mark Stubbs: This was basically the first week of February 2020.

Clare Delmar: Right.

Mark Stubbs: And unfortunately, due to Covid, the day before I was due to have the biopsy, I got a phone call, basically cancelling it, and I had to wait another just over two weeks to have this template biopsy

done. Clare Delmar: Which you did have done? Mark Stubbs: I did have that done, yeah, I had that done. And unfortunately, the letter I got from the consultant basically said, well, look, we realise that you wanted HIFU, but unfortunately it's showing that cancer in almost the entirety of the prostate, including some high grade Gleason 9 cancer. So then I actually sort of looked into having treatment done privately, and that's when I sort of was recommended to Mr Dudderidge. Clare Delmar: So, Mark, you're clearly a very strong advocate of second opinions. Can you explain why this was so important in your case? Mark Stubbs: Well, I'm actually a stronger advocate of a second opinion now than I would have been at the time. It was only really when I discussed with Mr. Tim Dudderidge – a telephone consultation – that he actually suggested revisiting the biopsy samples – letting his lab check the actual biopsy samples to make sure that the Gleason score of the cancer was actually, as was said in the histology report I got from the consultant. Clare Delmar: And was that easy to do? Mark Stubbs: It appeared to be, yes, I got some feedback very quickly from Mr. Dudderidge. It's coming out at Gleason 7 rather than Gleason 9, he said, which does give us quite a few more options in terms of nerve sparing during surgery and also sparing the lymph glands, which to me was priceless. If I'd have probably stayed in the NHS loop, I've got a feeling I wouldn't have got the same level of treatment. I wouldn't have had the second opinion and they would have probably operated assuming that the cancer was Gleason 9. So really the second opinion, I think, was absolutely pivotal in the choice of treatment. Clare Delmar: Given the timing of this, did Covid-19 and the refocusing of resources in the NHS affect your experience and the decisions you made? Mark Stubbs: Yes, it did, because what happened was if it wasn't for Covid, then the waiting time under the NHS wouldn't have been as long. So in a way, Covid has actually done me a favour because what happened was, it basically forced me to go into the private sector. So it was actually fortunate that I did come across a person, as you know, with the experience and expertise as Mr Dudderidge. And I think that without that, the end result would have been quite different than it is. Clare Delmar: So you came to The Focal Therapy Clinic and Mr Dudderidge hoping to be treated with HIFU. I mean, were you disappointed or were you in fact relieved that you were given the best treatment for your situation? Mark Stubbs: Well, mixed feelings, really. I think that after I was basically given the biopsy results, I realised that getting rid of the cancer was the primary end result. But unfortunately, there was Gleason 7 in one part of the cancer and then there was other suspect areas. So even if the Gleason 7 cancer had been sort of eradicated by HIFU, there was a chance it could come back with these other suspect areas. So really, I was actually glad in a way that, you know, that I did have the prostatectomy, hopefully now the cancer is gone. So, yes, I was disappointed at first that HIFU was not on the table, but I was relieved in another way that I actually got the expertise and experience to give the best outcome using robotic prostatectomy. Clare Delmar: And as you said before, it was probably a more nerve sparing and probably more efficacious treatment in the end, having had your biopsy revisited and regraded? Mark Stubbs: Yeah, right. And I think also that when the actual prostate was removed and went to the lab, the report came back that it was actually, as Mr Dudderidge had said, it was Gleason 7 cancer. But I think that's probably the best outcome I could have hoped for, to be honest. Clare Delmar: Do you think that the wait is really difficult for a lot of people? Did you find it particularly difficult? Mark Stubbs: I would say that anybody that's been diagnosed with any form of cancer, is going to go through hell. I think me and my partner Lindsey, we were basically going through quite a lot of trauma; the waiting time for the biopsy I think that was probably the worst thing. And obviously the time scale of having subsequent treatment was, you know, was pretty horrific. Serious mood swings, and I suppose with the Covid thing going on at the same time, that basically just rubbed salt into the wound, I suppose. Clare Delmar: So, Mark, what advice would you give to men that have had a recent prostate cancer diagnosis? Mark Stubbs: I think what I'd be tempted to do, they need to do the research. And also they need to check that the biopsy they're offered is the correct biopsy for that sort of treatment. And if they've got savings put away for a rainy day, which is the situation I was in, then, you know, for God's sake, you know, use that resource and be open minded as to the type of treatment so that you come across, ask other people who had prostate problems. I mean, I know three people personally who've had their prostates removed and all three have had very different outcomes. So obviously, use that information and obviously information on the Internet really, to try to sort of come to a conclusion as to the best of the treatments, the options available, whether they were private or on the NHS or whatever. Unfortunately, I think that, you know, in the NHS, it is, you know, obviously going through a hard time, especially at the moment with Covid. And unfortunately, I don't think the consultants actually have the time to explain to all the patients in massive detail what the options are. So sadly, I think people really need to do their own research and ask questions. Clare Delmar: Mark, thank you so much for sharing your experience and your insights with me today. If you're

interested in contacting Mark or engaging with other patient stories, visit our website at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with patients and clinicians about their experiences with prostate cancer.

Covid19 And Its Impact On Men With Prostate Cancer Earlier this week, the BBC asked the question "Is it time to return to normal", citing the current level of deaths from Covid19 at 10 per day and comparing this to the current level of deaths from prostate and breast cancers at 30 per day. "Neither of these figures is read out nightly on the TV news, unlike the statistics for cases and coronavirus deaths" said Fergus Walsh, the BBC Medical Editor. Whenever and whatever the new normal is, 30 deaths each day from prostate cancer is not something anyone wants to return to, and the renewed focus brought by the BBC piece should make providers, policymakers and patients alike take action. At present, for men with prostate cancer, things are far from normal within the NHS. We are seeing considerable delays to diagnostic tests and treatments, and in many cases optimal treatments are being compromised. In a recent OnFocus interview, TFC Consultant Urologist Raj Nigam pointed out that this has led to a large increase in men with early-stage, localised prostate cancer being treated with hormones. "This is an unfortunate negative outcome of the Coronavirus era, if you like, that traditional treatments have all had to be halted for at least three or four months, in particular radical prostatectomy and radiotherapy. And as a result of this, men have inadvertently been advised to go onto hormonal therapy without, I hate to say, you know, proper and adequate discussion," says Raj. It's just the position that they have been placed in in terms of trying to control the condition, at least so we think with limited time and often in telephone consultation to say we're having to put you on hormones until and unless we start just services up and running again." In some cases, patients have responded to the changed circumstances by making faster decisions. Based on his biopsy results, he was recommended a radical prostatectomy, which he was then told would only be available in 4-5 months time. He then began to research other options, and learned about focal therapy, which required a template biopsy. This, too, was only available in 4-5 months time on the NHS, and so he came to the Focal Therapy Clinic to seek advice and treatment. Delays in the early stages of the diagnostic pathway are more worrying, and it is difficult to get accurate estimates of how many men with suspected or confirmed prostate cancer are on NHS wait lists and at what stage of the diagnostic process they are. Various media have reported figures up to 35,000 of excess deaths due to cancer because of Covid19 delays. Prof Karol Sikora, an oncologist and former advisor to the Department of Health and World Health Organisation, has been vocal about the impact of cancer delays, stating, 'I've criticised stark predictions in the past.' Further information can be found in this Daily Mail article. Have you been impacted by Covid19 in your diagnosis and/or treatment for prostate cancer?

Tim Dudderidge Gives an In-depth Guide to Prostate Cancer Diagnosis The Focal Therapy Clinic's consultant urologist Tim Dudderidge discusses the stages in the imaging-led prostate cancer diagnostic pathway, and outlines what patients need to know. What patients need to know Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus brought to you by The Focal Therapy Clinic, where we connect you with issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Today I'm speaking with Tim Dudderidge consultant urologist at Southampton University NHS Trust and The Focal Therapy Clinic and a pioneer in non-invasive treatments for prostate cancer. We're going to discuss how advances in the diagnostic pathway for prostate cancer give patients more opportunity to engage with their care and treatment. I mean, I think we all agree that the diagnostic pathway for prostate cancer has been revolutionised – I know that's a strong word and I'd like for you to comment on that – over the last 10 years. In the past where we used to have a high PSA or an abnormal prostate examination, which might have been found when men had symptoms, the decision was whether to biopsy or not. And basically this MRI scan allows us to have diagnostic imaging and people are familiar that with all sorts of other tumour sites. The big change with biopsy, I suppose, is and it helps to try and understand some of the terminology here. In the past, what we used to use was a systematic biopsy, and there are a number of different patterns of biopsy through the transrectal route that people used to follow. And so a lot of the academic focus was about trying to work out which of those patterns of biopsy was the best. And there are different ways of targeting the biopsy and a good clinician will be able to just use their skills to target the needle into the lesion. And they can look at the MRI scan, find the same area using the ultrasound and get a good target. And so the other big revolution is the use of software fusion to basically enhance the accuracy of that targeted biopsy. So and there's a lot of terminology, as you quite rightly pointed out, which is that it's fair to look at this pathway and it's sort of sequential elements, almost like a supply chain and one that patients can focus

on any one link and begin to understand how that might affect him and what questions he should be asking. First of all, you've got the type of scanner and you can do a very good multi parametric MRI scan on a 1.5 tesla scanner. But some centres will have access to 3 tesla scanner and it can give slightly better resolution. So I think in an ideal world, you might go for 3 tesla scan every time, but some people aren't suitable for that. The magnet strength means that some people can't go in there and some of the side effects – some people will get nausea in a stronger magnet. Tim Dudderidge: I think you can get adequate images with a good well conducted 1.5 tesla scan, but I think maybe a 3 tesla scan would be preferable if one had access to that. But even in our centre where we have one, not all of the scans are conducted on the 3 tesla scan. The radiologist might sort of pick and choose a little bit which one's done on the 3 tesla scan. I think most of our initial scans are actually done on a 1.5 tesla scanner just because of the volume. Tim Dudderidge: Well, I think that the way that the scan is conducted should follow most of the protocols laid out in, for instance, the ESUR guidelines. And there are several publications I think will put a link of one up just to give an idea of the technical detail that goes into making a really good prostate MRI. And that's not just how the sequences are put together, which include the T2 weighted sequence, diffusion related sequences, making sure you get the v-value that's appropriate for prostate and also the use of contrast. I mean, contrast is my preference, but I know there's a lot of debate about it and it adds some additional diagnostic kind of resolution, if you like, but a lot of... Clare Delmar: Diagnostic how? Tim Dudderidge: It just helps interpret areas that may look like cancer, but the enhancement characteristics might add to the radiologists ability to differentiate between inflammation or scarring, and particularly after previous treatment it's really helpful to have contrast. But in terms of the efficiency of an NHS pathway and the supply chain, as you put it, it's challenging. Sometimes for centres to have contrast because it takes longer in the scanner and therefore one can do fewer scans in a day. So there's a lot of work going into looking at the use of bi-parametric – is the sort of terminology – MRI scans, and I think it's a pretty close thing where actually the contrast in the initial diagnostic setting is really necessary and I think more research will come out. Clare Delmar: OK, so I'm a patient and I now know that I need to have an MRI and the MRI is going to determine whether or not I need to have a biopsy. He understands that it's going to be interpreted to determine whether or not he needs a biopsy. Tim Dudderidge: Well, I think that the first thing is, in an ideal world, a prostate MRI should be reported by somebody reporting a lot of prostate MRIs and uro-radiologists will have this as one of their main chunks of their work, because there's a high volume pathway. And if they've been through the sort of training of prostate MRI reporting, then hopefully you will get a kind of standard of report which meets those ESUR guidelines. Now, not all centres again for time pressures are able to produce a report which includes an image representation of the location of any lesions. And that is really the ideal where you get a graphical representation and maybe even some representative images embedded in that report to show you where abnormalities are. But I think at the very least, you do want to be having reporting using the Likert or PIRADS reporting system – these are two different systems. The PIRADS one purely relies on the imaging characteristics, whereas the Likert score does incorporate some of the clinical characteristics. And the bottom line is, if you've got a three, which means equivocal, there's a strong chance you should have a biopsy. But in patients who have a low PSA density that basically measures the amount of PSA relative to the size of the prostate. In those cases where you score a three, you can consider avoiding a biopsy and maybe reviewing the situation after a year with repeated imaging. And people use cut points of, say, 0.12, for whether you have a biopsy or not, with high PSA density above that level triggering a biopsy. So I think you can discuss that with the patient and also have a sense of their comfort level with risk. Other people want to make sure we don't leave a stone unturned and get every bit of information. Clare Delmar: So you have PIRAD and that's a piece of information that the radiologist determines through from the image. Tim Dudderidge: So Likert is effectively is a sort of parallel system which incorporates a sort of clinical judgement. And so if with the PSA and the interpretation of the image, the radiologist feels that they want to sit on the fence, they'll give it a three, if they think they're suspicious, they'll give it a four if they're absolutely sure it's cancer they'll give it a five. And on the other side, if they think it's probably benign but there are some characteristics which are not entirely normal, they might give it a two. Clare Delmar: OK, so the patient should know that the communication between the radiologist and the urologist based on the image is going to be based on this score. Tim Dudderidge: After treatment, it's probably more appropriate to use the Likert scale because after any ablation and so on, the PIRADS is not really designed for that situation. So to me, those are the big critical things to understand, at least at a surface level about the imaging. I know you've touched on this a little bit earlier, but maybe you could just sum that up here as we move down the supply chain, so to speak. Tim Dudderidge: I'll just get transrectal out of the way,

because I think it's not completely historic. It's a very convenient way of having patients come through the system and get through maybe six or seven patients in a morning quite comfortably. But really, you are limited to sampling the peripheral zone and you can do some targeted biopsies. And even some of the systems allow for software fusion during transrectal biopsy, but it's quite difficult to sample the front of the gland. It's quite painful to have to insert the needle a couple of centimetres in and then fire it rather than just firing it when it's been inserted five millimetres or so through the rectal wall. It depends on the local flora – the bugs basically that are around and also what antibiotic protocols used. Some centres are avoiding infection by giving three different types of antibiotics, others maybe using a pre biopsy test to look for resistant organisms just by culturing the fecal flora. But I mean, it really is trying to avoid a very avoidable problem if you just don't put the needle through the rectal wall. Now the problem historically has been that with a transperineal biopsy and this is a biopsy where the needle travels through the skin just in front of the anus and behind the scrotum, the problem is that that's quite uncomfortable to do that on the local anaesthetic historically. And so it's not just the needles passing but actually we've used this thing called a stepper and a template. And the trouble is, if you're awake and that is sitting in the rectum, it's very uncomfortable, not just the passage of the probe, but the fact is sort of on a fixed jig and the patient is having this thing moved in and out and patients don't tolerate that so well and they end up moving around, which really then compromises that situation if you're doing software fusion. And I think for delivering outpatient ambulatory transperineal biopsy, this allows the ultrasound to be free hand, which means you're not forcing it against the patient, which is what causes the discomfort. And a combination of the transperineal approach and the avoidance of this kind of fixed stepper means that the procedure is pretty well tolerated and then overcomes the problems of transrectal biopsy, which is you can't sample the anterior part of the gland. With the precision point biopsy it's quite straightforward to sample the front of the gland. So I think that we're going to see in the high turnover situation where resources are important and general anaesthetic is not possible that the precision point biopsy will largely take over. And I think there will still be a place for general anaesthetic, targeted biopsies and systematic biopsies. So I think that the fusion is probably going to be a bit more reliable when you've got a static situation and you don't have the free hand ultrasound probe. And I think when you need to take lots of biopsies in a prostate mapping situation - which doesn't apply to all – but when you need to take lots of biopsies, I think it'll be more comfortable for patients to have that under a general anaesthetic. So for the time being, I think my preference is to offer a general anaesthetic where it's possible but where that's a challenge for resource purposes, then the precision point transperineal biopsy is probably the favoured approach.

Clare Delmar: But the key takeaway is that a transperineal over a transrectal is ...

Tim Dudderidge: I would say so, yes.

Clare Delmar: From both an infection point of view and often from a targeting point of view and often from an anaesthetic point of view.

Tim Dudderidge: One thing that people ask me a lot about any kind of biopsy is about seeding. And I think for a tumour to seed through a prostate biopsy, you're dealing probably with a very aggressive type of cancer anyway, not the sort of standard type of prostate cancer.

Clare Delmar: OK, so now let's move on to the sort of not final, but the maybe the last stage before you ultimately have a diagnosis, I guess. I mean, is the provider in the process for pathology or histopathology something a patient should be concerned about?

Tim Dudderidge: Well, most uropathology will be reported by specialists, but if you're in a centre where it's not a specialist centre where maybe prostatectomies are not being undertaken, just the diagnostic side of things, you may have a generalist reporting the biopsies. And in some centres, those biopsies are then re-reported at the tertiary centre where we have MDTs occurring. But if that's not the case, particularly if the biopsy grade or the details on the biopsy are critical to your decision making, you may wish to consider getting a second opinion on that. We've certainly seen cases where that has changed and where that has led to an alteration in the decision. Some pathologists who are still not familiar with the use of focal therapy may not give the details of each individual core, which allows you then to plot whereabouts the cancer is and help to plan focal therapy. So I think that making sure that you've got in the report enough information to determine the location where the disease is and where it is not, and also which side has what grade. So the right might have a low volume Gleason 3+3 and left, might have a moderate 3+4 and that kind of case would be suitable for focal therapy. But if the summary is just that you've got cancer on both sides and it's 3+4, which is still correct, it's just too much of a generalisation.

Clare Delmar: And then finally, I mean, all this so-called supply chain gets pulled together through something called the multidisciplinary team or the MDT. And I know you've been a strong advocate and innovator around MDTs, which I guess in some ways can be considered the most important part of the pathway, because I guess this is where you determine what are the options for the patient and where you really engage him.

Tim Dudderidge: The

first thing that the MDT is not something which engages with the patient, which is its chief problem. But in the private sector, these meetings have also sprung up but they serve slightly different purposes. Within the NHS the first target was to make sure that patients have an opinion about their cancer, which included all of the relevant specialists, including the radiologist, histopathologist and the oncologists and the surgeons. And I think that there's a bit of a difficulty with recommendations coming out of MDTs because the person who's missing from that room is the patient. And it may be that some of that is captured in the clinic letters where the patient has been involved. And so I think at best, the MDT can assimilate the information, although sometimes it fails to do that. And again, sometimes MDTs fail to do that and then it can allow the clinician who sees the patient to discuss the findings, a bit of a guide as to where the likely best option for the patient is, but the person who sees this MDT report really should start afresh with the patient and use the MDT opinion as a sort of a clue, but not as a sort of a diktat. And I think this is where things can sometimes go wrong, especially where the MDT has misinterpreted something. They have a biased view against it and just say because it's not in a guideline, it shouldn't be even talked about. I think that that is unfair because we have sufficient evidence, in my view, to say that men should be presented this as an option where it's a suitable option. And so I think it may be that the MDT that your case has been discussed that just wouldn't have considered it at all.

Tim Dudderidge: I think as far as the patient is concerned, I'm not sure they should take a great deal of attention to it because there is a tool in the NHS as much for managing the workflow of cases coming through so that people end up in the correct clinics and so on. But I think in terms of trying to make a decision, I think it's far more valuable to have a discussion with a clinician to get a feel for how the options are being explored and whether all of the options are being considered. And then you can say, well, I know a bit from my reading, I would like to know more from an expert. I think that if a patient has an interest in a type of treatment, answers should be provided in a balanced way. And, you know, sometimes people ask me about types of radiotherapy that I don't know about. I know that my colleagues might say, oh, like proton beam therapy, we don't normally recommend that and gives a few reasons.

Clare Delmar: You operate that way, I know you're a big advocate of the so-called Montgomery ruling from a few years ago, which kind of upholds what you talking about.

Tim Dudderidge: Well, I think that patients don't just give informed consent about procedures. I mean, your job is to explain why you don't think it's a good idea if you don't think it's a good idea. So I think that if you've not had that experience out of the MDT or out of your clinical discussion and you feel that you haven't been provided with that rounded opinion, that's where a second opinion can be helpful, because what it might do is completely just repeat what they've already told you and then it gives you confidence that what you were told the first time was correct. But sometimes, especially when you speak to someone who does get involved with focal therapy, you can find out whether or not you are a suitable candidate.

Tim Dudderidge: And I think it's important that people seeking a focal therapy opinion should be reassured that they're not just going to get a yes or no about focal therapy, they're just getting an overall holistic opinion about their case.

Clare Delmar: Excellent. If you're interested in contacting Tim or learning more about imaging led diagnostics and treatments. Visit our website at www.thefocaltherapyclinic.co.uk, where you can access additional interviews with patients and clinicians about their experiences with prostate cancer.

Covid19 has recycled the phrase commonly offered to older prostate cancer patients "you don't die of Covid19/prostate cancer, you die with it". The implication is, of course, that little will be done to treat because you're going to die anyway. But in the case of Prostate cancer, hardly relevant in an age when more and more men are living healthy and active lives throughout their 60s and 70s and well into their 80s and 90s. In a recent OnFocus interview, patient advocate Jackie Reubin told us that she and her husband Barry felt "written off" by their initial consulting urologists because they were over 70 at the time of Barry's prostate cancer diagnosis. Its author, Prof Mark Lawlor of Queen's University Belfast, pointed out that more than 70 per cent of deaths caused by prostate cancer occur in men aged over 75 years, who usually have more aggressive disease. Few older patients, however, receive treatment for localised prostate cancer, and in most cases they are denied access to chemotherapy for advanced disease. Professor Lawlor calls for a new strategy for older patients, and concludes: "Such a strategy will also have to ensure that the principle of early diagnosis (underpinning more effective and less aggressive treatment) is applied in older patients as well as in their younger counterparts. Only then can we truly deliver a comprehensive cancer service to the elderly population in our society." Six years on, we get many approaches at The Focal Therapy Clinic from patients who are fit and thriving at 70+ and yet only offered treatments that compromise their quality of life and those of their family. We know that expectations have changed, and look to both the emerging science supporting longevity and the

continual increase of fitness and activity in the over 70s, and recognise that all of this must be taken into account when recommending treatment. If you or someone you know has felt discriminated against in their prostate cancer treatment because of their age, we'd like to hear from you.

How Technological Developments Are Making Focal Therapy More Accessible & Effective

Focal therapy is all about precision and accuracy. The more precise and accurate the diagnosis, the more precise and accurate the treatment can be. And the more precise and accurate the treatment, the better the outcomes in destroying cancerous tissue with minimal side effects. The good news for those seeking focal therapy is that technology is advancing in three areas that are aiding the pursuit of higher levels of precision and accuracy in both diagnostics and treatment.

Imaging & Reporting

The advances in imaging technology over the last decade cannot be overestimated and their impact has been led by no less significant advances in imaging techniques, expertise and reporting. Since the publication of the PROMIS trial in 2017 and the wide reception to its evidence on the diagnostic efficacy of mpMRI studies of the prostate, 1.5T MRI scanners are widely available on the NHS, and calibrations for mpMRI studies of the prostate are increasingly understood and practiced. While the supply of expert uro-radiologists is limited, there is well-defined software available to help and support radiologists in reading, interpreting and reporting on prostate MRI studies. This involves identifying and contouring areas of interest, and traffic signalling to prioritise potential severity. The continual development and adoption of PIRADS – Prostate Imaging Reporting and Data System - is contributing significantly to this process. The PIRADS score classifies MRI lesions on a scale from 1 to 5, which reflects their level of suspicion from least to most. PIRADS 3 lesions are considered equivocal. Multiparametric magnetic resonance imaging (MRI) and MRI-directed biopsies using the PIRADS improves the detection of prostate cancers likely to cause harm, and at the same time decreases the detection of disease that does not lead to harms if left untreated. The keys to success are high-quality imaging, reporting, and biopsies by radiologists and urologists working together in multidisciplinary teams. Reporting design is improving all the time and integrating critical imaging information, PIRADS, and in the best cases, contextual information including patient PSA and biopsy history. This enables efficient, comprehensive, and accurate communication between radiologist, urologist and other members of an MDT responsible for diagnostic and treatment decisions. A good example of high-standard prostate MRI reporting has been set by Prostate Care Ltd, viewable [here](#).

Pathology

A number of researchers and organisations are working on applying machine learning to prostate tissue samples from biopsies in order to improve the accuracy and speed of pathology analysis and reporting. Still in early development, these efforts are continually improving and gaining acceptance. Earlier this summer, a deep-learning system developed at Google outperformed general pathologists for Gleason grading of prostate cancer biopsies. In a validation set of 498 specimens that were positive for cancer, the deep-learning system came up with the same result as the panel of sub-specialists in 71.7% of cases, versus 58% for general pathologists, a statistically significant result. More on this study [here](#). Another team at the University of Pittsburgh set out to develop an algorithm that could more accurately identify prostate cancer. The team trained the tool on images from more than a million parts of stained tissue slides taken from patient biopsies. Each image was labelled by expert pathologists to teach the AI how to distinguish between healthy and abnormal tissue. The algorithm was then tested on a separate set of 1,600 slides taken from 100 consecutive patients seen at University of Pittsburgh Medical Center (UPMC) for suspected prostate cancer. During testing, the AI algorithm achieved 98 percent specificity and 97 percent sensitivity at detecting prostate cancer, which is significantly higher than previously reported for algorithms working from tissue slides. More on this study [here](#).

Ultrasound Ablation

While HIFU adoption continues apace, a new approach to applying ultrasound for focal therapy is emerging called TULSA. This approach uses transurethral ultrasound in place of focused ultrasound, and the key difference between it and HIFU is how ultrasound energy is applied to prostate tissue. During HIFU prostate ablation, the ultrasound energy is focused through the rectal wall towards a specific location in the prostate. The prostate tissue is therefore ablated from an 'outside-in' approach by delivering the focused thermal ultrasound from the rectum inwards to the target region of prostate. During the TULSA Procedure, thermal ultrasound is delivered directionally from a device within the urethra (there is no energy passed through the rectum) this device rotates and delivers heat in a sweeping pattern contacting a large volume of tissue in minimal time. The prostate tissue is therefore ablated from an 'inside-out' approach by delivering the directional, thermal ultrasound from the urethra outwards to the edge of the target region of prostate. The key benefits of the TULSA approach are higher levels of accuracy and reduced levels of damage to healthy tissue. The Focal Therapy Clinic is actively engaged in each of these areas of technological development, and will update on progress regularly.

Prostate Cancer – Women and Partners, Advocates and Sufferers An

interview with patient advocate and partner Jackie Reubin Patient advocate Jackie Reubin discusses women's and partner's roles in supporting men with prostate cancer, and the impact these have on their own health and well-being. A video of Jackie and her husband Barry can be seen [here](#). Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

Clare Delmar: Hello and welcome to OnFocus, brought to you by The Focal Therapy Clinic. My name is Clare Delmar, and in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this year, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. In the eighth of our series, I'm speaking with Jackie Reubin, whose husband, Barry, was diagnosed with prostate cancer in 2019. Jackie climbed a steep learning curve in supporting and guiding Barry's journey through diagnostic and treatment decisions and is becoming an advocate for men and women accessing second opinions and full information on treatment options. And I'm going to refer to that a little bit later because we did a wonderful video of you and Barry. And I wanted to pick up on that point as we begin our conversation by just mentioning that when we met at the end of 2019 things were just settling down, I think, for you and Barry after his diagnosis and treatment. Absolutely back to normal.

Clare Delmar: So good to hear.

Jackie Reubin: We can't believe it because having spoken to so many other friends who've had it and who are still suffering side effects, Barry has nothing. And we're just so grateful.

Clare Delmar: So, again, I should let our listeners know that Barry had HIFU treatment with one of The Focal Therapy Clinic leading urologists, Raj Nigam. And I just can't speak enough highly.

Clare Delmar: Well, if I can just kind of change the tone a little bit because coming from this high, which we will come back to about how you're feeling now, can you talk a little bit about what went through your head when Barry was first diagnosed?

Jackie Reubin: When he was first diagnosed, it was oh no, another cancer. How long have we got left?

Clare Delmar: OK, so Barry had previously had cancer?

Jackie Reubin: Barry's had cancer, and stem cell transplant. Our first appointment, of course, we didn't know, but was with the doctor who then told us because of the blood test. We had to wait for an appointment, then we had to have a test, then wait for another appointment, then have another test. And Barry was getting more and more uptight.

Clare Delmar: Give us an idea of how the length of time you're describing.

Jackie Reubin: We were well over a month, six weeks before we had the final proper diagnosis. We knew it was there, but before we had the proper diagnosis and this is not the way we do things. We had a test and then we had to wait for our appointment with the specialist for him to tell us the results of that test. And then we go back and wait for the next appointment we had with him when he'd had the results. And that's why it took so long.

Clare Delmar: And that was just causing lots of anxiety?

Jackie Reubin: Terrible, terrible anxiety. In fact, just to interject here on something else, after Barry had been treated for the prostate cancer, early this year, he was diagnosed with Graves' disease, an overactive thyroid, and it's being treated. Which actually leads me to something else that struck me when we met, which was that you are clearly a real fighter and facing some tough challenges which you overcame with incredible determination in my view. Can you tell me more about that?

Jackie Reubin: Well, I suppose I was very young when I was diagnosed with cancer and I had to have chemotherapy and I'm living to tell the tale. Mine was over, well over, I think, about thirty three years ago now.

Clare Delmar: Well, congratulations.

Jackie Reubin: Thank you. And each of these things, I believe, make you very strong because when you've lived through something and you've had to overcome it because you have no choice. But you do think that you've had enough and you shouldn't be getting anymore.

Clare Delmar: So what were some of the particular challenges of Barry's diagnosis that really forced you to call on that strength?

Jackie Reubin: Well, I just felt we just can't go through something else like this. I remember one friend who was having the hormone treatment and that just had been a couple of years before. So I remember vividly his hot flashes and being just, I can't say unwell, but not comfortable all the time. Barry just had had so much treatment and he didn't want to be facing more and more and more treatment. I found it by sheer determination and research, and that's how I overcome all the things that we have to do is by research. Thank goodness for the internet.

Clare Delmar: I remember being very, very impressed with your doggedness on that front. You know, one of the things that I do remember you saying from some of your initial consultations and you spoke very poignantly about this, which was that the whole idea about your age and Barry's age and how you felt that your initial engagement with the doctors made you feel old, I think you said irrelevant and unimportant. And we all feel because we're all the same age and we all feel the same, that once you reach that seven zero, that's your life, that's your three score years and ten and anything over that, you're lucky. You'll die of something else and this will be there.

Clare

Delmar: And you felt that that was sort of a prevalent attitude that was difficult to get away from. Jackie Reubin: Absolutely. I even know from when Barry had his past problem with cancer, he had amyloidosis and myeloma amyloidosis, which is quite rare, but it affected his heart. And when I asked if he could have a heart transplant, I was told, you can't get one if you're over 70. Clare Delmar: That was here in the UK? Jackie Reubin: That was here in the UK whereas I know in the States, don't do it at 90. This is how you're looked at when your 70 year old that, well, you've had a good life and that's it. Clare Delmar: And that's irrespective of, as you said, your health itself, but also your attitude towards life and then everything you feel that it's just a very blanket cut off? Jackie Reubin: Yes. Clare Delmar: I think that really is something that I'm hearing more and more. I mean, I know you felt that way on behalf of Barry, but did you yourself feel that you were treated as slightly irrelevant? Jackie Reubin: Yes, we're a pair. And what affects him and his mood or his aura or whatever is going to affect me, too. Clare Delmar: Of course. Thinking about another aspect of all this, how about the presentation enabling you to understand the side effects of the various treatments that Barry was potentially having to consider and in particular sexual function? Because this is often something that people, particularly British people, don't like to talk about. Was this openly discussed or did you feel it was hidden away? Jackie Reubin: It was openly discussed. But that wasn't the biggest thing for us, because Barry had had a problem because of having had so much chemotherapy. I think Barry would have been absolutely mortified if he didn't have bladder control, which I can thankfully say he has. Clare Delmar: And did you feel that you were sort of advised of that, or was that because of your own dogged research? Jackie Reubin: I had looked everything up. I knew the side effects to everything that was going; apart from the focal therapy, because at the time he was diagnosed, I didn't know about the focal therapy. Two points on that, one is that often people don't hear about it unless they go looking for these other options, as you did so diligently. And two, one of its main features is that the side effects, as in bladder control and sexual function, are reduced or non-existent. And it sounds really wonderful that this has been successful for Barry. Jackie Reubin: When we saw Dr. Nigam for the first time, obviously he explained all these side effects to us, but he gave us such confidence and we were so excited to be able to have this treatment. And then when Dr Nigam saw some of the MRI results, we had a call to say he might not be suitable for the treatment. There was no thought of going any other route whatsoever. Clare Delmar: And you felt that Raj was particularly sensitive to both of your situations and was helpful in explaining pretty much everything you needed and wanted to know? Jackie Reubin: Absolutely. I felt as though I've known him always. Clare Delmar: I think he is exceptional because he's also an andrologist and I think he really believes in the sort of whole man, whole person approach. So it's not just a particular function; obviously the highest priority is to manage the cancer. So it sounds like you really benefited from that in your engagement with him. Jackie Reubin: To go back to the age thing a little. That was the first way we were told. Clare Delmar: That was active surveillance that you were being advised to undertake. Jackie Reubin: Yes, just watch it. So if it had come in a short time and grown very fast, it could continue to grow fast and then it's too late to do anything. Clare Delmar: When you were discussing active surveillance with the initial consultant, did you get an understanding of how this active surveillance would be managed? Would there be regular tests, whether they were a PSA test or.... Jackie Reubin: Regular blood test, regular MRI, I think that was it. Clare Delmar: OK, and how did you both feel about that? Jackie Reubin: Well, I wanted to get it gone, get rid of it. Cancer's grow and you get them out of your body. Clare Delmar: I know when you met Raj Nigam, you felt that he was very supportive. Did you feel prior to that that there was support there for you during this process? Jackie Reubin: Not at all. I was recommended to the prior specialist by a very, very close female friend of mine who was undergoing at the same time bladder cancer. I just didn't have that feeling. Clare Delmar: So how would you advise women going through what you went through now, Jackie? Jackie Reubin: I would tell them to research and research until they find the HIFU, and hope that they were a candidate for it like Barry was. Clare Delmar: Well, I must say you are an incredibly positive person and it's just so impressive and so wonderful to hear what you have to say. And I really wish you all the best in the next stages of your journey. Jackie Reubin: Thank you. And I just don't want other people to have to go through what we went through. Clare Delmar: Absolutely. A link to our video: Barry & Jackie's Story is available on the programme notes to this interview on our website, www.thefocaltherapyclinic.co.uk where you can access additional interviews with patients and clinicians about their experiences with prostate cancer. A Woman's Perspective On Prostate Cancer While prostate cancer is a men's disease, its impact is significant on women who are the wives and partners of prostate cancer patients. Suddenly, life becomes defined as "before" and "after", as multiple challenges emerge, and while navigating the optimal diagnostic and treatment programme to ensure the survival and health of her partner is first and

foremost for most women, other aspects of the disease can rear their ugly head in insidious, uncomfortable and sometimes painful ways. For some men, mental health is compromised by a prostate cancer diagnosis and in some cases through certain types of treatment, and both anxiety and depression are common side effects that begin to play a role in a couple's relationship and ability to navigate the treatment journey. This can be exacerbated by the state of each party's emotional health, as feelings of fear, anger, and guilt come to the fore. The prospect of various treatment side effects compromising a couple's sexual relationship can be terrifying for many women, and for individuals who find this uncomfortable to talk about long-term relationship damage can ensue. Reduced sexual and urinary function will of course affect a man's sense of masculinity and how this translates into an intimate relationship is something that most men and their partners are not prepared for. The uncertainty that a prostate cancer diagnosis brings coupled with new challenges in the relationship mean that for many women they must adopt new roles and identities. "Suddenly I had to take on the role of nurse, accountant, handyman and actress" says Vivian Pipe, sharing her experience with Prostate Cancer UK. When her husband Barry was diagnosed with prostate cancer in 2019, Jackie Reubin developed a side of her personality she had never before revealed and became a patient advocate. She held high expectations for her husband's care and when she felt this wasn't being delivered, she navigated another route. One of her main concerns with initial consultations was what she perceived to be age discrimination. It was Jackie who researched treatment options and found the Focal Therapy Clinic where Barry was treated with HIFU by Raj Nigam. If you have a story to share about how prostate cancer has affected your experience as a woman and partner, please share it with us so we in turn can help other women who are struggling with prostate cancer. When Success with HIFU Focal Therapy Inspires a New Charity An interview with Prost8 founder and focal therapy patient Paul Sayer Prost8 founder Paul Sayer discusses his personal journey to establish a charity aiming to change the conversation around prostate cancer treatment. Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Helping men to live the best lives possible after prostate cancer Clare Delmar: Hello and welcome to The Focal Therapy Clinic. My name is Clare Delmar, and in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this year, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. In the seventh of our series, I'm speaking with Paul Sayer, founder of the charity Prost8, which describes itself as a new force in the fight against prostate cancer. Diagnosed with prostate cancer in 2018, Paul rejected his consultants' advice to undergo invasive treatments and opted for focal therapy. It's a pleasure to be here. Clare Delmar: Can you just talk really quickly about... you've got a very interesting spelling of prostate. So I think it'd be interesting just to start off with why it's spelled the way it's spelled. Paul Sayer: It's actually Prost8, which is P R O S T and the number eight. Basically the eight stands for the one in eight men who will actually be diagnosed with prostate cancer in their lifetime, which is quite a staggering figure in itself. Clare Delmar: Yes, it is indeed. But can you tell us a bit about your personal experience with prostate cancer? Paul Sayer: I guess the story starts fully back in about mid 2015. A very good friend of mine, Steve, had gone through a very nasty prostate cancer journey himself in his early 50s, which he almost didn't survive. And as a result, he kind of made it his personal crusade to make sure other men got themselves checked and that included me. Anyway, one, I guess, fateful Saturday morning late in 2015, I had an unrelated doctor's appointment and having seen Steve the previous evening, it was on my mind. I said that I had no symptoms, but to his credit, he said, as I had just turned 60 at that point, it might be a good time to have a look. So he did the rectal examination, found some enlargements and a bit of hardness, but said it was probably just age related. Clare Delmar: And you had no symptoms at all? Paul Sayer: No symptoms at all. And I didn't visit the doctor again until very early in 2018, which is two and a half years later... Clare Delmar: OK Paul Sayer: ...again, for an unrelated issue. It was a different doctor, but while I was there, I thought I'd mention to her that I was meant to have my prostate checked along the way. It was a case of if you have no symptoms, don't worry, which is quite common, unfortunately. In fact, she was kind of so unnecessarily anti that she made me take exception, especially knowing that I did have some enlargement. And eventually she reluctantly agreed to arrange for me to see another doctor at the same practice for a rectal check a few days later and arranged a PSA test. Clare Delmar: OK. Paul Sayer: PSA test reading came back at about three point eight. But then I was seen and examined by another doctor and he immediately said my prostate was hard and grainy. So he wanted to refer me for further investigation, which is the first sort of worrying sign. Clare Delmar: Indeed. Paul Sayer: So I zoomed off to

the hospital and following a series of scans and a biopsy, I was told that I had quite a sizeable tumour on one side and some lesser spots on the other. Clare Delmar: Wow Paul Sayer: Yeah, that sort of set the worry even further. Clare Delmar: Of course Paul Sayer: The usual happened, I was referred off to the urology department at the local hospital to see the specialists and to decide upon a treatment pathway. Fortunately, I did some homework ahead of that, made myself aware of all the possible options, sort of both mainstream and those that were in trial at that time. As you probably know, even now, most resources just point to either radiotherapy or surgery, removing the prostate completely. There's not a lot out there on focal therapy or maybe you get offered hormones and watch and wait. But I also found some information on the newer focal therapy treatments, such as HIFU and cryotherapy. So it doesn't need saying that I certainly wasn't keen on the possible side effects of radiotherapy or surgery, there being a very high chance of both incontinence and erectile dysfunction. When I got to see the surgical consultants, I saw both the radiotherapist and the surgeon within about 20 minutes of each other, I asked them about HIFU among some of the other options that were available. But remarkably, between them, they said that HIFU was not suited to my kind of prostate cancer, that it was highly experimental and it was only available as part of trials for advanced cancer. I knew differently to that, but they were saying I needed more traditional treatments and quickly, basically. Clare Delmar: And did you get a sense that it was considered risky or simply that it wasn't available? Paul Sayer: It was really a lack of knowledge. You could almost read between the lines when you were told they didn't really have the knowledge, so they were hiding behind their own specialisations to cover that lack of knowledge. Clare Delmar: OK Paul Sayer: So from my research, I knew that I could have different options, but when I spoke to them, they were actually almost annoyed that I dared to question them and one of them even got almost angry about it. And I have to say, I did actually phone back into the hospital later to make a complaint that I was being sold their choices rather than being told my choices. Clare Delmar: And this is NHS? I mean... Paul Sayer: This is NHS, my local hospital, urology department. Clare Delmar: Of course. So I opted for the radiotherapy simply to buy time because I'd got this HIFU thing in my head and wanted to explore it. The radiotherapy I chose purely because it involved six months of hormones ahead of the actual treatment. So in those following weeks, I researched, wrote, phoned, badgered every consultant I could find in the UK working on alternatives. Clare Delmar: Wow. Paul Sayer: And cutting a very long story short, I eventually found Professor Hashim Ahmed at Imperial College Hospital in London and saw that he was working at the forefront of focal therapy and offering it as an NHS treatment at that point. So I wrote to his secretary, she advised me to get a referral to the prof from my GP, which again I managed but with resistance. And as a result, I first saw the prof in March of 2018 to be told I was actually an ideal candidate for HIFU and he would readily accept me as an NHS patient. Clare Delmar: Wow. Paul Sayer: And I then went to have some updated scans at Imperial College. I was in theatre under a general anaesthetic for a couple of hours and that evening went home with a catheter fitted, basically. One week later I returned for the removal of the catheter, a quick check up and they said all appeared well. So basically go and get on with my life. Clare Delmar: So you had quite an experience and you obviously built up quite a foundation of knowledge. How did this lead to the founding of Prost8? Paul Sayer: I previously worked in the charity sector organising major events and consulting for charities, everything from a major HIV charity through to Help for Heroes for more than 15 years. Ironically, I'd taken a break at that time for a couple of years to help my son in his technology business. Having come through the cancer, I kind of felt the time was right to get back to what I knew. Explained my plans to Professor Ahmed, and was shocked to find out that almost 12,000 men every year with a low level, treatable prostate cancer like mine were being given the same invasive treatments as those with advanced cancer. So that was the driver. Clare Delmar: Absolutely. Paul Sayer: All those men were suffering life changing side effects, it just wasn't necessary. So that's what drove me to go further. Clare Delmar: Well, that certainly sounds like one of the most significant things. But has there been another very significant thing you've discovered about men receiving prostate cancer treatment in the U.K.? Paul Sayer: Yes, that basically the same journey I had really, that they've gone through the procedure of visiting their urology department, but being offered nothing more than the tools that the hospital has in its toolbox, basically, which is usually watch and wait with a few hormones, radiotherapy for five weeks, five days a week, or surgery to remove the prostate. I started looking around to see where men could get treatment for focal therapy if they did find out about it, and I was even more shocked to find that they were literally only a couple of NHS hospitals with focal therapy equipment in the entire UK, and they're only in London and the south east. There's fortunately private facilities such as yours, but that's obviously not accessible to everyone. And I know that some hospitals

rented in equipment for a few days a year, but for the average man with prostate cancer, they'd never even be told that they had that less impactful option. Clare Delmar: So, yeah, quite. But equally, I mean, you must have some thoughts since you've set up Prost8 and talked to men that had experienced what you'd experienced, that they don't really have the knowledge or the awareness to even ask the right questions. Paul Sayer: They don't, no, that's the trouble. I guess our mission statement, if I was to say, is just to help men to live the best lives possible after prostate cancer. And that means they need to know the best treatment options that are available to them. Clare Delmar: And what's the reception to that? I mean, on the sort of prospective patient side, do you feel that men react in wonder, in horror, in gratitude for the awareness you're raising? How do they respond to the fact that there is something else that they haven't been told? Paul Sayer: Well, most of them, like myself, they're quite shocked that they were never told this at the point of diagnosis. We've had quite a bit of reasonable national press coverage in the last year, sort of in the Times and the Mail on Sunday.... Clare Delmar: Indeed, yes. Paul Sayer: ... and men have picked up from that. So very luckily, the Imperial College London have taken quite a number of men that we've managed to redirect away from their local facilities to be given HIFU treatment there. I know a couple have also gone with the private route, so we're having an impact along the way to get people better lifestyles. Clare Delmar: And why do you think that focal therapy doesn't get the attention it deserves? Paul Sayer: That's a good question. I think the NHS has invested heavily in recent years in the traditional methods, shall we call it, so they've upgraded radiotherapy suites dramatically at great cost. And I think that they are too keen at the moment to get the best value out of those rather than looking at the alternatives out there, especially when you think that for focal therapy, it's a fraction of the cost to install the equipment, one day stay so there's no hospital stay involved, and recovery times are phenomenally quick and the ongoing care is almost nil. And you certainly can't say that about radiotherapy or surgery. Clare Delmar: No, I mean, you're absolutely right. And then not to mention that, you know, with minimal or zero side effects, you don't have the follow on or associated problems that you might have that would require someone to seek further treatment. Yeah, the economics of it, I totally agree, seem to really be one attraction, certainly for a hospital, not necessarily from the patient's point of view. But do you think that's really the main reason or do you feel it is anything else you've learned in your work in the last two years? Paul Sayer: There's a lack of knowledge right the way through from GP's to urologists, basically, that some have a vague recollection in their periphery that there is another option out there. Some will have done the usual thing, gone to the Internet, found out that the information is probably 8 to 10 years out of date, and it's talking about it being a trial and suchlike. So as a charity, our job is basically to get that knowledge out there from GP through to urology department. So when they rock up at their GP or the urology department, they can ask, they can say, no, I know there are other options and that's the problem. Men turn up and they don't have a clue other than what they're told and they trust what they're told. Clare Delmar: Yeah, I mean, that's an interesting point. I mean, are you getting any sense that that you're breaking through? Paul Sayer: We've had an incredible number of calls during the COVID period from the men who have just been dropped out of the NHS, basically, and can't get anywhere. Clare Delmar: Yes. Yes. Paul Sayer: But the ones that are coming to us when we're pushing them back towards their urologists and sometimes their GPs, we are now seeing that they're prepared to give them referrals on to, as it has to be Imperial College or someone like yourself at the moment. They are getting the referrals now, whereas in the early days, going back to a year or so ago, the resistance was incredible from the medical profession. Clare Delmar: So do you think that, just kind of pulling the last two strands together, that as the NHS moves into a post COVID recovery phase and has to address quite significant backlog of patients, do you think that focal therapy might have a new place in prostate cancer? Paul Sayer: I think it's crucial on many fronts. I mean, not just the fact that it gives men a lifestyle following their treatment, but in terms of cost for the NHS, it's got to be a better option. Clare Delmar: Do you think that that's resonating with the population and with the NHS, or do you think that the driver is really the patients being more informed and having the confidence to ask more for alternative treatments? Paul Sayer: I think it's going to be a combination of many things. We're working with Imperial College and other departments like theirs to start lobbying within the NHS and where possible and I suppose just make a big nuisance of ourselves until someone listens. Clare Delmar: And how about follow up? I mean, do you find that people who've had focal therapy have actually I mean, in addition to being relieved that they're disease free with no side effects, do you think that they've also placed lots of gratitude in you and your campaign and may really help become advocates themselves? Paul Sayer: They do, yes. Some people just disappear off the radar and get on with their lives because they've got what they wanted. We have a few who are becoming almost ambassadors for us now who are pushing that message and are going

back into the NHS to let them know what their outcome was compared to the one they were being offered. Clare Delmar: So, Paul, how do people then find Prost8? Maybe you can just run through... Paul Sayer: Yes it's on social media, mostly as Prost8, P R O S T 8, again. We have the website, which is prost8.org.uk or we have our telephone line, which is 0203 8580848. Clare Delmar: And if somebody listening to this decides to get in touch with you, what can they expect on first engagement with either you or one of your team? Paul Sayer: The first thing we do is make sure they're aware of the choices they have. We provide them with the information they need to return to their urology department or GP to get referred to the right treatments they're looking for and we help them through that by keeping them informed of their rights within the NHS and wider as to how they can insist almost on these referrals. Clare Delmar: And by rights, are you referring to like the Montgomery ruling, for example? Paul Sayer: Yes, that's part of what we refer them to. So we give them quite a comprehensive package of information. Clare Delmar: That's really good to know. And really it's about... I mean there's a lot of information out there, as I'm sure you would agree. And when you are in a situation where you've just been diagnosed with prostate cancer, you're not always in the best place to absorb all that information. As I'm sure you'll agree... Paul Sayer: Certainly not. Clare Delmar: ...having the ability and the capacity to counsel men who are in that sort of state of mind and build that confidence, I think is really crucial in this. Paul Sayer: It is. We've actually got a campaign starting later this year, which is: Prostate cancer, Know your choices. Behind that is a huge campaign to raise some significant funds to start buying, donating and deploying focal therapy equipment into strategic NHS hospitals, basically. It's been an absolute pleasure talking with you and best of luck with Prost8 and the campaigns that you're that you're developing. Paul Sayer: Thank you very much. Clare Delmar: A link to Prost8 and it's social media content is available in the programme notes to this interview on our website, www.thefocaltherapyclinic.co.uk, where you can access additional interviews with patients and clinicians about their experiences with prostate cancer. TFTC Working in Partnership with The Harley Street Hospital <https://vimeo.com/442839009> We are delighted to have established a partnership with The Harley Street Hospital, offering our patients safe and timely access to focal therapy treatment. The Harley Street Hospital is situated at the centre of London's most prestigious medical district. Leaders in specialist healthcare and day surgery, The Harley Street Hospital offers the highest quality of personalised care and state-of-the-art facilities. Located at the Oxford Street end of Harley Street, The Harley Street Hospital is a short walking distance from both Oxford Street and Bond Street tube stations. As we are increasingly aware, the NHS is experiencing significant delays in cancer diagnostics, with limited access to facilities. If you are concerned about a prostate cancer diagnosis and have been unable to be seen on the NHS, we can help. Call our patient advocate team on 0207 036 8870. TFTC Consultants working at The Harley Street Hospital: Mr Raj Nigam Consultant Urologist Mr Tim Dudderidge Consultant Urologist Mr Marc Laniado Consultant Urologist <https://vimeo.com/440971720> Treating the Whole Man for Prostate Cancer In a recent On Focus interview, TFTC Consultant Urologist Raj Nigam used the term "Whole Man" in describing treatment decisions for men with prostate cancer. By this he referred to the multiple aspects of a man's health and lifestyle that come into play when he undergoes any form of treatment, and which taken together are crucial for any chosen treatment to be successful. Broadly, these can be categorised as physical, mental, and behavioural. By far the most important aspect of a man's health in any treatment decision will be the cancer itself – its stage, its location and its aggressiveness. Men with advanced or metastatic prostate cancer will face very different treatment decisions than men with early stage, localised cancer. But other aspects of physical health matter too – comorbidities, or other types of disease that are or have been present in a man's body will impact the safety and success of a particular form of treatment. The mental health of a man diagnosed with prostate cancer will also impact this. In a recent On Focus interview, TFTC Consultant Urologist Marc Laniado emphasises the importance of discussing mental health issues with his patients, and giving men "permission" to talk about how they feel and their ability to cope with having prostate cancer. When it comes to treatment decisions, many men are not counselled about long-term side effects of individual treatments, which can impact mental health. "While they want to get rid of their cancer, they don't want to lose sexual or urinary function. It's a balancing act, and men are best able to cope with this when they have the information they need at the right time and in the right place". A number of organisations are specifically addressing the mental health needs of cancer patients, and one of these is a charity called Working With Cancer. WWC recently published the results of a Dutch survey which specifically addressed mental health in patient recovery. As they point out, "One of the things those of us who have had cancer tend not to discuss with friends, family and especially with our employers is that the emotional and psychological impact of

cancer is often as great if not greater than the physical consequences of treatment.”And finally, behavioural patterns in a man’s lifestyle will often have a significant impact on the response to treatment decisions.In a recent On Focus interview, Alan Doherty of the Birmingham Prostate Centre discusses patients undergoing Active Surveillance who find complying with continual diagnostic tests a behavioural challenge and one that many cannot sustain.In these cases, the treatment will not be successful (or even safe if a man refrains from attending testing appointments).Understanding what a man is capable of behaviourally and what support he has to sustain successful behaviours is crucial to a positive treatment outcome.Understanding the physical, mental and behavioural aspects of our patients’ health is central to our approach at the Focal Therapy Clinic, where we engage and treat the Whole Man.A recently published survey of European men examined how different prostate cancer treatments affected quality of life.The men surveyed had undergone radical prostatectomy, radiotherapy and active surveillance.Focal Therapy was not included, and had it been we would have a much fuller picture of treatments and their impact on quality of life.But by its absence, focal therapy stands out in this survey.Active Surveillance performs best on many quality of life measures, including erectile function, continence, and fatigue.However, in addition to focal therapy, the survey omitted two things:Compliance: did the process of complying with the treatment impact quality of life?Mental health: how did the treatment impact patient mental health?On these quality of life aspects, Active Surveillance often scores quite poorly.As Alan Doherty, Clinical Director at the Birmingham Prostate Centre, suggests in our recent On Focus interview, patients undergoing Active Surveillance must comply with a sustained level of diagnostic activity, and many aren’t prepared to continue this indefinitely.“The cancer isn’t going to go away under AS”, says Alan, “and this can cause needless anxiety in some men.If a curative treatment exists that is safe and effective, as is focal therapy, why wouldn’t you use it?”TFTC patient Perry Letcher also has strong views on AS.In his case, described with great honesty in a recent On Focus interview and in his own words here AS didn’t accord with his personal mental and physical needs.A committed triathlete, Perry admits that he “needs to be in control” of all aspects of his life and is prone to anxiety.“I needed to feel in control, not that the prostate cancer was in control of me.”TFTC Consultant Urologist Raj Nigam sees this all the time.As he states in his recent On Focus interview, “Too often AS is prescribed without an understanding of the whole patient context, or of the ‘whole man’”, says Raj.“Mental health is as important as physical health and must be investigated before proceeding with any treatment.”The main issue today – as compared with five years ago – is that a treatment for prostate cancer exists that is continually improving in its efficacy and availability, and incurs minimal, if any, impact on quality of life.This is focal therapy, and The Focal Therapy Clinic is proud to be a world leader in its continued development.Gogs Gagnon: Prostate Cancer Warrior and Author Writing from the heart about his experience with prostate cancer Prostate cancer survivor and campaigner Gogs Gagnon discusses how writing and promoting his book "Prostate Cancer Strikes: Navigating the Storm" served as a catharsis on his personal journey.Gogs shares insights on a range of learnings and experiences, including how to challenge diagnostic information and treatment recommendations.Gogs has become a social media phenomenon - find him at his website, on Twitter, on YouTube, on Facebook and on Amazon.Press play in the audio player below to hear the interview.Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.Claré Delmar:Hello and welcome to The Focal Therapy Clinic.And in this audio series, I’m going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about.Earlier this year, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK.In the sixth of our series, I’m speaking with Gogs Gagnon, a prostate cancer survivor and campaigner based in Vancouver.Gogs has shared his journey through a book published last year that is currently the best selling book on prostate disease on Amazon in Canada.“Prostate Cancer Strikes: Navigating the Storm” has made Gogs a social media phenomenon advocating for men with prostate cancer.Gogs, thank you so much for joining me.Gogs Gagnon:Oh, thank you very much, Clare, thank you for having me.Claré Delmar:And all the way from western Canada?Gogs Gagnon:Yes, that’s right.It’s a beautiful, sunny day.Claré Delmar:First of all, I just want to say congratulations on the book, which I have read and even notated.Gogs Gagnon:Well, thank you very much.I’m just so pleased that it’s helpful for lots of men and their families.Claré Delmar:So tell us what you were aiming to achieve with it and what’s transpired so far since it’s been published.Gogs Gagnon:Well, I have to tell you, when I was first diagnosed, I really had no plans to write a book.It was quite devastating when I was in the office and I heard the doctor tell me that I had cancer.And basically it was just really for me, it was a private journal of my doctor’s appointments and things I was feeling, the test results.And over time, a lot

of my friends and family, they kind of asked me how I was doing and I decided to share some of my journaling with them. I was a martial artist and it really hit me out of the blue, I had no idea what prostate cancer was. And hearing it was just so shocking, especially since I figured I was in good health. Clare Delmar: So what lead you to get the diagnosis? You said you were surprised, so you did you have symptoms or... sounds like you didn't have any symptoms. Gogs Gagnon: I had no symptoms of any kind. Basically, I lived a healthy lifestyle and I realised that I needed to have annual physicals, annual checkups. I went in for my blood work and as I did every year for all the other things that they do, cholesterol and all these other checks. And my doctor told me that he wasn't too concerned about it because it was only my first reading. So he still wasn't too concerned, but he decided to send me off to a urologist just to see what they thought. And at the time, I had no idea – you'd kind of learn as you go... And this was one of the reasons why I wanted to write the book to help men know ahead of time what to expect and the questions that they should ask. Because at the time when I had my biopsy, I didn't realise it was just a blind biopsy, meaning they pick just random samples of your prostate where they think cancer might be. I didn't realise that because it's random, they could simply just, you know, miss the tumour. Clare Delmar: And why didn't you have an MRI before that biopsy? Gogs Gagnon: I think that's just standard protocol and it might come down to cost through our insurance company. So what happened is I was sent on my way and my doctor recommended that I continue with PSA testing. And then when I was 57, my doctor at the time was... I actually changed doctors because we had moved... my new doctor examined my charts. So I went for an MRI and the results came back as a significant anomaly that was suspicious of high grade cancer. So now it was recommended that I have another biopsy, but this time they knew where to target. And that's the question I was I had the devastating news that I had cancer and so it was quite a process, and I'm really thankful that, you know, my doctor recommended that I continue my PSA testing because it turned out that my cancer was in the final stage before breaching the prostate. So most likely, if I would have not had that PSA test regular, my cancer would have spread without my knowledge. Clare Delmar: And another question is, back in the start of that five year period when you had the first so-called random biopsy, do you think that if you had had an MRI then. You know, if it was the size of two golf balls probably four years ago, it would have shown up on an MRI. So what that means is my first biopsy missed the tumour and just let it continue to grow undetected. And because I had no symptoms, most likely by the time I had symptoms, it would have spread, especially since I was already at that final stage before breaching. Clare Delmar: I know you talked about this in the book and that's, you know, again, part of your journey that's really helpful to others. But most of all, there's a real human focus, which is, of course, you and what you were experiencing emotionally. I decided that it was important that I detail my entire journey and include all the intimate details and not to leave anything out. I thought, well, what's the point of writing a book if I don't just get everything off my mind? And I was really, really focused on writing from the heart and ensuring that all my facts were correct. I probably read at least 30 to 40 different books on prostate cancer. Clare Delmar: Wow. Gogs Gagnon: And talked to dozens of cancer patients and cancer survivors. And I wanted it to be something that I would want or would have had, if it was available to me at the time. Clare Delmar: And that comes out. I mean, there's, for example, a very strong message about screening and recognising that screening programmes differ considerably between places and systems. I guess my question there is, what do you think is necessary to get more men screened for prostate cancer? Gogs Gagnon: Well, I think awareness is a huge thing because I know so many men who haven't seen a doctor in the last 20 years and they don't know what their blood pressure is. So I encourage men to at least go to the doctor and have an annual physical head to toe just to get your heart listened to and everything. But most men, they don't know what prostate cancer is. Clare Delmar: Well, I've noticed that you've become quite a social media sensation. And do you think social media can help men and their families to access the information and support they need? Gogs Gagnon: Well, absolutely, social media can be a very powerful tool, but a word of caution that it can be a little overwhelming. And there's so much information out there that I think it's very important that anyone who is using social media or the internet to ensure that the sources of the information are coming from a reliable and well-known site or person. Clare Delmar: Absolutely. Gogs Gagnon: There's just there's just so much information out there you could get lost. So sticking with the well-known reputable sources is strongly recommended. Clare Delmar: Well, your book has been very much advocated by quite a number of highly reputable clinicians and hospital groups and patients. But what's interesting is you and the book have become sort of one and the same. Gogs Gagnon: Well, that's quite a compliment. Thank you very much, because the book really is my heart and soul, and I am just overwhelmed by the response. I've had messages from all different parts of the world from not only doctors, but other

patients. And one of the things that I really wanted to ensure that men were aware of their options, first of all, they're aware they should be aware of their health. They should know what their different scores are, their blood pressure, the PSA, and they should get regular checkups. And also, I wanted to make sure that they were aware of all the different pitfalls that I went through so that they could be better prepared for dealing with all the different health challenges that they may encounter.

Clare Delmar: One of the frequent comments in the multitude of positive reviews I've seen of the book is that you give men the confidence to knowledgeably engage and even challenge their doctor's treatment decisions. And the one thing that I've been thanked for is... most men, as I said, they really don't know a lot about their health, but they also really don't know that there's a lot of different treatment options available. So it's very important that men realise that there's probably dozens of different options that they can do and even active surveillance if safe and if appropriate in a particular case is an option for them. I really do encourage men to not only question the doctor so that they understand what the doctor's saying, but they can also question their test results. It's really important... So I list a lot of different questions and things to consider.

Clare Delmar: Yeah you do, I mean, even on the MRI, you know, which is now I mean, even since your first... you know, your first PSA test has become pretty much the standard of care. But even the variability in how the MRI is interpreted and the variability in reporting can make, as you say, you know, can make a big difference in the next stage of the process.

Gogs Gagnon: Oh, absolutely. And that, you know, I put in the book as well as I put in a lot of different reflections on if I had to do this over again. And this is so many things I learned after the fact that I would like men to know before, such as even a prostate biopsy, for example, the tissue that's removed from the prostate is sent off to the lab to a pathologist who then gives it a Gleason score. But I didn't realise at the time that the Gleason score is really a manual assessment based on the skill of the pathologist. So a lot of little helpful tips.

Clare Delmar: Just what are the other... the top three tips that you would like to share with our listeners now, the first one being to question the Gleason scoring, can you add two more?

Gogs Gagnon: Why sure, I think the first one really was, it could be in any particular order. But one that's really up there is when you're first diagnosed is to recognise that you're probably gonna be in shock just from hearing the word cancer. And then also to make it three... another top one is to make sure you talk to more than one doctor. Don't just talk to the surgeon or don't just talk to the radiation oncologist, talk to many different doctors and get multiple opinions and also talk to many different people who have already gone through it. And as I said, the way you provide that advice in the book is with lots of good humour and very diligent evidence gathering, which is a really fabulous recipe for, you know, consuming very important information. Now the book, once again for our listeners is called "Prostate Cancer Strikes: Navigating the Storm".

Gogs, can you just say a final word to our listeners, how they find the book and how they might find you on social media.

Gogs Gagnon: Oh, yes. So you can borrow and also available at a lot of bookstores as well.

Clare Delmar: That's such good news to hear that it has been so widely spread and so become so widely available. And for our listeners, we'll make sure that all of those links that Gogs has just talked about will be available on our website, too. It's been an absolute pleasure talking with you and good luck with the book.

Gogs Gagnon: Thank you very much, Clare. Thank you so much for the opportunity to be on your programme.

Clare Delmar: And as I said before, a linked to Gogs's book and his social media content is available in the programme notes to this interview on our website: www.thefocaltherapyclinic.co.uk where you can access additional interviews with patients and clinicians about their experiences with prostate cancer.

Active Surveillance and Anxiety : Perry Letcher's Story

The Focal Therapy Clinic patient Perry Letcher discusses his experience with early-stage prostate cancer and why he moved from Active Surveillance to Focal Therapy in his treatment. 'One of the big issues with Active Surveillance is that one's perception changes over time' Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870.

In this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this year, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. In the fifth of our series, I'm speaking with Perry Letcher, a recent patient at The Focal Therapy Clinic who was diagnosed with early stage prostate cancer in 2018 and spent a year on active surveillance before having his prostate cancer treated with focal therapy earlier this year.

Clare Delmar: Before we launch in, maybe you could tell us a little bit about your background and your quality of life at the time of your diagnosis. In 2010, I recognised that I was an alcoholic, and fortunately got a lot of help on that front and have been sober ever since. So I guess this has a slight bearing just in terms of the mental side of this, because sobriety is probably now the most important thing in my life, basically, because if I didn't have that, I wouldn't have anything else, I

wouldn't have my wife, I wouldn't have the children in my life. I was also fortunate that I owned and ran pretty successfully a little business in Lymington. And it enabled me to... I've loved every minute of retirement and it's enabled me to do all the things that I wanted to do over the previous 25 years and didn't really have time for. Perry Letcher: Well, in early 2018, I noticed that I had got changes in urinary habits and I was getting up in the night a lot more frequently than I had been before. And with prostate cancer in the news and everything else, I tootled off to see my GP, that in turn led to a blood test, PSA, and that was a little bit elevated. Clare Delmar: When you say that was elevated, was that it relative to a previous test or benchmark? Perry Letcher: No, my memory tells me it was about four point six, which isn't particularly high. It's quite a problematical thing in a way, because it is difficult to know how to respond to these things. The National Health Service, which when I retired I gave up all my health insurance and everything else because we weren't fanatically wealthy. So I was in the NHS and I take my hat off to the NHS because I think they do an absolutely superb job in very challenging conditions. Clare Delmar: So walk us through a little bit about what would happen so we get a sense of what this means. And so they said, you know what, we'll do another PSA in I think it was four weeks later and I had that PSA and that was further elevated. So the GP then referred me to a urologist and of course suddenly you're into fast tracking on 14 day response for cancer, which is quite scary when that happens. And I went off and saw one of the team at Southampton on the NHS, who said, this is what we will do. Very promptly after that you'll have results and we'll be able to tell you exactly what's going on. I was then suddenly told before I had the MRI that the MRI would be booked in about four weeks. And depending on the results of the MRI, they would then book in the biopsy, but that would be another four weeks after that. So suddenly, the time frame that I had originally been told and accepted was moving out very rapidly. And at that stage, because I had things in my diary and I wanted to go abroad to cycle, and one thing and another, I thought, actually, let's do this investigation privately. Clare Delmar: OK. Perry Letcher: I was told that I was a very good candidate for active surveillance. Perry Letcher: At the time I was relieved because I had been worried that I had a life threatening illness. Perry Letcher: And I was suddenly told, actually, this isn't, in your case, a life threatening illness. And at the time, you know, when I was told active surveillance, that seemed perfectly logical and I was perfectly happy about it. Clare Delmar: OK. Perry Letcher: I think one of the big issues with this is that one's perception changes over time. Perry Letcher: And I think that it's very easy for the NHS to say, you know, he's on active surveillance and that's OK and we'll just leave it. Not realising that that person can have massive changes in their own feelings about how it goes. You were put on active surveillance and as you described really well and explicitly how you felt initially, and then was there a programme for the active surveillance. Perry Letcher: One of the issues is that the biopsy I've had, which was a trans rectal, upset me physically - Clare Delmar: OK. Perry Letcher: - with the result that three times I ended up back in the hospital to check for sepsis, which they said I haven't got, but I'd got terrible flu type symptoms and I hadn't got sepsis - they did a couple of blood tests and one thing or another. And of course, that did not leave me feeling anything other than terrified at the prospects of getting a biopsy. But my consultant said don't worry because this will be monitored, you know, in six months time, we'll do another PSA. So we won't be biopsying and hopefully we'll be able to do this active surveillance just on MRI and PSA for a while. So that left me reassured because I was thinking actually if I end up having to have a biopsy every year and it wipes me out for two months, I'm going to... So of course having paid for the initial consultations and thinking I was going on to active surveillance, which would be probably an MRI every year for the rest of my natural, I thought I'd get that done on the NHS. And again, as far as I was aware at that time, and it may be that I'd misinterpreted or anything else, being on active surveillance meant that... I was told that at any stage I wished to come off active surveillance I could. That the cancer could be treated with radical prostatectomy or radiotherapy, but that actually that would be a very high risk thing to do with a cancer that appears to be relatively stable and pretty insignificant, and which might do nothing for quite a long time or indeed forever, the reality is, yes prostate cancer kills far too many people, but more people die with it than from it. Perry Letcher: The issue, of course, is I was quite young, but also being quite young, still enjoying an active sex life, not wanting the prospect of something interfering with that or indeed with incontinence was pretty bleak. So we tootled along like that for a bit over a year, I suppose, because September 2019 I had an MRI on the NHS and again we had the issue of over promising and under delivering. If you want a happy customer or a happy client under promise and over deliver, not the other way round. If you tell someone when they are having an MRI that they'll get the results in about a week. If you tell them that they'll get the results in 14 days and you provide them in 13, they're perfectly happy. And time and again, I think this is, you know, and I think it's the one thing that I think the NHS could actually up its game on remarkably cheaply, is to not over

promise. You know, the waiting game... Perry Letcher: When I had this MRI, I was expecting the results in a week because that was what I've been told when I had them. I then phoned up the urology clinic in Southampton on the NHS and was told, no, there's no way we can have them now, that it would be two weeks. I phoned them after two weeks and I said, oh, yes, well, of course, I don't know whether they've come in yet, but in any event, the multidisciplinary team would have to review them before we could do anything and say anything. And I was fully aware that it was affecting my mental sobriety and, you know, my mind can take me to some fairly dark places. And I truly believe that because when I was an active alcoholic, my mind took me to some very, very dark places to the point where I was seriously contemplating ending everything. Clare Delmar: Wow, so you mean, interestingly, you've sort of, you know, been there before and in even feeling this anxiety in this case was probably, you know, you'd be able to fight it more than most. Perry Letcher: The other interesting thing, actually, because I spend quite a lot of my time trying to help other people in the same unfortunate situation that I was in. And as a result of which I know a lot of alcoholics who are in recovery and some who aren't and I know a number of them who had prostate cancer. There were complications because one of my MRIs had been done on the private sector and one on the NHS. And I said to Elaine, do I consider a radical prostatectomy and a 50 percent chance, Elaine being my wife, that, you know, I could end up with erectile dysfunction and... but do I take that chance in order to safeguard my sobriety and my sanity? Perry Letcher: I was sending yet another email to somebody and I spell checked "surveillance", with Google, and it came up with active surveillance on the Google search, and the first thing there because somebody at the focal centre is very good with search engine optimisation. Clare Delmar: OK. Perry Letcher: And the next thing I found is I was reading something that says, you know, are you happy on active surveillance? And he just confirmed what was on the website, basically, which is that actually... I had appreciated that there were other alternatives. I had thought that they were still in the experimental stage because that was the impression I got from I guess partly the press, but also maybe from the NHS, I really don't know. Clare Delmar: So Perry, let me just ask you, at this stage, had you heard of focal therapy before? Perry Letcher: Yes, I had, effectively, I mean, I'd heard of it as the high intensity ultrasound. But my understanding, and I guess it may be that... it may be that I had heard something about it way back in early 2018 when I was first diagnosed, because I think I read something in the newspaper saying they were doing trials in Bristol. This wasn't an insurance thing, this was, you know, I may be retired and sold a business, but actually part of that deal was that my pension was going to hopefully have to last a very long time, so this was not inconsiderable sums of money. Clare Delmar: Sure Perry Letcher: And if you haven't got your health, you haven't got anything. But I thought, well, actually, I do need to just find out from the NHS whether it's okay to take this course of action. But of course, that timing issue on this was, as always, that you ping off an email to the NHS and you get a response two weeks later. Perry Letcher: And if your email is saying, have you got any... you know, I'm seriously considering having focal therapy, have you got any concerns about that? First of all, my consultant phoned while I was out and spoke to my wife and terrified her actually, and said do you realise this could make your husband impotent and he might never cycle again and all sorts of other stuff. Would you rather I had a radical prostatectomy on the NHS or radiotherapy on the NHS or that I had HIFU? I know it's not a service that you provide in your private clinic, although I was seeing him on the NHS, but actually it's not about staying on active surveillance. Perry Letcher: Because by then the PSA had gone up again and Tim said, you can see it here. And that's why I said to the original consultant, look, you know, it's not about active surveillance or HIFU or radical prostatectomy or radiotherapy, because active surveillance is no longer something that I am prepared to put up with. Perry Letcher: And he said, well, actually, you know, under those circumstances, then you probably should be looking at HIFU. Clare Delmar: Wow so they did concede that, but yet were not able to offer it to you on the NHS. Perry Letcher: Because, you know, someone says this is my recommendation and your mind is saying that actually I'm not mentally strong enough to put up with that. So you were you felt that, you know, you were recommended active surveillance but because you weren't comfortable with it, you were somehow deficient. Perry Letcher: Without taking the enormous risks of radical prostatectomy and without hopefully prejudicing that course of action in the future. Perry Letcher: Which, of course, one of the problems of radiotherapy, of course, is that that can make it difficult to do a radical prostatectomy later. Perry Letcher: So I had the HIFU treatment on the 5th of December at the Spire and... Clare Delmar: With Tim Dudderidge? Perry Letcher: Well, and also actually since you and I last spoke, I've had a further PSA and it's down even further. Perry Letcher: We know that the news is all good, but even if the news weren't good, I would still feel that at least I had done what I could. Because it could all have been more difficult, although actually Southampton's been remarkable. Perry Letcher: But even if this doesn't have the ending that I would

like it to, which is just, you know. It's totally changed my mental outlook... Clare Delmar: You've gone from being a permanent patient to being someone who is cured? Perry Letcher: You're very welcome Clare, and as I say, I still say I'm the luckiest man around. If you would like to learn more about Focal therapy and engage with patients who have chosen to undergo focal therapy instead of active surveillance, please visit our Web site at www.thefocaltherapyclinic.co.uk, and from me, Clare Delmar, see you next time.

Prostate Cancer Patients Must Have Access To High-Quality Imaging Many in the prostate cancer community will have reacted with grave concern over yesterday's news that MRI scanners and the expertise needed to use them are in short supply in the NHS as we emerge from the Covid-19 pandemic and face a backlog of cancer patients. MRI scanners are not only an essential part of diagnosing prostate cancer. They are the very reason that prostate cancer patients today have more options in their treatment, and are the foundation for non-invasive procedures. Not only does the MRI allow for us to see where the cancer is, measure how big it is, and determine how severe it is, it forms the basis for the entire diagnostic and treatment pathway. To understand its targeted treatment, let's work backwards through the diagnostic supply chain. The biopsy plan is done by an expert radiologist who reads an MRI scan and applies technology and knowledge to identify areas of interest for biopsy. The MRI scan requires a radiographer to ensure the patient is best positioned to capture the required images and to operate the scanner. The scanner needs to be calibrated a certain way to maximise image capture, and needs to be maintained to ensure consistent quality. The consulting urologist that makes a diagnosis of prostate cancer and recommends treatment based on its scale and severity is relying on all of this information in a consistent, comprehensive and straightforward report, something that is often unavailable in the NHS. Focal Therapy and Active Surveillance alike depend on seeing cancer with great accuracy. Without the capacity to do this, we risk regressing back to the dark days of once-size-fits-all radical treatment that cures the cancer but damages the man. That's why at TFTC we maintain the highest standards of MR imaging, using world-class radiologists who report with unmatched accuracy and precision to our consulting urologists. Without good imaging, we have no focal therapy. Read more on this topic in this article in The Guardian.

Alan Doherty: Why HIFU Focal Therapy is Preferable to Active Surveillance Consultant Urologist Alan Doherty from the Birmingham Prostate Centre discusses the advances in imaging and radiology that now make focal therapy a preferable treatment to Active Surveillance. Press play in the audio player below to hear the interview. The benefits of focal therapy for treating prostate cancer Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. And in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this year, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. In the fourth of our series, I'm speaking with Alan Doherty, one of the UK's most renowned prostate cancer specialists and clinical director at the Birmingham Prostate Clinic. Alan has completed one of the largest case loads of prostatectomies in the UK, undertaking more than 3000 operations. He's recognised for his expertise in nerve sparing techniques, reducing the risk of erectile dysfunction and incontinence from prostate cancer surgery, and has published extensive results from his nerve sparing procedures. Recently, he was voted one of the UK's top ten prostate cancer specialists in a national poll of consultant urologists published in The Daily Mail. Alan, thanks for joining me. Alan Doherty: Hi, Clare. Clare Delmar: Wonderful to have you on our audio series. I'm going to dive right in with a little bit of irony, I mean, having just described you as a leader and innovator in radical prostatectomies and other so-called invasive procedures, it's kind of amusing that I've asked you to chat with me today about non-invasive procedures like focal therapy and active surveillance. So can you tell me how you came to embrace focal therapy into the treatments that you offer your patients? Alan Doherty: Well, it's a really good question. I think prostate cancer has such a multitude of different pathways and patients differ in how they value various outcomes. And it's not for me as a clinician to just offer one form of treatment, it's for me to offer a range of treatments which will be appropriate to the patient and their problem. And I think focal therapies have some advantages, but also some disadvantages. Clare Delmar: And why has focal therapy in your practice become more popular? If I could use that word, but do correct me if that's not the right word. Alan Doherty: I think it's because focal therapies, particularly HIFU, which stands for high intensity focused ultrasound is evolving and we are getting a better understanding of how it works and how we can deliver it and the benefits and the risks involved. So my patients are now able to perhaps understand what the advantages and limitations are a bit better. I mean, I have been doing HIFU for well, gosh, must be seven or eight years that we've been I've been involved in HIFU. I think the treatment was offered to perhaps too broad a spectrum of

people. It was before the day of MRI scanning and we can now perhaps better identify where the cancer is. So my enthusiasm has increased as we've got better understanding of it. Clare Delmar: So better imaging has clearly led to better diagnostics. And we can now see where prostate cancer lesions are and even measure how aggressive they are. And I think the people who are enthusiasts of focal therapy do put a lot of value on the MRI scan. Of course, it's going to be a good MRI scan and there are various levels of quality to an MRI scan. They assume that the machine is the machine and the answer is the answer. I think a really high quality MRI scan where you can identify the higher grade cancer does open up this whole chapter of focal therapy to allow you to pinpoint destruction of the cancer and yet not causing a lot of collateral damage, which is what essentially gives the side effects to most treatments. Clare Delmar: So as well as opening up for focal therapy it, the better the MRI, the better we can see this cancer. Does that mean now that it's a real option for some men and that we can literally watch them or surveil them, as the term suggests, regularly and closely? Alan Doherty: Well, that's very true. And yet you can also argue that if you have a treatment such as HIFU with very little co-morbidity, then why just watch the cancer go from a situation where it's not particularly dangerous to one where it is dangerous, when you could alter the natural history and at worst delay the progression or at best cure them? And I think people forget with active surveillance the monitoring does involve quite a lot of... the reasons it is called active surveillance because it is an active process. You have regular PSA blood tests, which of course can be stressful if the PSA is going up. You have numerous MRI scans which can be expensive and then sometimes you need repeat biopsies and so there is a strong argument that, you know, instead of putting people on active surveillance, well, you should consider treating the abnormal area. You think, well, why not treat that abnormality? I can see why, if the treatments available are potentially going to make your life miserable, that you might want to just monitor it. But if the treatments don't do that, then, you know, why not have it treated? Clare Delmar: We often find that patients come to us who are on active surveillance and it kind of comes to them a bit late in the game that the active, as you suggest this is on their part as well as the clinician. Alan Doherty: Well, I think people forget with active surveillance that, you know, what are we waiting for? It's a probabilities game. You go from a very high likelihood of being cured to a lower probability of being cured. Are you comfortable with a 70 percent? So in other words, the higher the PSA goes, the lower the likelihood of you being cured is. So it's all very well and good being monitored, but you have to understand the consequences of the monitoring. And the fact that it isn't quite as scientific as you might think – this is very much looking at a window of curability, which is closing the longer you monitor it for. Now, that doesn't mean that you necessarily will die of prostate cancer if you missed the window of cure, because we can control cancers very well with hormone treatments, radiotherapy, chemotherapy and lots of new treatments that are coming out. So, you know, when people see you're not going to die of prostate cancer if you go on to active surveillance. But you may end up having lifelong treatments, which had you gone for a curative treatment, that wouldn't be the case. Clare Delmar: Yeah. Some people often have told us, too, that one of the challenges they face under active surveillance are more behavioural or psychological. I think the average time people can stomach active surveillance is about two years. Clare Delmar: Have there been studies on that, or is that your observation? Alan Doherty: Observation, but also from studies, so if you look at studies like the ProtecT trial it's within the first two years that you tend to get that change. It's around two years where people just seem to have had enough of it and they say, well, fair enough, let's have treatment. So it's I suppose it's more observational than anything else. But certainly in the studies I've been involved with, I'm not surprised seeing patients at about two years saying enough's enough, the PSA has gone up and it's got into my head. And so, you know, sometimes people get sort of relief that the PSA has gone down a bit or was stable. But if the PSA doesn't and it's sort of slowly climbing up, which it tends to do over a two year period, you know, people just sort of say enough's enough, let's have treatment. Clare Delmar: So, like, let's just assume this two year period is an average of sorts. Would you say that there is a risk if you wait two years that, you know, the curative treatment that you mentioned might have to be more invasive? Is that something to warn someone on? Alan Doherty: Yeah, not only more invasive, but also more prolonged in that you've missed the opportunity to go for a curative intervention and instead you're getting a sort of controlling intervention. So every now and then, you're going to have someone who you thought was going to progress slowly, who progresses more aggressively. And that's where this window of curability starts to close in terms of percentage likelihood of cure. Clare Delmar: So you will suggest to patients that focal therapy is a real alternative for active surveillance? Alan Doherty: That's very much my philosophy, which is if you are prepared to monitor it, then, you know, why wouldn't you want to go for a treatment that could potentially cure you? Almost certainly will delay

the progression of it in that if you kill the majority of it, that's surely going to be helpful. Clare Delmar: And do most of your patients agree with that and take that action? Alan Doherty: Most of my patients will sort of get that. And I think, as I mentioned at the beginning, when it was used probably incorrectly and in too widespread a fashion, it's made some people wary. Certainly other urologists are a little bit wary of it and I think patients pick up on that. I think because of better imaging, as we said at the beginning, HIFU is going to become a bigger player. Clare Delmar: So a slight shift from this, but picking up on this whole idea of having to wait. How are the delays in the diagnostics and treatment for prostate cancer based on Covid-19 in the last few months, how have those delays impacted your practice and your patients' treatment? Alan Doherty: I think there are patients who were halfway along the diagnostic pathway and it all suddenly came to an end. And in that group, you know, I've seen patients who really got quite stressed by it because they didn't get to the stage where we were able to tell them whether this was an aggressive tumour or not or if they did have an MRI scan and it suggested that it was aggressive, they weren't able to go and have the biopsies to confirm it. So I think what's interesting is that a lot of patients won't have had their PSA blood test. Now, as you know, PSA is the way that we assess the risk of having prostate cancer. And the charities that used to do the PSA measurements, the GPs that would have done it as part of the sort of symptoms assessment. So there are probably people who just don't even know they've got a high PSA who will no doubt be found in the next few months or so. And I suspect that's quite a big cohort of people. So we've definitely had a big effect, the Covid. And I think that the whole process can be expensive for a self-funder if you include MRI scanning and biopsies and the like. Clare Delmar: So are you optimistic that the NHS will be able to pick up some of this? Or, how would you advise somebody listening to this who has an early stage diagnosis and has been delayed? Alan Doherty: First of all, I think these sorts of interviews are really helpful to patients to sort of understand the issues. And you can be very clear on what questions you're trying to ask when when you have a PSA blood test. I mean if you really think about it, the active surveillance group shouldn't really exist because, you know, if you have an MRI scan that is normal, you know, why we biopsying them? And if a patient is found to have a cancer and then you say we'll leave it alone, well again, that doesn't make sense, because before you biopsy them, you should say to them, what are you going to do if I find a cancer? And you say the likelihood is if I finally cancer with a normal MRI scan is that it's not gonna be an aggressive one. So why am I biopsying you? So I think patients really need to be first of all clear on what they're asking and what they're going to find. But if they decide that they do want to proceed. Am I optimistic that the NHS will catch up? Well, I have found in my experience that the NHS will not tend to have specialists who do nothing else but report MRI scans. And then when they do the biopsies, they don't necessarily do them in a way that I would say minimises false negatives. I think they're more obsessed about doing it in a way that is quick, easy. And for example, there are different ways and taking biopsies, you can do it through perineum but through one or two holes rather than through 20 holes. So, I think maybe, perhaps nobody's looking at the efficacy of the interventions and what they are trying to find. So, yes, I think patients need to ask that question to the urologist saying, how do you know the MRI scan's up to scratch? Will it serve my purpose? Clare Delmar: It's almost like a supply chain, you know, audit. Alan Doherty: Yeah. Clare Delmar: There are these key stages, as you say, that have a massive impact on the sequential stage. Alan Doherty: Absolutely right. People often get to the end of the pathway without even thinking about what they're gonna do with the information or how valid the information is. Clare Delmar: Alan, I really want to thank you for your insights. I think this has been incredibly helpful, certainly for me, but especially for our patients who are listening. If you'd like a consultation with Alan Doherty, please contact us at The Focal Therapy Clinic. And if you'd like to learn more about focal therapy and engage with patients who have chosen to undergo focal therapy instead of active surveillance, please visit our website at www.thefocaltherapyclinic.co.uk. Consultant Marc Laniado explains how Focal Therapy helps to reduce Anxiety and other Mental Health Challenges for Men with Prostate Cancer How the option of focal therapy might offer relief from anxiety The Focal Therapy Clinic Consultant Urologist Marc Laniado discusses the mental health challenges facing men diagnosed with prostate cancer, and explores how these are best managed. In this interview, Marc highlights the anxiety caused by perceived trade offs between curing cancer and losing sexual and urinary functions and suggests that focal therapy helps more men deal with this. Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Clare Delmar: Hello and welcome to The Focal Therapy Clinic. My name is Claire Delmar, and in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. In the third of our series, I'm speaking with

Marc Laniado, consulting urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatments for prostate cancer. Marc has been a vocal advocate for focal therapy from his base at Frimley Health, where he is prostate cancer lead at Wexham Park Hospital and has contributed to several pivotal clinical studies and trials on prostate imaging and focal therapy. Marc's known for the exceptional levels of understanding and empathy he develops with his patients and it's for this reason, we're going to talk about the mental health challenges he helps his patients to manage. And before we dive into mental health, specifically, can you tell our listeners what your journey was to becoming a leading practitioner and a champion of focal therapy?

Marc Laniado: Well, many years ago, of course, I went to medical school like everyone else, and I wanted to be a doctor to understand the human body, to be able to help people. I was very much involved in trying to understand why prostate cancer spreads from its local site in the prostate gland to going out into the bones. And then during my training, it seems like many years ago now, but we used to do lots of open operations to remove prostates and send patients for radiotherapy. And I was always struck by the seeming difference between the severity of the disease and the consequence of the treatments that they received. So I was always wondering how we could make our treatments fit the struggle or problem that the patients had. And so whilst I tried to improve my surgical delivery of treating prostate cancer through robotic prostatectomy, eventually, the keyhole way, there was always a feeling that I had that many of our patients probably could be helped by other means. And so I looked for treatments that could be focused literally on the cancer itself and an area around it, rather than necessarily treating the whole prostate. So the basis has been trying to keep men as healthy as they are with their normal way of life, treat the cancer, but not to give them so many side effects as we had experienced in the past.

Clare Delmar: And at that time, what was your sort of model of treating the disease rather than the gland or organ? Was there other treatments for other diseases and organs that you saw as sort of a beacon for this?

Marc Laniado: Well, I mean, perhaps people have heard about breast cancer. You know, breast cancer many years ago used to be treated by removal of the whole breast and tissue around it. Then it became apparent that you could just actually remove the lump itself and you get the same sort of outcomes after 10 to 15 years. That was really the paradigm that really made people think about maybe not treating the whole gland when treating cancer. And in our particular speciality, in urology, certainly when I grew up, I was taught to remove the whole kidney, for example, if someone had kidney cancer. But, you know, we now really try to just remove that part of the kidney where the cancer is itself and preserve the rest of the kidney when we do it. We now try to remove the cancer plus say a margin around it and preserve the rest of the organ, if at all possible.

Clare Delmar: And of course, this is all made possible by vastly improved diagnostics.

Marc Laniado: So, as you say, in the past, when we treated prostate cancer and many other cancers, we really didn't know much about it. We'd have an idea that cancer was there, perhaps because prostate cancer, because the PSA was high, we then we would examine the prostate, make a guess, perhaps if prostate cancer is present based on that alone and then do biopsies that the biopsies usually were not targeted because we didn't really know where the cancer was located. And then when we did the biopsies we might make a diagnosis of cancer, but really, we didn't know how much cancer was there. So because we didn't know the burden of the disease, we didn't know how much disease is present, we really applied everything we could to deal with it, which would be usually either surgery or radiotherapy. So in recent times, that's changed our ability to know where the cancer is located has improved dramatically since we've had the introduction of multi-parametric MRI. So if you imagine when a doctor sees a patient, if he examines a prostate, he has to put a finger in the back passage to check it. It can check the front of the prostate, the sides of the prostate, top end, the lower end, can look inside the prostate and it can literally see where the cancer is located in the vast majority of cases. So with that, with our ability to see where cancer is located, we can then now target our biopsies very carefully so we can sample the areas that look abnormal with precision. And when we do that, we can then make sure that our needles go in the right place.

Clare Delmar: So the fact that you have such precision biopsies and therefore a knowledge of exactly where the cancer is and how aggressive it is, that means you have better treatment options. In the past, we always did transrectal biopsies which were biopsies through the back passage which carried a great risk of infection. Those are biopsies done through the skin between the anus and the scrotum because there's very little risk of infection and we can reach parts of the prostate and couldn't find before through the typical transrectal route.

Clare Delmar: So that all sounds like there's been some major improvements both in the technology and actually in the actual procedure. So I guess the question I really have is, does that actually help or in any way hinder the anxiety levels in your patients when they are told that they possibly have prostate cancer?

Marc Laniado: Well, as you can imagine, yes it has

helped. In the past when someone had a negative biopsy before, many years ago, they still had about a one in three chance of having significant prostate cancer. Now, with precision MRI scans and precision biopsy procedures, we can say with almost 95 percent certainty someone does not have prostate cancer if they are negative. So now we can categorise into men who have low risk disease, which is very unlikely to affect them in their lifetime. So being able to stratify men into risk groups has helped men deal with the disease much better than before, and also has opened up many more options for treatment as well.

Clare Delmar: And in your own experience, what are the main mental health challenges, that a man faces when he is diagnosed with prostate cancer?

Marc Laniado: Well, although men come in with a suspicion that prostate cancer is present. Often it's a great surprise or a great shock that they find that prostate cancer has been diagnosed. And then to be given a diagnosis of a cancer that essentially is life-threatening is a big shock to the system. Some men take some time to recover and then want to react very strongly towards it and other men can cope quite well. It helps, though, when dealing with the disease, when we are able to give much more precise information about how severe it is and what treatment options there are. Often it was knowledge about treatments from the past, and they were very worried and anxious about the potential for problems such as urinary leakage or loss of erections. As you can imagine, men, their mojo if you like, about being male, about getting erections and the thought of potentially losing that would be very worrying for lots of people to have.

Clare Delmar: How willing are they to talk about this?

Marc Laniado: As you can imagine, men are somewhat reticent. So it has been an issue for many men.

Clare Delmar: And do they often involve their families in some of these discussions and ultimately their decisions on treatment?

Marc Laniado: Certainly when I see a man who is at risk of prostate cancer and is coming back for diagnosis, I always ask them to bring a member of the family with them. It's often that, you know, when you hear that you have cancer, that's the only thing you hear and you don't listen to any more information that's brought into the discussion. So a wife or a loved one or some other supporter, partner of any kind is very helpful for that men dealing with a diagnosis. And so we do encourage that.

Clare Delmar: And do you actually feel that that helps with various levels of anxiety?

Marc Laniado: Yes, I certainly think it does. So, yes, I would recommend that.

Clare Delmar: So basically the mental health challenges are around anxiety and depression. So if a man is diagnosed with cancer, for example, and then he's told that actually we're not going to necessarily treat it. So if we try to explain to men that this is a low risk disease, that in some cases, not always. You know, that time, if you imagine a man has to have a test, a blood test every three months or so initially in the beginning. And so there can be a lot of worry waiting to hear the next PSA result and similarly of all the other tests we might need to do whilst we're monitoring men so they might need another MRI scan after a year, potentially more biopsies. And each of those interactions can lead to more anxiety.

Clare Delmar: So it's interesting, Marc, because what I observe are two things with the patients we deal with. And how you present the information to them is almost more important than what you present because your state of mind and absorbing new information about your own situation, your own future is very much dictated by your state of mind. Shopping for a holiday or a car when you're excited to spend is very different than looking for treatments for a disease that you are facing that is making you fearful. So that I find this is something that we deal with men with anxiety and how we help them absorb the information. So you mentioned earlier about active surveillance and how some men actually would embrace that because they can schedule their tests when, where, how they're going to receive them, maybe even do things like look at the data. So I wonder how you see men managing some of this anxiety through their online searches and also through their choice of treatment.

Marc Laniado: So managing the anxiety, it helps to know more about the disease that they have and the likely impact of that disease. So what I often recommend patients do is to try and look at the site that gives probably the best idea of how well they'll do over time. And there is a site called Predict Prostate in which a doctor or a patient can input his variables regarding the prostate cancer. So, for example, their age, their PSA, what was found in the prostate biopsies, stage of the disease and their general health. And then on that website, they'll get information about the chance of dying from prostate cancer, chances of dying from some other cause, chance of surviving. And that's presented in a very clear way to patients so that they can see, for example, if they have a significant chance of surviving the disease without problems or they're more likely to get issues which will potentially cause problems for them over time. And it also helps them make a decision about whether, for example, they want to have treatment now or later. So making sure that they're looking at a whole body, all aspects of their lives, a holistic approach to their health and those aspects of things make life much better. Prostate Cancer UK has plenty of information which patients can use also to help guide them through their journey. And in fact, Prostate Cancer UK does consider depression to be an

important problem that men have to deal with when they're diagnosed with prostate cancer. The most important thing about, I think, dealing with cancer and when people are anxious or concerned about it, is trying to work out as much information or find as much information about the disease, how it's relevant to them. So if the problem is lack of control, then work out what aspects of that disease can I manage? But what you can do is influence those factors that can alter the progression of the disease. So weight down through diet and also by exercise, both are independently important in reducing the risk for cancer overall, but also probably the progression for prostate cancer. So we know that a diet rich in red meats and animal protein and dairy protein seems to increase the chance of prostate cancer development, but also the chance of it progressing, and possibly prostate cancer related deaths. But also, you can choose or help to choose what form of management of the disease you can have. Being informed about the various types of treatment can put you in a better position where you are controlling disease and disease is not controlling you.

Clare Delmar: And you would probably place focal therapy in that space.

Marc Laniado: Absolutely. So early on in the disease - so many of the patients we see who will have significant disease but many, many years of life to live do not necessarily want to have a life where they're constantly just being monitored. So focal therapy enables you to destroy or get rid of that part of the prostate where the cancer is located, again with a small margin around it. And by getting rid of the cancer, you can deal with the anxiety relating to prostate cancer itself. But at the same time, by preserving your prostate, you can maintain those aspects of your life which are important. I mean, one of the main problems with, for example, surgery of the prostate, is that men leak urine afterwards, even though we've improved our techniques. And so by preserving the prostate, you can keep your erections, you can keep your bladder control. So if you play football or you like to cycle or you run, or you do heavy activities, then you can keep doing that as well. Worrying about having to wear a pad, for example, or you know what, having to change underwear multiple times during the day. So now with focal therapy we've reached a situation where you can deal with a cancer and still keep your life pretty much as it was before. You know, significantly, at least a quarter of the men who have been diagnosed with early prostate cancer are suitable for focal therapy. And for them, it gives them a great opportunity to really perhaps change their lives for the better and hopefully permanently.

Clare Delmar: Yeah. I mean, you've made a very strong case linking how focal therapy also can reduce the anxiety associated with either end of the spectrum, more radical treatments and equally active surveillance. I mean, do you feel that many patients are counselled in that way?

Marc Laniado: Currently, no, they're not. And the reason they're not is because there is still somewhat lack of awareness of focal therapy as a potential treatment. Also, the other reason, probably, is because most of us who are trained, are trained to operate or trained to give radiotherapy. Many of the patients who see need for it are people have looked out for alternative treatments for prostate cancer that can give them what they want. That peace of mind that they can have prostate cancer treated with less side effects and conditions we're keen to offer.

Clare Delmar: So one thing that's been in the back of my mind, given the time we're having this conversation, is that we hear about these large delays in both the diagnostics and treatment of all cancers, but prostate cancer is included in that. I mean, could you comment on the extent of the delays and how that's affected prostate cancer diagnosis and treatment specifically and maybe link that back to levels of anxiety that patients may be feeling because they are on this kind of backlog, as it were?

Marc Laniado: As you can imagine, if you've just been diagnosed with cancer, you want obviously to have the best diagnostics possible and be offered the best treatment that you can. And with the Covid crisis, of course, many patients have not been able to see their GPs in the way they normally would do. And then in hospitals, some of the hospitals were not offering MRI scans and were not offering prostate biopsies. So many patients were told, well, you know, I'm afraid you may be at risk of prostate cancer. But at the moment, we're going to have to defer till the Covid-19 pandemic has really passed. And so, of course, again, that's another troublesome situation for a man and his family to find that. Well, we've just been told you might have prostate cancer, but because your risk is not high enough, we're not going to be able to do anything at this time, we going to have to defer things for several months. And similarly, we've had patients who've had a diagnosis of prostate cancer who have been told, well, we would normally treat you by surgery or radiotherapy, but at the moment we can't do so. So what we're going to do is can we suggest you go into hormonal therapy, which is called androgen deprivation therapy, and that means effectively, chemically castrating men, which means getting rid of the male hormone testosterone that can have quite profound side effects. I mean, men get hot flushes, they can lose muscle mass, and sometimes they can get muddled thinking, they put on weight, you know used for very long periods of time it can cause problems with bones. So the traditional treatments, like the big treatments, like surgery, radiotherapy, have been very difficult to deliver. But some other

treatments like focal therapy have been more safely delivered because they're if you like, less toxic insults on the human body so that they're they're easier to sustain. So it is a treatment that we can deliver more easily during this time.

Clare Delmar: But is it being delivered by the NHS?

Marc Laniado: At the moment very few treatments for prostate cancer have been delivered, although it has restarted in many areas now, but in very constrained circumstances. I've heard some patients been told that they cannot have definitive treatment of any kind till probably the end of the year and that they'll need to stay on hormonal therapy till that time.

Clare Delmar: Yeah, that's a terrible thing to impose on somebody, isn't it?

Marc Laniado: Absolutely. And to know that during this time, that the cancer is being suppressed, but not actually treated is really less than ideal.

Clare Delmar: But the fact is that you and your colleagues at the focal therapy clinic are available to actually treat patients now in some dedicated private clinics.

Marc Laniado: We are able to treat patients absolutely so we can deliver focal therapy usually as a day case, as I said, so you come in and go out the same day with very high levels of protection to avoid any risk for infection and then the treatment is given, patients go home and then we see them again shortly afterwards. And again, it is something that could be done relatively safely compared to, for example, radical prostatectomy, which I also do. And so many patients have sought to have focal therapy for that reason.

Clare Delmar: Marc, thank you so much for your insights. If you'd like to learn more about Marc's work and about the focal therapy clinic, visit www.thefocaltherapyclinic.co.uk.

The Black Wall Street Times Article On HIFU Prostate Cancer Treatment First published in April this year, The Black Wall Street Times produced a compelling article on the story of three African American men who had successful treatment for their prostate cancer with HIFU Focal Therapy. Reggie Dye, Thomas Newell, and Victory Murray all had treatment for their prostate cancer with HIFU Focal Therapy instead of more radical treatments like prostatectomy or radiotherapy. All were concerned about the side effects associated with these two procedures such as erectile dysfunction, penile shrinkage, and urinary incontinence. "I'm very glad I chose HIFU for my prostate cancer treatment," Murray, a NASA lead engineer whose team repaired Apollo 13 said. He went on to say, "I also consider myself lucky because I was diligent about receiving my annual physical, and I feel honoured to share my challenge with prostate cancer." He echoed the sentiment many of our patients when Murray mentioned, "I hope in some small way I can encourage someone else who may be reluctant to get the right treatment to become a prostate cancer survivor. I did with the help of my doctors and HIFU!" In the video below they share their treatment journey and how they discovered that HIFU Focal Treatment was a viable treatment for them. The article also goes on to examine the research by the American Cancer Society. This shows that African American men are one and a half times more likely to be diagnosed with prostate cancer than white men. <https://youtu.be/11FG0953U2I>

Prostate Cancer Hormone Therapy Treatment – Friend Or Foe? Hormone Therapy for prostate cancer is a well acknowledged approach to managing advanced prostate cancer, effectively slowing metastatic prostate cancer progression. The trade-offs between cancer management and side effects are usually well understood by doctors and well accepted by patients. One trade-off of hormone therapy for prostate cancer is between physical health and mental health, as hormone therapy is increasingly associated with mental ill health, and specifically as this study reveals, depression. The Covid era has presented its own challenges with hormone therapy. According to TFTC Consultant Urologist and Andrologist Raj Nigam, men with early-stage prostate cancer diagnoses are being prescribed hormone treatment for prostate cancer as other treatments within the NHS are unavailable. "It is an unfortunate negative outcome of the Coronavirus era, if you like, that traditional treatments have all had to be halted for at least three or four months, in particular radical prostatectomy and radiotherapy", says Raj. "And as a result of this, men have inadvertently been advised to go onto hormone injections for prostate cancer without, I hate to say, proper and adequate discussion." Raj points out that this is not the fault of any individual surgeon or doctor. "It's just the position that they have been placed in in terms of trying to control the condition -- with limited time and often in telephone consultation they will say we're having to put you on hormones until and unless normal services are up and running again." At TFTC, we are approached by many men with early-stage prostate cancer who have been put on hormones, and whose normal, active (in some cases extremely active) lives have been severely compromised. "We have to start off by qualifying this because there are some men that have to have hormones. Disease that has spread to the bones or to the lymph nodes and beyond, and they will have to have hormone treatment for prostate cancer to control the disease. There are some men who they know that they are definitely going to have radiotherapy and it has been shown that those men will do better with at least a three month period of antigen deprivation therapy normally involving a series of hormone injections for prostate cancer designed to shrink prostate cancer cells prior to having radiotherapy. So those two

groups aside, there are a lot of other men that have been put on hormonal therapy, which under normal circumstances would not have been."This is a significant problem, in Raj's view, because hormone therapy does not come without side effects."In my recent experience, some men who have not been advised which side effects to experience are now complaining about it and wondering why they getting these side effects", he says. Not necessarily because men have had hormonal treatment, but they are what we call hypogonadal in the sense that they have low testosterone levels. Because the hormonal therapy is designed to reduce the testosterone levels in men."There a number of serious side effects that hormonal therapy can have."We all know about sexual side effects that decrease testosterone level can have in particular loss of libido, erectile difficulties, ejaculatory difficulties and so on."We also know about its effect on muscle mass and bone density, particularly with longer term treatment. And this can lead to increasing and early fatigue, a desire of not wanting to do exercise, a constant feeling of weakness. So those are physical, real physical issues that men are experiencing whilst on hormonal therapy."Asked about the effect of hormone therapy on mental health, Raj worries that men are not aware of this potential side effect. "I think that the effects of testosterone on the brain are under recognised and underplayed. Men who come to my Andrology clinics often do complain of a loss of cognition or loss in the speed of thought. They may still be at work and they're finding that they got sort of brain fog type symptoms. We know that you can also experience mood changes and depression with low levels of testosterone". BAUS – the British Association of Urological Surgeons – provides a set of recommendation for treating prostate cancer in the Covid era. BBC Panorama Programme On Britain's Cancer Crisis As the Covid-19 pandemic takes its toll on all areas of our lives, the process of identifying the immediate and the readily apparent issues is increasingly being shared by the secondary problems caused by the virus. Tonight (Monday 6th July) the BBC's Panorama investigates the pausing of standard NHS care models during the height of the virus and how long it could take for normal services to be resumed. Whilst the focus being understandably shifted to Covid-19 care and the backlog this has created is palpable, there is also an underlying element of those who have electively chosen to 'pause' further treatment or investigation due to fear of the pandemic or not wishing to further burden the health services. Tonight's programme looks in depth at the analysis conducted by DATA-CAN, the Health Care Research Hub (HDR UK) for Cancer which shows that there could be at least 7000 additional deaths cased indirectly by the pandemic with a potential for up to 35,000. The data models the impact on screening, referrals, and treatment in relation to those instances that would normally have occurred during this period. Cancer referrals during this period alone are down 45% based upon what would have been expected. As reported just a few short weeks ago, Prostate cancer is now the most diagnosed cancer in the UK with over 57,000 cases diagnoses in 2018. Early diagnosis and treatment is paramount to preserve life and the outlooks for those who live after successful treatment. If you can't watch tonight's Panorama episode details of how you can watch it subsequently are here at the BBC website A discussion with consultant urologist Raj Nigam – Hormone Therapy A discussion with consultant urologist Raj Nigam The Focal Therapy Clinic's consultant urologist Raj Nigam discusses the overuse and misuse of hormone therapy for men with early stage prostate cancer, and how this is reinforcing health inequalities. Press play in the audio player below to hear the interview. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. My name is Clare Delmar, and in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this month, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. In the second of our series, I'm speaking with Raj Nigam, consulting urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatment for prostate cancer. Raj has been a vocal advocate for focal therapy from his base at the Royal Surrey Hospital and has contributed to several pivotal clinical studies and trials on prostate imaging and focal therapy. He is also an acknowledged expert on andrology and in particular the use of hormones in treating urological disease. Raj, thanks for joining me. Raj Nigam: Thanks very much for having me. Clare Delmar: So why don't we just dive right in? I think this is an issue that's certainly of interest to a lot of our patients, which we'll come onto in a few seconds. But before I launch right into the role of hormones in treating urological disease, I'd really like you to just to say in your own way, what was your journey to becoming a leading practitioner and a champion of focal therapy? Raj Nigam: Yeah. So I've been treating men with prostate cancer as a consultant for over 20 years and I've seen huge changes over that time-frame from the advent of minimally invasive radical prostatectomy, for example, when I was training all the radical prostatectomies were open. Those then transitioned to laparoscopic or keyhole surgery and then moved

on to robotic controlled robotic prostatectomy. There've been massive changes in the improvement of the operation and the side effect profiles that they create. We've also seen great changes in radiotherapy in terms of shortening the duration of therapy and the advent of intensity modulated radiotherapy. So whilst there have been significant changes in the two main radical treatment options, I still felt that there were a lot of men that were perhaps being over-treated. We had no way of confirming this prior to their procedures when we only found out once it had the radical prostatectomy that, oh, they only had a small amount of cancer there or they had a low grade cancer there. So therefore, we have been seeking new means of diagnosis and more accurate means of diagnosis. So I came to this from a little bit of disillusionment with the type of biopsies that we were doing. There were transrectal biopsies which have subsequently been shown to be very insensitive – in the best studies only 48 percent sensitivity. I was also concerned that there were significant septic complications in a small group of men who were having transrectal biopsies, but in that small group of men, they were quite severe infections, sometimes leading to intensive care. So when transperineal biopsies came along, it's something that I jumped at and we moved forward fairly rapidly in developing transperineal biopsies and then moving on to far more precision diagnostics in the form of incorporating MRI scans into the fusion process of carrying out the biopsies. Clare Delmar: So all of that means it's become a much more targeted in what you're actually going to treat – is that a way to put it? Raj Nigam: Absolutely. So the concept of making an accurate diagnosis then leads on to adapting to techniques which will be minimally invasive and minimally harmful to the man and therefore creating less side effects than the two traditional radical options. Clare Delmar: And that's where focal therapy obviously comes into play. Raj Nigam: That's precisely where focal therapy comes in. Once you know where your cancer is and you know the type and the grade of the cancer on a well conducted MRI scan and that well targeted biopsies, you can then safely say, alright, we will treat that area of the prostate cancer with minimal damage to surrounding organs and therefore limit the side effects. Clare Delmar: I mean, it's wonderful to hear that, you know, this is all a lot of great concern for your patients and for, you know, the sort of unnecessary and costly over-treatment that they've been receiving prior to this actually coming about. Raj Nigam: Absolutely. I mean, I was one of the first surgeons to go over to France to learn the techniques back in 2006. But since then, we have found out that it actually it can be much more accurate in its treatment and therefore, we have moved on to focal therapy. Clare Delmar: So, you know, one way of looking at this is, you know, things are becoming more precise, more accurate, more targeted and, you know, can you actually extend that to say more more personalised? Raj Nigam: Absolutely. The one aspect of men and their diagnosis of prostate cancer is that we know that a number of treatment options for early localised prostate cancer are equivalent in their cancer outcomes, i.e. a lot of men will have the same outcome in terms of survival and so on, regardless of whether they have active surveillance, radical prostatectomy or radiotherapy. So we know that from an oncological i.e. a cancer point of view, we are achieving good rates with all the treatments. And that's where we come in, in the sense that the radical treatments are far more morbid in terms of creating erectile dysfunction and far more morbid in terms of creating incontinence, both of which are very, very damaging to a man's function and self-esteem. And we know from our own very large studies – multi-centre studies – that we have carried out in the UK that at five to six years, not only is oncological equivalence to the traditional radical treatments, but also a vast improvement in the side effect and complication profile following focal therapy. Clare Delmar: So, I mean, back to this idea of personalisation and bringing the patient into the decision process. So for many, many years I have been managing andrology clinics whereby I have been seeing men who have had some of the traditional prostate cancer treatments in terms of radiotherapy and radical prostatectomy. Andrology, for those who don't know it, is a field, is a sub-speciality of urology whereby we deal with men who have problems with hormones, who have problems with erectile dysfunction, who have infertility problems, and in particular penile problems, as well as incontinence. So therefore, I'd been seeing a lot of men over the years who had had a good cancer operation or good cancer treatments, but were paralysed by these side effects in terms of their ongoing function. You see, one has to look beyond oncological control when it comes to cancer treatments for early prostate cancer. One has to start thinking about, OK, after one year, two years, the man might be thinking, great, I've got over my cancer, but why am I incontinent for the rest of my life? So all of these things need to be taken into consideration at the time of discussion with the patient. There are some men who say, well, I'm not too fussed about erectile function at this stage, but I do not want to be incontinent. Clare Delmar: Well, can I add mental health into some of the side effects. Does that play into some of the whole sort of person approach? Raj Nigam: Yes, absolutely, absolutely. But men in particular who are worried about what is now the commonest cancer in the UK by

far will be considering what's it going to leave me with? You know, is it worth me continuing with this treatment in terms of the side effects I'm going to get? So there are some men who will say, you know, I've got a cancer I don't care what side effects I get. But now more and more men are beginning to look round and saying, well, what are my alternatives? And are there less morbid treatments that I can have? Clare Delmar: Well, it's interesting because, you know, we're actually getting approached by quite a few men – and I'd say it's on the increase – who have early stage prostate cancer diagnosis and seem to have been put on hormone therapy. And again, this is now kind of observational and but it seems to be happening more during the Covid-19 pandemic. I mean, this is an unfortunate negative outcome of the Coronavirus era, if you like, that traditional treatments have all had to be halted for at least three or four months, in particular radical prostatectomy and radiotherapy. And as a result of this, men have inadvertently been advised to go onto hormonal therapy without, I hate to say, you know, proper and adequate discussion. It's just the position that they have been placed in in terms of trying to control the condition, at least so we think with limited time and often in telephone consultation to say we're having to put you on hormones until and unless we start just services up and running again. Clare Delmar: OK. And how are you seeing this play out with some of your patients? Raj Nigam: The men that have been put on hormones, the vast majority of them don't like it. We have to start off by qualifying this because there are some men that have to have hormones. There are some men who they know that they are definitely going to have radiotherapy and it has been shown that those men will do better with at least a three month period of antigen deprivation therapy prior to having radiotherapy. So those two groups aside, there are a lot of other men that have been put on hormonal therapy, which under normal circumstances would not have been. Clare Delmar: Right. And this is a problem? Raj Nigam: This is a problem because hormone therapy does not come without side effects. And some men who have not been advised which side effects to experience are now complaining about it and wondering why they're getting these side effects. Not necessarily because men have had hormonal treatment, but they are what we call hypogonadal in the sense that they have low testosterone levels. Because the hormonal therapy is designed to reduce the testosterone levels in men. Clare Delmar: Right. I mean, for example, some of the men who come to us will say that they are particularly fit. A lot of them are very committed to sport, to exercise, to healthy, healthy living and a very high quality, active quality of life. And then they tell us they've been put on hormone therapy and it's you know, they become a different person, both mentally and physically. Raj Nigam: Yeah. Like I said, we see this all the time in our andrology clinics and we are now seeing it in the hormone therapy population. We all know about sexual side effects that decrease testosterone level can have in particular loss of libido, erectile difficulties, ejaculatory difficulties and so on. We also know about its effect on muscle mass and bone density, particularly with longer term treatment. And this can lead to increasing and early fatigue, a desire of not wanting to do exercise, a constant feeling of weakness. So those are physical, real physical issues that men are experiencing whilst on hormonal therapy. Clare Delmar: And cognitively? Raj Nigam: I think that the effects of testosterone on the brain are under recognised and underplayed. But men who come to my andrology clinics often do complain of a loss of cognition or loss in the speed of thought. They may still be at work and they're finding that they got sort of brain fog type symptoms. We know that you can also experience mood changes and depression with low levels of testosterone. Clare Delmar: Sounds like menopause. Hot flushes are very, very common sign of hormonal therapy. Clare Delmar: So it's interesting because in talking with some of these men, you know, some of them haven't had this hormone therapy, you know, sort of imposed or, you know, offered to them. So one of the things that has come into my mind is that there appears to be almost a health inequality around the country. And I know that we talk about health inequality, especially during the pandemic, amongst different different types of population groups, but I'm interested in your thoughts on how this might apply to men with prostate cancer. Raj Nigam: Yeah. In fact, there was indeed an all party parliamentary group which published a document about 10 years ago talking about health inequalities in cancer in general and also in prostate cancer in particular. And we know factually, both here and in the United States, that black men in this country, we call them Afro Caribbean, in America they are called African-Americans, have double the average risk of being diagnosed with prostate cancer. And there have been studies which have shown that they have poorer experiences of NHS care. So this is an area that certainly needs targeting in terms of trying to address inequality based on ethnicity. But there are other inequalities, and I'm one of them that we're finding appears to be partly geographical, is based upon age. We are finding and this is again, factually shown that men over the age of 75 tend to have a poorer outcome in prostate cancer, even though their level of fitness if you allow for all of those features, maybe just as good as a man of 65. So there appears to be a subconscious sort of bias saying, OK,

you've reached 75 and so on. Yes, you might be fit and well, but actually we may not go down this route or this treatment route and so on, and we may just watch things and so on. That the largest area, largest group of men that die in terms of age between 75 and 84. Clare Delmar: Has this been documented or investigated in any way? Raj Nigam: Yeah, absolutely. And so, you know, there should be targeted programs at least that was advised that men in that age range and above the age of 70 should have the same access to treatments and diagnosis that men of a younger age do. And there is definitely an inequality of access depending upon age, partly because we know that a lot of men who develop prostate cancer later in life are unlikely to succumb from it. But the actual mortality data suggests that that is the highest age group which men die. Clare Delmar: Yeah, I mean, I think one of the things that came to light during the pandemic was, you know, there's this phrase that was used. A lot of the different country level data on Covid was, you know, some people are dying of Covid and some are dying with Covid. And, you know, this was kind of, you know, similar to prostate cancer? Raj Nigam: Yeah, absolutely. And this is one of the things that has been shown that the health inequalities which existed in a lot of other conditions, including prostate cancer, appear to now being replicated in the Covid era, in the sense that, you know, older people perhaps are not getting access to the high level intensive care. And the third area that I think it's important to highlight, apart from age and ethnicity, is equality of access, access to diagnosis, access to good information and access to all the treatment options. One thing that I've discovered in my work in focal therapy is that there is a huge difference in different geographical areas around the country about awareness of other treatment options other than the two standard radical ones of radical surgery and radical radiotherapy. Clare Delmar: Even though all men have a right to this treatment, as you said before, and that it's codified in law. Raj Nigam: Absolutely. And I think it is important that a discussion should take place with the man at the time of diagnosis of all of his treatment options and not just what is available locally. And I think both for our patients and anybody else interested in hearing about some of these things that are not very often talked about with regard to prostate cancer. Thank you. Clare Delmar: If you'd like to learn more about Raj's work and about The Focal Therapy Clinic, visit www.thefocaltherapyclinic.co.uk. Tim Dudderidge Discusses the Importance of The Montgomery Ruling A new audio series brought to you by The Focal Therapy Clinic, where our host, Clare Delmar, explores some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. In the first of our series, Clare discusses with The Focal Therapy Clinic consultant urologist Tim Dudderidge how prostate cancer patients in the UK have a right to know their treatment choices, embodied and codified in law through the Montgomery Ruling, and discusses how Covid-19 has impacted prostate care. Please find below a written transcript of the interview, and call The Focal Therapy Clinic today to discuss your prostate cancer treatment options: 020-7036-8870. Helping patients to make their own treatment decisions Clare Delmar: Hello and welcome to The Focal Therapy Clinic. My name is Clare Delmar, and in this audio series, I'm going to introduce you to some issues facing men diagnosed with prostate cancer that are little known, less understood and almost never talked about. Earlier this month, prostate cancer was acknowledged as the most commonly diagnosed cancer in the UK. I'm speaking with Tim Dudderidge, consulting urologist at The Focal Therapy Clinic and a leading innovator in imaging led diagnostics and targeted treatment for prostate cancer. Tim has been a vocal advocate for focal therapy from his base at University Hospital Southampton, and has contributed to several pivotal clinical studies and trials on prostate imaging and focal therapy. He's also chairman of Doctors of the World UK, a charity that helps people to access healthcare through free clinics and helplines, advocacy work and international programs. Clare Delmar: So why don't we kick off straight away just to allow our listeners to understand who you are, where you come from? Tim Dudderidge: Well, I guess early in my career as a trainee urologist, open prostatectomy was a big deal is, you know, a big operation for big surgeons and the patients had a big recovery as well. And that really started to show us that this operation could be done in a more sort of gentle way with smaller incisions and easier recovery. And it was around the same sort of time that we saw innovations with imaging and with technology that allowed minimally invasive treatment. And really the combination of things, you know, where we're pushing for more minimal access surgery, where we started to realise that cancer in the prostate didn't necessitate the whole prostate to be treated, we got better and better with the new technology of identifying where the cancer was; mapping biopsy became a thing and we could start to prove the location of the cancer with biopsies; and the technologies for treating the cancer became more widespread and gave us more options – we could start to tailor these treatments to individual patients. And the other really big change that happened in the same period was that we started to have an environment where patients were more and more empowered to make choices about their

treatments. And even if we recommended one above the others, you know, the patients were empowered to choose the one that suited them the best. And that has changed how we consult people for treatment and how we give them what I'd like to call an informed choice rather than just taking informed consent, which is perhaps, you know, where we've been starting from. I was thinking in my head is that because people are looking online more and they have more access to, you know, freely available information on their condition? In fact, I was on a panel with her just the other day at a medical legal conference, and she tells this amazing, tragic story where she wasn't fully informed of her choices for childbirth. She had very particular circumstances and somebody had a very fixed view on what should happen. And this eventually, after 15 years of legal fights, basically led to a ruling that changed the whole process of what our obligations are to patients in terms of explaining what the options are and making sure patients are empowered to have an individual choice and not just the sort of standard recommendation. And so that means that we are obliged as clinicians to make sure in every case that the patient's individual circumstances are taken into account when describing the options available. There may be multiple favoured options, but there may also be options that perhaps are second best, but certain patients may favour that as their first choice. And certainly patients who go searching for information definitely understand that because they look at things that might make the grade from a point of view of one outcome like cancer effectiveness. But other people may value other things more strongly and may be prepared to take their chances on cancer effectiveness. Particularly with prostate cancer, because we know that even if you do nothing, at 10 years, there's not a whole lot of difference in survival. And that's because I think people are still fixed in the idea of the doctors knowing best and relying on randomised control trials to sort of be the only thing to tell them what to do. And I think that we have to imagine a more holistic approach where, yes, it's really important to understand which treatment has the best outcome for cancer – that's an important bit of knowledge. So roughly from the point of time when this case occurred, which I think is like 15 years ago. And we're still... even today I was having email with my colleagues about how we adjust our practice to incorporate this into practice. And one of the interesting things is improving consent and information is still an ongoing journey for everybody. You know, it's been talked about for many years, but, there's still improvement and individualised consent forms – so related to the procedure, but also then individualised to the patient's circumstances, describing what alternatives have been talked about and what risks have been discussed.

Clare Delmar: So tell us how that might affect a man who comes to you and has had a diagnosis of early stage prostate cancer.

Tim Dudderidge: Well, let me just describe a case which I guess most typifies the difficult situation when it comes to focal therapy. So if you have a man who's had a high PSA, let's just say it's seven and they've had a scan and it shows a lesion very clearly on one side. And very clearly the rest of the prostate is normal and they have a biopsy, and for the sake of argument, they have a good quality biopsy with targeted biopsies and systematic biopsies going through the rest of the prostate. And just to make it really easy, let's just say that lesion was cancer and everything else was not cancer. They may be at a centre that goes you know, they discuss it in their meeting and they say you're suitable for surgery or radiotherapy. Now, in that circumstance, just because they don't practice focal therapy, I first of all think it's a mistake, not to mention it. People may argue about the lack of evidence for long term comparative effectiveness and I would agree, patients need to know that. Now, according to NICE guidance and I would agree with this, that ideally that patient should be having focal therapy within a clinical trial within the NHS where we are obliged to not only look after resources, provide good treatments, but also make sure that those treatments are effective. But if they can't go into a clinical trial, it's also important that these patients are studied within a clinical registry. But these are not reasons, if you don't offer those things locally, to deny the patients the knowledge of those options and the choice to seek them elsewhere, if they decide that they prefer that. Those clinicians are quite entitled to make a recommendation that surgery has greater evidence for long term success with the cancer point of view. But they're also obliged to say that the side effect profile is greater than focal therapy. And so unless the patients are armed with this information, I really don't think that any of those patients can be given an informed choice. And when they come to have a procedure like surgery, the consent is being offered, I just don't agree that that is proper informed consent. And we've got an article eventually developed in the Daily Mail which kind of covered these issues. What I tried to explain to that journalist was that this is actually almost a scandal that people do not understand that the breadth of choice for prostate cancer needs to be described to patients, even if clinicians don't necessarily agree. And if somebody fits the description of a suitable patient, I can't see any justification for denying patients the information that that choice is there. And it listed a bunch of choices and it did include this and that was obviously part of your input into that piece. So, I mean,

would you be willing to go out on a limb and say what percentage of consulting urologists that deal with men with prostate cancer actually practice according to the way you suggest? Tim Dudderidge: I think it's impossible to say like yes or no to individuals, because even in my own practice, I reflect on what I'm doing. Sometimes it doesn't matter because you've looked at a patient, you're both on the same page. And actually the choice that you're talking about, you may not be as good as you might imagine yourself to be, but actually you're on the same page as the patient and so for practical purposes, you've made a good judgement and it doesn't make a difference. And if you read the situation that a patient is looking to really understand this choice, then that's the job of the clinician, is to make sure that your... and this is why it's so hard - you can't have just a formula that you apply to every patient. And if you've got a patient is clearly wanting to... that they're anxious about side effects; they're anxious to get the right treatment to get the one that's the most effective. You've got to pick up on these cues and really help the patient explore what that choice involves, and what's important to them. So, of course, there are days when I look at a patient and go "I think you'll be great for surgery." They say, "Yes, please." And it's a very quick conversation. But if you misread that situation and the patient actually really wants to know everything and you haven't done that, then you could find yourself in big trouble. And I sometimes find that I'm coming to operate on a patient who's seen another clinician and they've directed them towards radical prostatectomy. And I meet them on the day of surgery and I see that they're an ideal focal therapy patient. On the morning of their operation I'm obliged to tell them what I think about the range of choices. And of course, I felt very bad that we then had wasted some time and everything, but I didn't feel that the consent process was valid. And I think that we shouldn't be trying to beat up the people who maybe don't meet the standard straightaway. I think we should be encouraging people to understand this Montgomery ruling, understand what it means for their practice, understand how to improve the information they're giving. And understanding how to identify all of the options that are suitable for patients with prostate cancer. Tim Dudderidge: And it's no accident that I have tried to offer all the treatment options available because, you know, I don't want to be giving patients away. But I've gone out and, you know, really learned how to offer all the good treatment options. But if a patient has any interest whatsoever in pursuing that, arguably they should see an oncologist anyway. But I think, again, you can't be 100 percent about that and everyone's circumstances are different. I mean, we hear in the media about this huge backlog of cancer patients at various stages of diagnosis. And I'm wondering how this has impacted your ability to care for your prostate cancer patients and possibly if you can extend how you see that impacting, you know, the wider issue of hospitals themselves and health systems? Will we have millions of prostate cancer patients waiting for the diagnosis and treatment at the end of the year. Tim Dudderidge: Well, I think locally in Southampton, we've been very lucky because we already had established relationships with the local private hospitals for NHS work. So we were able to, after a few weeks of a hiatus, work out what PPE we needed and we had the capacity away from the hot site where the Coronavirus patients were being situated. And actually we got better waiting times for cancer in the prostate department than we've ever had. Much of the country have their prostate services in the same site as where the Coronavirus patients were being looked after. So there are many patients who have been started - following the guidelines that were issued - on hormonal therapy, which we would not normally give. And they're basically patients on a very long waiting list, both for surgery and for radiotherapy and also for ablation. In the centres that are doing ablation, I think we are one of a few that have had more less uninterrupted services. Ablation encompasses focal therapy, but also whole gland ablation for some patients after radiation and things like that. Clare Delmar: So what you're saying that the impact of Covid-19 has been quite variable across the country? Tim Dudderidge: I think that's a good way of saying it, yeah, but certainly there are pockets of the country where there will be a lot of men waiting on hormone therapy for their treatment to go ahead. Clare Delmar: And it also feeds back to your comments earlier about the Montgomery ruling because I think in some cases at least certainly from what we are picking up. A lot of these men are sort of told to go on hormone therapy without, well, in many cases, they don't have a choice, I suppose, because things are so backed up. Of course, we know that prostate cancer moves slowly and in some cases it may not metastasise in the period of months and it's safe to just monitor people. Have all these patients been given a choice as to whether to be monitored or to go on hormones? And so that choice in itself and the other thing that's happening is that they've got a lot more time to consider what's going on. And so I think we're seeing a lot of patients who are only finding out about focal therapy after they're on a waiting list for surgery or radiotherapy and after they've already started hormone treatment. But it's just interesting how the Coronavirus has led to more inquiries for this type of treatment. Clare Delmar: And just to finish up on how Covid-19 is impacted health systems, or hospitals themselves, do you

foresee cancer hubs in more clusters of care for these patients, or how do you see changes playing out as a result of the virus? Tim Dudderidge: Well, I certainly know in London there have been kind of moves deemed necessary because of Coronavirus to change how cancer pathways are working. And there may well be some sort of politics going on, things that were sort of deemed to be necessary before this happened. In our region, we actually have maybe more collegiate way of dealing with it, helping to deal with waiting times. We haven't seen it sort of make a great impact yet, but it may be that hospitals that have a big problem with Coronavirus might shift cases to one centre one day. So I think that sort of team working in the NHS is great, whether it leads finally to an even bigger regional reorganisation of prostate cancer services. You could see on the south coast how having a big prostate cancer hospital might make sense in some respects, but I don't see that happening in the short term. I mean, the one thing I will say about this prostate cancer in the UK right now is it continues to enjoy innovation from people like you and your colleagues.

Tim Dudderidge: I'm really pleased that I'm part of a kind of a part of urology, which is constantly on the move, constant improving and really responsive to patients' needs. If you'd like to learn more about Tim's work and about The Focal Therapy clinic, visit www.thefocaltherapyclinic.co.uk.

Prostate Cancer is Another Inequality Faced by Black Men It's been a sobering week for the black community in the USA and the world has responded with both revulsion at the injustices exposed through law enforcement and solidarity with the inequalities the black community has endured, particularly during the COVID-19 pandemic. What most people do not appreciate is that another big contributor to Inequality in health outcomes is Prostate Cancer, for which black men in both the UK and USA are diagnosed at twice the rate as non-black men. Despite the many advances in our understanding of prostate cancer, why black men are more likely to get it is not well understood. Prostate Cancer UK is undertaking vital research in this area. Research in the US shows that in addition to their prostate cancer diagnosis, black men are more likely to have cardiovascular disease and obesity, which can separately shorten their lifespans. While the US data show that black men don't appear to intrinsically and biologically harbor more aggressive disease, they generally get fewer PSA screenings, are more likely to be diagnosed with later stage cancer, are less likely to have health insurance, have less access to high-quality care and other disparities that can be linked to a lower overall socioeconomic status. The study, conducted at the University of Michigan, emphasises the role that doctors who treat cancer have in knowing there are multiple factors in play in any patient's health, and stresses the importance of focusing on the health of the entire patient and, as a society, on addressing racial inequities. You can read further about this on the Prostate Cancer UK, NHS England and M Health Lab websites.

Challenges to NHS Care as Prostate Cancer Becomes Most Common Cancer in the UK Two news streams came out in the media this week which, taken together, paint a very serious picture for men in the UK at risk of prostate cancer. The first presented new data that show Prostate Cancer to be the most commonly diagnosed cancer in the UK, surpassing breast, lung and all other cancers in its incidence. The second revealed the changes within NHS hospitals generated by Covid-19 and the implications for care going forward, citing resource constraints and new protocols which are doubling waiting lists by the end of the summer. Individually these stories are impactful; taken together they are cause for great concern as more men are delayed diagnosis and treatment for prostate cancer. It is well understood that men diagnosed with prostate cancer at an early stage have a high likelihood of survival and, with continually improving and more accurate diagnostics, this is increasing all the time. The worry in this new environment is that many prostate cancers won't be caught early as the diagnostic process is slowed down through backlogs of delayed patients and new post-Covid protocols which slow down the process of moving along the diagnostic pathway for prostate cancer. In terms of treatment, long wait lists are likely to favour men with more advanced stages of prostate cancer, meaning that men with early-stage cancers are delayed yet again in their treatment. This could result in cancers advancing and requiring more radical treatments, with negative implications for patients and the NHS as a whole. We will be watching developments closely. In the meantime, we continue to reach out to men with early stage prostate cancer and offer advice, support and non-invasive treatment. Further details on these developments can be found on the Prostate Cancer UK and Nuffield Trust websites.

Research on Focal Therapy Published This Week In Uro Today Research published this week in Uro Today reviewed 24 studies of patients who have undergone Focal Therapy, concluding "most patients will remain free of a radical procedure. The vast majority of patients maintain urinary continence and good erectile function after FT." You can read the full article [here](#).

TFTC's Tim Dudderidge Contributes To Trends in Urology and Men's Health The Focal Therapy Clinic's Tim Dudderidge has contributed to the latest edition of Trends in Urology and Men's Health. The article is entitled 'High-intensity focused ultrasound focal therapy for prostate cancer'. The full version

can be accessed here. Tim co-authors the article with Deepika Reddy which examines in depth all aspects of current knowledge in relation to suitability, outcomes and understanding of focal therapy in treating prostate cancer. The section 'Why focal therapy?' looks at some of the reasons why focal therapy is considered instead of more radical options. It also looks at the reasons why focal therapy is still not being suggested to patients who are suitable. In the part of the article relating to 'Counselling men suitable for focal therapy' HIFU or NanoKnife Therapy, thought is given to the information the patient requires to make the most informed decision about treatment. We conclude that detailed counselling is crucial in order for the patient to receive the treatment that is right for them and their lifestyle requirements post treatment. The detailed schematic that addresses the procedure in relation to hemiablation and wide local ablation (WLA) gives great insight into how the treatment is performed in relation to the position, spread and placement of the prostate cancer. The 'Evidence acquisition for HIFU in partial ablation setting' section of the article looks at the clinical information that has been amassed in significant evidence-based outcome data for focal therapy in the treatment of prostate cancer.

Mental Health Awareness Week and Prostate Cancer This week is Mental Health Awareness Week, and it's been both revealing and inspiring to see and hear so many stories from men living with prostate cancer who are also dealing with challenges to their mental health. Covid-19 has, in some cases, exacerbated this. One of our patients, Perry Letcher, has written about his personal struggle with extraordinary honesty. Perry was put on Active Surveillance by his consultant urologist last year and felt unable to cope with the realities of this form of treatment, experiencing anxiety that he found unable to control. A recovered alcoholic, Perry had developed mental and emotional tools to overcome his personal challenges, and had a longstanding relationship with anxiety for which he had a battery of tried and tested coping mechanisms. But in his current state he couldn't effectively manage the anxiety that stemmed from knowing he had cancer inside his body. His is a wonderfully open and honest story about how he felt and what he did about it. Three pieces of research also came to light this week which address mental health challenges for men. We get calls all the time from men who, despite having prostate cancer, are fit, active and positive – but once they start this treatment their physical and mental state is seriously compromised. The study brings out how and why this happens. Second is a study by Tackle Prostate Cancer, a UK-based charity. It looks comprehensively at the mental health needs of cancer patients and how these are being met – in the case of prostate cancer, the research shows there is a long way to go in meeting the needs of patients. Third, a survey by the Movember Foundation, which focuses on men's health, which addressed the needs of men in discussing their concerns about anxieties brought on by Covid-19. They've developed a toolkit to help men and their colleagues with this, which seems like a great step forward. Below is a link to each of these studies. Hopefully, 2020 will be the year of a step change in men talking about their mental health concerns with their partners and colleagues and, most of all, their doctors.

Hormonal Treatment In Men With Prostate Cancer Triggers Depression
Turning The Spotlight On Mental Health In Cancer Care
New Movember Survey Results Show More Conversations Are Needed For Men Who Are Struggling During Covid-19
TFTC Consultant Raj Nigam Co-authors International Study on Focal Therapy

In undertaking this comprehensive review of literature on the oncological and functional outcomes of men receiving focal therapy, Raj Nigam and colleagues set out to address the ongoing question of data on outcomes by framing it around the now-routine implementation of mpMRI as an essential part of the prostate cancer diagnostic pathway. In so doing, they emphasise that success with focal therapy is dependent on highly accurate patient selection and localisation of disease, which is underpinned by the routine use of mpMRI. The more men undergo mpMRI, the more localised cancers will be seen which could potentially be treated with focal therapy. Prior to the establishment and adoption of mpMRI as a standard of care, localised cancers were unseen, often leading to unnecessary radical treatment. As more and more hospitals provide this pathway to patients, it's just a matter of time before we develop more data on long term outcomes of Focal Therapy – and a number of studies are underway to do this. It is crucial to understand the link between mpMRI and the implementation and success of Focal Therapy, and to recognise the pioneering role of Raj Nigam in integrating this pathway into the standard of care for men with localised prostate cancer.

Regret Over Treatment of Prostate Cancer: A Patient's Story Any regret over a course of treatment is always difficult to hear and whilst every good intention may have been given we see many occasions where patients are particularly regretful regarding their ongoing side effects after radical prostatectomy cancer treatment. This article from MedScape looks at this area in detail and particularly from a patient's perspective. This highlights further our passionate belief that all prostate cancer patients need to be presented with 'all' of their treatment options and particularly if the cancer has been diagnosed early. Tim Dudderidge Featured In The Daily Mail Article –

Me and My Operation The Focal Therapy Clinic's Tim Dudderidge's patient David Tallant is the lead story in the Daily Mails' article – ME AND MY OPERATION: Ice cold gas that kills prostate cancer and cuts side-effects. Marc Laniado contributes to an article by The Mail Online The Focal Therapy Clinic's Marc Laniado contributes to an article by The Mail Online entitled, "Are men dying needlessly because we don't make all over-50s have prostate tests?" Marc Laniado's Article in The Guardian on Technological Transformations to Urology The Focal Therapy Clinic's Marc Laniado is the subject of an article in The Guardian called - Consoles and lasers have transformed my job as a urologist. Marc explains that the side effects of prostate cancer and its treatments can be life-changing and why he is passionate about improving outcomes for his patients. Tim Dudderidge Speaks With Dr Mark Porter On Radio 4's Inside Health Programme The Focal Therapy Clinic's Tim Dudderidge, Consultant Urologist speaks to Dr Mark Porter on Radio 4's Inside Health programme. For convenience interview transcript related to prostate cancer discussion from the radio 4 website is provided below. Discussion with Dr Mark Porter and Consultant Urologists, Prof Marc Emberton and Mr Tim Dudderidge, and patient Mr Howard Spranger. Last week's Inside Health special on prostate cancer prompted many of you to get in touch and we put some of your comments to one of the main contributors to the programme, Mark Emberton, Professor of Interventional Oncology at University College London. Emberton I've seen a lot of patients since the programme and they loved it. I thought it would be a little bit too complex but actually no they liked the detail that you went into. Porter Well you say that but it seemed to raise as many questions as it answered but of course that's the nature of prostate cancer and the uncertainty that surrounds so much of its diagnosis and treatment. There was a lot of interest in conventional ultrasound guide biopsy missing cancers and one listener wondered about the TURP operation. He said – given the scrapings were sent away for analysis would they be a reliable guide to whether his prostate was cancerous or not – because that's a form of biopsy? Emberton So the TURP typically we do for enlarged prostates where we don't think cancer is present. And the procedure basically removes the apple core of the apple and makes men pee more easily. Now we look at that tissue very carefully but that's not typically where cancers originate from. And so whilst it tells us that there's no cancer within that tissue it doesn't provide the reassurance that this man is after. If there's any doubt at all we'd tend to let the prostate settle down for a few months and then do an MRI. Porter We also mentioned, of course, the results of the Protec study which found no difference in outcomes in men who opted for active surveillance compared to surgery and compared to radiotherapy. But one listener was wondering about brachytherapy, this is a form of radiotherapy that he had, is that lumped in with radiotherapy, is it equivalent to the rest? Emberton There are many ways of delivering radiotherapy. The Protec study could only do one, which was external beam radiation therapy, listeners will have heard of proton beam therapy, which got into the news last year, brachytherapy is another way of getting the radiation into the prostate. They're all considered to be equivalent in terms of their ability to control the disease. Porter We also spoke a lot about clinically significant disease and that MRI's better at detecting it than ultrasound guided biopsy. One listener asked us to clarify what we actually meant by clinically significant. Emberton You're smiling, as I am, because this is a difficult one. So there's a disease out there that we could all identify as being important in that if left untreated it is very likely that that man's quality or quantity of life will be diminished. Porter So by clinically significant what you're saying is this is a potential threat to the wellbeing of the man and we need to do something about it? Emberton Exactly right. And this is disease that is typically of increased volume, so in other words big, and high grade. Porter One of the key messages to come out of last week's programme was that advances in MRI mean we are now much better at determining where cancer is within the prostate, raising the possibility of a new generation of targeted treatments. So, instead of irradiating or removing the whole gland, you just treat the part with the cancer – hopefully reducing the risk of side effects like incontinence and erection difficulties. Killing tumours with high intensity focussed ultrasound (HIFU) is one such technique that is currently being trialled at Southampton General Hospital. I went to see consultant urological surgeon Tim Dudderidge to learn more. Dudderidge The prostate gland, I'm holding a small model here which is probably about 50 cubic centimetres in size and this is a 3D rendered model of an MRI scan of someone's prostate. And you can see that the tumour in this particular case may be between one and two cubic centimetres and this is a fairly small tumour that one might consider suitable for HIFU treatment. Porter So it's like a small pea in the middle of a plum. Dudderidge That's right. So when I see people with these kind of findings, as I was doing this morning, you go through the different options and this is a means of treatment that involves heating up the prostate and that's done using this probe here, which produces ultrasound which is focused. And that heat energy is concentrated in a small area about the size of a grain of rice and that focal point will get to about 80 or 90 degrees Centigrade. Now

obviously the prostate is bigger than a grain of rice and so when you're planning this treatment you have ultrasound images which you capture using the same device and you can plan on the screen where you want to treat. And so originally we were treating the whole of the prostate but we realised that actually this is a much better technology for just partially treating the prostate. And so you would plan out the areas based upon your understanding of where the cancer is, based upon the imaging, and that will enable you to ablate the tumour and the surrounding area and avoid important structures like the urethra or sphincter, the bladder and the neurovascular bundles.

Spranger: My name's Howard Spranger, I was diagnosed with prostate cancer December 2014. For a couple of years before I'd sort of had trouble going to the loo sometimes in the night.

Porter: Getting up for a pee.

Spranger: Yeah, yeah and I did recall my father once having to have an ambulance to take him away because he had a similar problem. I suppose at the back of my mind there was always the possibility that it might be a cancer in the prostate. But you don't want to think that way and nothing led to it really at that time.

Dudderidge: Howard's PSA was rising and at that point we felt it was necessary to get an MRI scan. In his case the MRI scan showed an area on one side of the prostate which appeared to be abnormal. And those biopsies really identified that the disease was only on one side, matching up with the imaging findings, and then that led us into a conversation about his options really between focal therapy or between having surgery or radiotherapy.

Spranger: The surgery to remove the whole gland – it felt to me like overtreatment but that was just because all I knew was that the cancer was fairly localised. And it was a big thing to go into as well, the potential side effects – incontinence and impotence really was what it boiled down to, neither of which prospects were particularly appealing. The fact that it was not surgical just appealed to me, I mean I've a fairly technical background and it was something I thought yeah this is a good novel new way of doing something and the least worse option, if you like.

Dudderidge: Now as a general rule when we're treating the prostate what we're trying to do is trying to obtain lower side effects than you get with surgery, so this is the main advantage – you want to not have any incontinence, not have any erectile dysfunction. And so whilst we're treating half the gland you might treat one of the nerve bundles but we know that by completing untreated the other side most people will have normal erections afterwards. And so what we find is about quarter of people may need to use a Viagra or one of these drugs afterwards but only one in 20 probably don't have erections despite that.

Porter: So how do you actually operate – presumably the patient's lying on their back, this probe goes into the rectum, up their bottom effectively...

Dudderidge: That's right.

Porter: And then that gives you the pictures that you're looking at.

Dudderidge: So we start off by bringing the patient into the operating theatre under an anaesthetic. We put the legs up so we can access the perineum and the probe goes into the back passage, it's got lots of lubricating jelly and that makes a good contact for the sound energy to travel through. We then take some images of the prostate and then we mark it out in three different areas typically – the front, the middle and the back – and these areas overlap so you don't get any gaps in the treatment.

Porter: But the idea effectively is to leave as much healthy prostate tissue as possible and the surrounding structures, like the nerves, untreated?

Dudderidge: That's correct. And so the degree to which you do that is something that's of interest to us because we might be able to bring it closer and closer to the lesion, the more and more confident we are that we know where the lesion is.

Porter: And how long does the procedure take?

Dudderidge: You're talking about two hours in theatre. So we normally do four cases in a day.

Porter: Of course the big difference between this procedure and removing the gland completely is the cancerous tissue is potentially still inside the patient, you hoped to have killed it but do you know for sure?

Dudderidge: So I'm someone who does surgery and I do focal therapy and so I'm often torn with this situation where somebody who on paper is somebody who could be a candidate for a trial. And yet despite that there'll be a bit of me anxious about whether they should be having a complete removal of the prostate. And the reason I'm uncertain is because we don't know and we're running a trial and we're taking these patients where we don't know which is best for them and we're offering them the chance of randomisation. And I think this is the best way to answer this question and I really encourage all the patients to consider this. But let's say we've treated someone with HIFU and we're monitoring them, they will require long term follow up, which may involve repeated imaging and biopsy and they may require repeated treatment if they're unfortunate enough to have a recurrence. We know from the data about one in five will need a retreatment and about one in 10 will need their prostate removing and patients have been told that beforehand, they've signed up to that but for the majority of patients they will have one treatment episode which gets rid of their disease, leaves them with few side effects. A substantial number of patients will avoid major surgery who will have otherwise had it or radical radiotherapy and I think for those men who do avoid it successfully, which is the vast majority, this is a really important thing for them.

Porter: Tim Dudderidge

talking to me in Southampton. Mark Emberton, you're also working on a new localised approach to treating tumours in the prostate and one that's been in the headlines recently. Emberton Yeah so you're describing focal treatment. It's interesting prostate's probably the last organ that exists where we typically treat at the whole gland level. When I was training as a urologist I was taught to remove the whole kidney if somebody had renal cancer, today we go to huge efforts to try and preserve as much kidney as possible. And obviously mammography has changed the way we manage breast cancer, that happened 40, 50 years ago. MRI is now identifying disease, we can see very, very tiny cancers that measure 0.2 ccs, that's about eight millimetres across and it's not beyond the wit of man then to direct energy at those cancers plus a little margin around them and by doing so treat the cancer and try and preserve function. Porter Now Southampton are using HIFU as we've just heard, what are you using? Emberton We're using a range of treatments at present. This is a slightly complicated treatment in that we give a drug that sensitises the body to light and then we introduce light fibres into the prostate and that interaction between the light and the photosensitiser releases what we call free radicals which damage the cancer cells and actually stop the blood supply to those cells. Porter And this combination of photosensitising and laser light has been used elsewhere. Emberton It has been used actually, particularly successfully in difficult to treat areas, such as head and neck cancers where there are lots of key vital structures where typically surgery and radiotherapy result in damage – loss of voice, loss of being able to swallow. Photodynamic therapy or VTP is fascinating and offers a great opportunity to patients because it represents a new class of therapy, in other words a new way of treating prostate cancer. This is the first mature trial of photodynamic therapy that shows benefit over and above a control, which in this case was active surveillance. Porter Now HIFU's work in progress, your own work presumably is still very much work in progress, how long do you think it will be before we'll know for sure whether these treatments are safe to use in men? Emberton We know quite a lot about these treatments because HIFU, for instance, has been around for about 10 years now and there's quite a lot in the published literature. So we know about the safety, we know about the tolerability, so men having tissue preservation are very likely to be the same in functional terms – and by that I mean erections and incontinence – than they were before treatment. We also know what we call the early oncological outcomes, so in other words the cancer results at one and two years. What we don't yet know is what the outcome is going to be in 10 years because all new treatments we just have to wait for that long term data. Porter But you see localised treatment as the way forward? Emberton Very much so. I think our ability to risk stratify, so in other words to be very, very precise about the true cancer that that man has, puts us in a position now to offer a range of treatments that include surveillance, that include very radical surgery and radiotherapy for the very aggressive disease and then in the middle there's an opportunity for men to have their cancer treated but really diminish the side effects that have been typically associated with standard treatments. Porter Professor Mark Emberton. And if you want to know more about that technique – and the HIFU being used in Southampton - then there are links on the Inside Health Page of the Radio 4 website. Investigating the Psychological Impact of Active Surveillance We are highlighting here an extremely interesting article on the Wiley Online Library website which explores the mental impact of being on active surveillance on the cancer patient. The continual nature of worry, tests, consultations and the very nature of being a 'cancer sufferer' is often overlooked in choosing this as a treatment option. Whilst active surveillance was introduced to create a defined 'stage' of a cancer patients treatment journey and was welcomed to provide a different option to early stage cancer patients. However, active surveillance is not without its own difficulties both from a mental and practical standpoint. The analysis concluded that prostate cancer patients on active surveillance had 'significantly higher anxiety symptoms' than AT and non-cancer participants, contradicting previous literature. The Focal Therapy Clinic Featured In The Mail on Sunday Recently The Mail on Sunday and The Mail Online featured The Focal Therapy Clinic and Tim Dudderidge in their article, "There's a prostate cancer cure that can spare a man's sex life – so why won't doctors tell us about it?" How high-intensity focused ultrasound could transform treatment of disease". You can read the full article here. The article focuses on Paul Sayer, 64, from Southend-on-Sea in Essex, diagnosed with cancer in his 60s. Paul's surgeon was 'strongly in favour of surgery' and the operation could have been carried out within 10 days of the consultation. During discussions with his consultant Paul mentioned that he had heard about HIFU Focal Therapy and wanted to know if this was a treatment option he could consider. In the article Paul says the doctor 'shut down the conversation' and said that HIFU Focal Therapy was not a viable treatment option for him. Paul successfully had HIFU Focal Therapy treatment after going back to his doctor and contacting a consultant who specialises in ablative treatment for prostate cancer. The article also mentions our consultant Tim Dudderidge who says 'Patients have a

right to know about it, so they can make an informed choice about their options.'We are grateful for this coverage and especially so as it challenges why focal therapy isn't suggested as a treatment option for all suitable prostate cancer sufferers. Dr Art Rastinehad On Who We Should Consider for Focal Therapy & How This article on the URO Today website covers the SUO session at the AUA 2019 meeting where Dr. Art Rastinehad discusses the selection of patients for Focal Therapy for their prostate cancer. It highlights how focal therapy evolved from the over diagnosis and over the treatment of prostate cancer in relation to treatment's side effects, primarily sexual and urinary in nature. Particular note should be paid to the diagram highlighting the various paradigms in relation to the risk associated with the cancer stage. The main takeaways for clinicians were that patients eligible for focal therapy should have biopsy-confirmed imaging, biomarkers and MR imaging should be used with targeted biopsy in conjunction with the standard biopsy when evaluating patients and patients should have a biopsy to confirm ablation by 1 year post-treatment. In this slide presented at the SUO session by Dr Rastinehad, focal therapy is placed in the current and future paradigms in relation to the stage of a patient's prostate cancer in relation to risk. The paradigms include the current broad treatment options and places focal therapy treatment options, HIFU Focal Therapy and NanoKnife Focal Therapy into a specific one for focal therapy and looks at a future potential paradigm. The cancer risk stages range from very low to very high and looks at how both active surveillance and radical therapies can be augmented by focal therapy as a defined treatment option. Focal Therapy Offers Advanced Treatment Options for Prostate Cancer In this article and video on the UCLA Health website, UCLA urologist Leonard S. Marks talks about how he and his team are pioneering focal therapy as a treatment for prostate cancer. He explains further advances in MRI scanning and a greater understanding on how this can shape treatment options. He also talks openly about HIFU Focal Therapy being a 'middle ground' in prostate cancer treatment. In the associated video he shows first hand the patient diagnosis and treatment process of focal therapy and gives further insight into how he and his team uses it as an effective treatment. Misinformation on the Internet regarding Ablative Therapies for Prostate Cancer In this article on the Pub Med website a study has been made into the misinformation on the internet regarding focal and ablative treatments in regards to the treatment of prostate cancer. In the study the researchers used both Google and Bing search engines to assess the top 50 web results for the term 'prostate cancer' in addition to the terms 'HIFU' and 'cryotherapy'. The main conclusion was that there were 'substantial inaccurate and incomplete information' in the results and this needs to be addressed in order for independent patient web research could be conducted with a balanced and informed information set. We concur entirely and are actively involved in ensuring that HIFU Focal Therapy treatment for prostate cancer is accurately portrayed on the web. In this article and video on the Grand Round In Urology website, John W. Davis, MD, presents "Focal Therapy for Localized Prostate Cancer: Is There a "Middle Ground" Between Active Surveillance and Definitive Treatment?". His presentation was during the 29th Annual International Prostate Cancer Update on January 26, 2019 in Beaver Creek, Colorado. Dr. Davis explores the lack of consistency regarding the definitions and benefits of focal therapy for prostate cancer. He looks at the treatment options for prostate cancer and defines the sufferers who would gain most from ablative therapy. He also looks at current challenges in this approach and how all options may not be presented to the patient.

Subheading 2

This is some more text for the second page.