

‘Where should I go?’

Experiences of Cancer
patients and their carers



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Disclaimer

This report relates to our findings taken from our surveys and from the patients that spoke to us at the Time Out Groups we attended. Our report is not a representative portrayal of the experiences of all patients only what was contributed by those who took part.



Foreword

The purpose of this study is to gather the experiences of cancer patients and carers who attend Coping with Cancer Leicester, Leicestershire and Rutland (CWC) support groups with a focus on their experiences of waiting times for referrals (before treatment) and the care and support available to patients after their treatments.

We sought to engage with patients and carers through the support groups and we wanted to look at the patient's experience. What we found is that:

- A significant number of patients visited their GP three times or more before being referred to a specialist and were later diagnosed with cancer.
- Just over a third of patients waited over 14 days to a month before being seen by a specialist.
- The majority of patients said that they did not receive any information about how to access support groups and if there are any groups in their local area.
- There appears to be a general lack of support available for patients following treatment.

We are extremely grateful to all the patients and carers who shared their experiences of cancer care, treatment and their personal experiences.

Thank you also to all the therapists and volunteers at the Coping with Cancer Time Out Groups for allowing us to attend and speak to the group.

We hope you find this report of interest.

Rick Moore
Chair
Healthwatch Leicestershire



“Counseling is desperately needed and not available when the people need it. I couldn’t see a counselor until it was too late and I had essentially resolved my mental health trauma linked to my cancer myself. The waiting times for counseling are too long. Increase the number of counselors to reduce waiting lists. people can’t wait for this service as they are getting through each day my hanging on with their fingertips.”

(Female, 35-44, Melton)



Methodology

A survey was designed by Healthwatch Leicestershire (HWL) working together with CWC to gather the experiences of patients and carers who access health services including GPs, Leicester Hospitals and Coping with Cancer Support Groups.

Our overarching aims were to assess:

- the holistic care received by cancer patients and their carers
- any barriers that prevent people getting the treatment, care or service they need
- gaps in support services

Who we spoke to

We visited:



8

CWC 'Time Out' Complementary Therapy Groups

The 'Time Out' Complementary Therapy Groups are for anyone affected by cancer - patients, their carers and families. Patients are able to self-refer to the services provided by Coping with Cancer (CWC). People can have complementary therapy treatment in a calm and relaxing environment as well as meeting and chatting to other patients or carers over refreshments.

We spoke to:



54

people at the groups

CWC Time Out Group	Number of people spoken to
Hinckley	10 ●●●●●●●●●●
Wanlip	12 ●●●●●●●●●●●●
Loughborough	10 ●●●●●●●●●●
Leicester	4 ●●●●
Leicester	5 ●●●●●
Harborough	4 ●●●●
Coalville	4 ●●●●

We also visited the University Hospitals of Leicester (UHL) Cancer Support Group at CWC and spoke to 15 people.

57 service users completed a survey

The survey was made available online and cascaded to all HWL contacts, Cancer Support Groups and other networks. The survey was also promoted via social media.

Findings

In this section of the report, we present the findings from the questions we asked patients and the themes that have emerged. We have also included quotes and personal stories from patients to support the findings.

Getting a diagnosis

Patients are diagnosed with cancer through a variety of pathways e.g. after being referred by their GP to a specialist, after a visit to the hospital whilst being treated for something else, through a routine check-up or screening programme or through an admission to a hospital's Accident & Emergency (A&E) Department¹.

Findings suggest that patients diagnosed by their GP or via routine check-up or screening are diagnosed at an early stage and the outcomes are much more positive in comparison to those diagnosed at A&E or as an emergency admission.

Those diagnosed through an emergency admission tend to have worse outcomes, due to the cancer being more advanced or more aggressive. This suggests that if the cancer had been diagnosed earlier there may have been more positive outcomes.

We wanted to know at what point during the initial process did patients we spoke to receive a diagnosis. We asked patients how they were diagnosed as evidence suggests that this can affect a patient's care, recovery and chances of survival².

"My dentist identified a problem and referred me to maxillofacial. The consultant was unhelpful in the extreme and I was left for 5 years before a registrar did a biopsy at the outpatient appointment. I had no idea I had cancer or even anything of that type. After the biopsy, I was told, "we can operate on this cancer" these were the precise words".

(Female, 55-64, Charnwood)

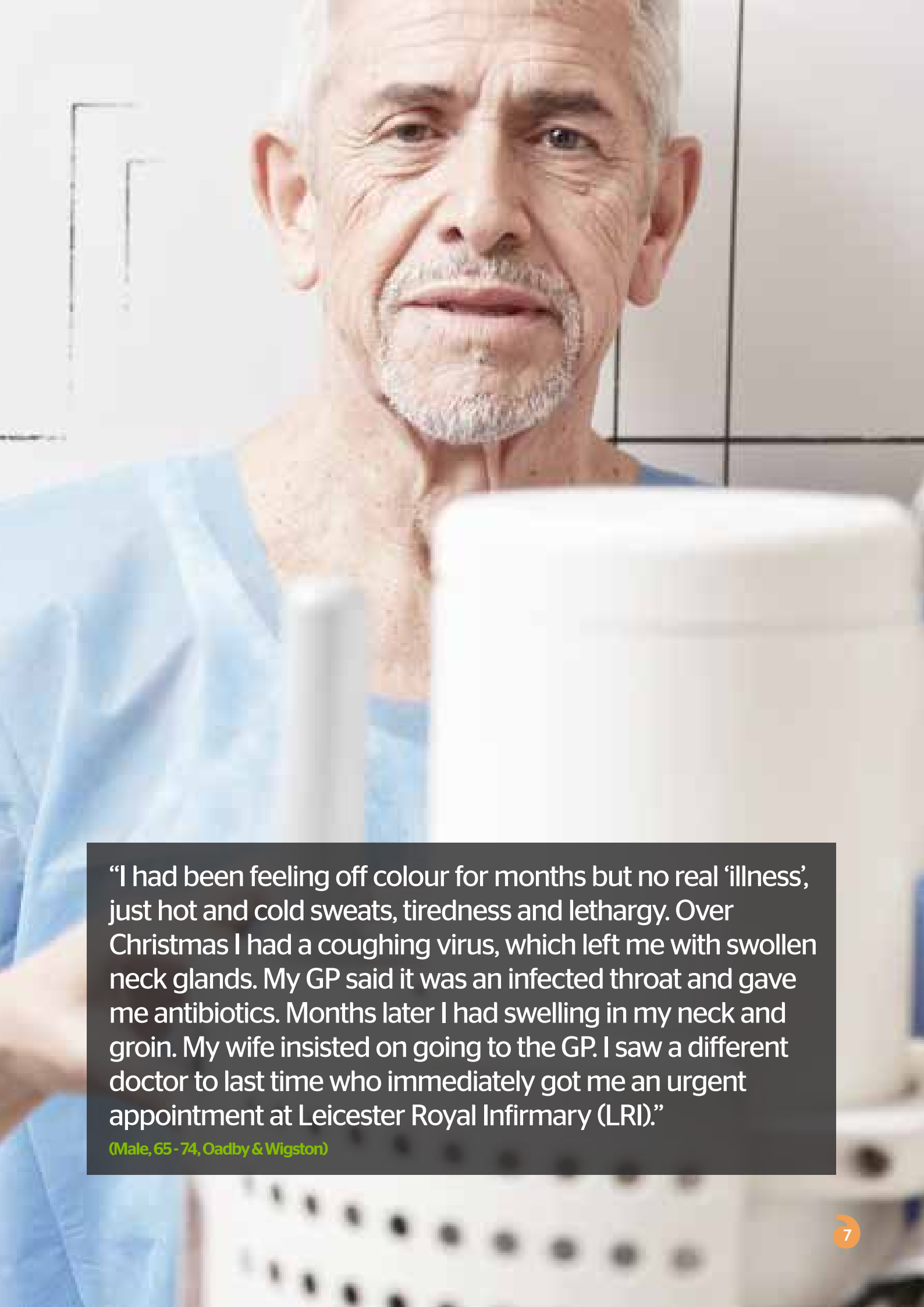
All 57 patients who completed the survey answered this question, however some selected more than one option. A quarter (16) of all patients told us that they recognised the symptoms and almost half (28) were diagnosed through an investigation of symptoms by their GP.

From our secondary research, we are aware that in many cases symptoms are not related to cancer and are caused by other health conditions. Some patients are diagnosed with cancer after their GP or a hospital consultant picks up on the symptoms when presenting for another illness/ condition³.

¹ <http://scienceblog.cancerresearchuk.org/2015/09/11/how-are-cancer-patients-diagnosed-and-could-it-be-better/>

² <http://scienceblog.cancerresearchuk.org/2016/01/22/improving-cancer-survival-by-understanding-how-patients-are-diagnosed/>

³ <http://www.nhs.uk/Conditions/Cancer/Pages/Symptoms.aspx>



“I had been feeling off colour for months but no real ‘illness’, just hot and cold sweats, tiredness and lethargy. Over Christmas I had a coughing virus, which left me with swollen neck glands. My GP said it was an infected throat and gave me antibiotics. Months later I had swelling in my neck and groin. My wife insisted on going to the GP. I saw a different doctor to last time who immediately got me an urgent appointment at Leicester Royal Infirmary (LRI).”

(Male, 65 - 74, Oadby & Wigston)



Waiting times

We asked patients how many times they visited their GP before they were referred to hospital for an investigation of symptoms and diagnosis. The majority, 21 patients, said they had visited their GP once or twice before being referred to hospital. 10 patients visited their GP 3 or 4 times and 8 patients visited their GP more than 5 times.

Although the majority of patients saw their GP one or twice before referral to hospital, there was a significant number of patients who visited their GP 3 times or more before being referred to a specialist and later diagnosed with cancer.

The NHS national cancer waiting times guidance states that patients should have a maximum wait of two weeks (2WW) to be seen by a specialist following a referral with suspected cancer symptoms⁴. We have recently seen hospitals in England that are struggling to meet the 2WW and 62-day targets; this includes Leicester's Hospitals⁵. The most recent figures show that Leicester's Hospitals have not met the 82% of patients with an urgent cancer referral receiving treatment within 62 days of referral target since July 2014⁶.

In order to gain a better understanding of the services in Leicestershire we asked patients how long they waited before a specialist saw them. 34 patients reported that a specialist saw them within two weeks. 11 patients waited over 14 days and 12 patients waited more than a month before being seen by a specialist.

The delay in being seen by a specialist could be a result of patients not being available for appointments, lack of available appointments or delays in endoscopy or imaging. An imbalance between demand and capacity can also cause delays. If the demand exceeds capacity then the number of patients waiting will grow, along with waiting time for an appointment⁷.

It would be useful for GPs to provide patients with an easy to read timeline of what to expect and when, and to provide a list of useful contact numbers for local support groups.

⁷ https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf

“My GP practice failed me on many occasions, delayed diagnosis resulting in it being too late to preserve fertility and meant the cancer was worse when it was eventually diagnosed.”

(Female, 35-44, Melton)

⁴ <https://www.england.nhs.uk/wp-content/uploads/2015/03/delivering-cancer-wait-times.pdf>

⁵ <https://www.theguardian.com/society/2016/jul/14/nhs-england-cancer-waiting-list-targets>

⁶ <http://www.hinckleytimes.net/news/local-news/demand-causes-leicester-hospitals-miss-1222499>



Elizabeth's Story

Age 45-54

Elizabeth highlights the fast care and treatment she has received.

"I was diagnosed with cancer on Christmas Eve 2015 following an MRI scan.

Within two weeks of being diagnosed I had my first meeting with my consultant. Within four weeks I had an appointment with a urologist. I did not have to wait too long which was a relief. I was extremely pleased with the fast care and treatment I received and I am now waiting for the next stage of treatment and radiotherapy to see if it will be successful."

All names in case studies have been changed in order to maintain anonymity.



Information provided

It is important that cancer patients have access to a wide range of information and support in order to understand their illness and make informed decisions regarding their treatment options and choices⁸. Their support system, ability to make decisions and accessibility of support services can impact on how they are able to cope and live their lives following a diagnosis and treatment for cancer.

Patients told us that the Hospital Consultant/Staff and Cancer Nurse Specialists provided them with the most useful information. We asked them what information they were given. Patients received various types of information and the top three were:

1. Information about the patient's specific illness
2. Where to get support
3. How to manage their illness

Even though patients said that they received information on where to get support, the majority of them told us that they did not receive any information about how to access support groups and if there are any in their area.

Those who selected 'other' had read books about cancer, were not given any information or spoke to their friends who told them about support groups.

"I was given a little bit of information about the operation, although like several others I know, we were given the impression we would be perfectly well after two weeks."

(Female, 55-64, Charnwood)

"I only knew about Coping with Cancer through a friend (wasn't told)."

(Female, 55-64, Hinckley & Bosworth)

Was the information you were given about your treatment, clear and easy to understand?



45 YES



12 NO

It is important for patients to be provided with the right information at the right time but it also needs to be easy for them to understand the information they are given. The majority of the patients that completed the survey said the information they received was clear and easy to understand.

"My surgeon was brilliant, he realised there was an underlying issue and it had not been picked up in over a year, so was very thorough. He explained what it meant and we discussed how my mum died and so how to look out for changes. My research team are very supportive when I see them."

(Female, 45-54, Leicester City)

⁸ http://www.macmillan.org.uk/documents/aboutus/commissioners/patientexperiencesurvey_toptipsguide.pdf



Saroj's Story

Age 55-64

Saroj highlights the need for patients to be better informed about services available to them.

"In 2013, I was diagnosed with breast cancer. I cannot remember whether I was diagnosed because I recognised the symptoms or whether it was a result of a mammogram.

I found travelling to LRI every day for treatment difficult. I was exhausted and the tiredness added to my stress.

I had somebody to drive me to the hospital but I can imagine that for those people who have no family or support it would be extremely difficult.

Nobody had told me that there are patient transport services available for patients and this is a concern. There is a need for continuous support and guidance for patients, especially following treatment. They should not be left to struggle on their own.

I struggle sometimes because I don't know who to talk to or how to raise any concerns I have".





Involvement in decision-making

There is a growing understanding about the importance of involving cancer patients in decision-making about their care. Evidence has identified an association between patients and their families' involvement in decision-making and improved patient satisfaction and quality of life⁹.

We asked patients how involved they felt in their care. 45 patients said they felt completely involved or fairly involved. 12 patients felt that they could have been more involved in their care or that they were not involved at all.

"I felt the decisions just went on around me and I was frightened of the eventual surgery, I was in shock really."

(Female, 55-64, Charnwood)

"I was provided with options and asked how I would like to proceed - I asked for recommended solutions"

(Female, 55-64, Blaby)

Care and treatment

38 patients were satisfied with their care and treatment

16 patients stated their care and treatment was okay

3 patients were dissatisfied or very dissatisfied with their care

We asked patients how satisfied they were with the care and treatment they received. The majority of patients (38) said they were satisfied or very satisfied with the care and treatment they received. 16 patients said it was okay and three patients were dissatisfied or very dissatisfied.

The overall feedback was positive and appreciative of hospital staff and their care.

"The psychological /emotional effects of cancer were not addressed initially. My cancer was seen as an easy one to treat and whenever I mentioned that I was struggling I felt I was not heard."

(Female, 55-64, Blaby)

"Detection of cancer & surgery should have been done much earlier with less traumatic results caused by delay."

(Male, 75-84, Charnwood)

"Excellent treatment once it got started, fully informed of what they were doing."

(Female, 65-74, Charnwood)

"Hospital staff were first class during treatment."

(Female, 65-74, Charnwood)

⁹ https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf



Support groups and local services

We asked patients which local services they had heard of.

The most common local services patients had heard of were:

- LOROS
- Macmillan Cancer Nurse
- Coping with Cancer
- Macmillan Information Shop

The least common services that patients had heard of were:

- Leicestershire Advice Service for Social Care
- CLASP – The Carers Centre
- Support for Carers – Leicestershire
- Together Against Cancer Leicestershire

We asked patients what services they would find useful at a support group. They were given the option to select more than one service.

We provided patients with a list of services and asked them how likely they would be to use them. The services most likely to be used by cancer patients and their friends and family were:

- Cancer support groups
- Complementary therapies
- Relaxation class

The services least likely to be used were:





- Carers support groups
- Telephone support
- Home visits

Patients told us that they would like support groups made available in central locations across the county so that they are easy to access and attend. For example, patients in Market Harborough told us that they would like a support group based in the town.

This information should be considered when designing or developing support services for cancer patients. It is important that support groups are accessible for all patients and include services that patients would find most useful.

We have listed the services in order of most selected.

	Practical advice	40
	Talks from specialists/experts	37
	Talks from other patients	37

	Information on related cancer	32
	Advice on other services, i.e. benefits	30
	Self-help	21
	Information on all cancers	12

“I am relieved to finally have a diagnosis. Initial support is very important and also after treatment. This is where it matters most, when you are left to deal with things on your own. I had to give up work and went 8 months without any benefits, as I was not aware of any. I feel that if I had a specialist nurse they would have advised me about this”.

Sharon, aged 40-45

Sharon's Story

Age 40 - 45

Sharon highlights a number of key issues and concerns in her treatment which may have been prevented.

"In March 2011, I started suffering from extreme back pain, which carried on for 2 weeks. I went to my GP who prescribed anti-inflammatory drugs and said it should go away on its own, which it did.

Two years later in March 2013, the pain came back but this time it was worse. Again, I went to my GP and they prescribed anti-inflammatory drugs and said it would go away in a week. Due to the intensity of the pain I asked my GP for stronger medication. After some time of going back and forth I changed my GP practice.

3 months later, I was sat at my work desk and couldn't get up, I felt paralysed. The next day I woke up in agony and called the GP. I was prescribed anti-inflammatory drugs and painkillers. The pain never went away and never got better but slowly I had to go back to work.

My GP agreed to carry out a blood test and referred me to physiotherapy. The blood test results came back normal. I called my GP repeatedly and they kept increasing the dose of painkillers. After each physiotherapy session I was in agony, unable to walk or move and felt like I had been "battered". I was only given 4 sessions of physiotherapy on the NHS.

In September 2013, I went to the GP because I was getting sharp pains when breathing. They just said it was muscular and no scans were given just more tablets.

A month later, I woke up and was unable to move. After 2 hours and 10 minutes I managed to get down the stairs. I rang my GP and

arranged for an appointment the next day. I was in a bad state; I could not eat, sleep or move. I went to the GP with my mother. The GP I saw was the same GP I had seen 3 months earlier. We pleaded with the GP to send me for scans or other tests; the GP replied, "My hands are tied". My mother said "we will pay if we have to" and the GP without any hesitation gave us some leaflets for private health care.

I went to Nuffield Hospital and had an MRI scan and got pushed forward as an emergency into NHS.

I then had an MRI at the Glenfield Hospital and a week later I received a call from the hospital to say "you urgently need to be admitted can you please come to LRI". I knew it was cancer. The consultant couldn't say anything over the phone.

I was told that I had secondary spine-bone cancer and breast cancer. The cancer had wrapped itself around the top and bottom of my spine. The consultant apologised for the delay in getting the results. I was told without emergency spine surgery I would be paralysed within days. I had surgery the next day and they removed as much of the cancer as they could and put pins in my spine.

The first blood test that I had showed that my bone density levels were very high which the GPs missed. The second blood test was even higher and still missed. Following investigation there were a number of red flags missed by five different GPs.

I am relieved to finally have a diagnosis. Initial support is very important and also after treatment. This is where it matters most, when you are left to deal with things on your own. I had to give up work and went 8 months without any benefits, as I was not aware of any. I feel that if I had a specialist nurse they would have advised me about this."



Additional views, opinions and experiences

Patients were given the opportunity to leave feedback on topics which may not have been covered in the survey and suggest any changes or improvements for local cancer services.

All feedback and comments have been categorised into themes.

Support after treatment

"After all the treatment programs I was suddenly on my own in getting back to health. A 'how are you' after cancer visit with someone would be beneficial to support the after effects of dealing with cancer and getting back to normality."

(Female, 45-54, Blaby)

"No support given after end of treatment (radiotherapy), Very stressful just being left alone after so many daily appointments. Some sort of counselling and support through recovery and rehab is necessary."

(Female, 45-54, Charnwood)

"Once the cancer treatment finished the follow up appointment is too long. Need to have a follow up at the minimum of 3/12 months following treatment. Set up a point of contact for any issues in between appointment as GPs are not up to date with some conditions."

(Female, 55-64, Blaby)

"At the end of oncology, you are very much left on your own which is very daunting. This is the time when you need most support. Information on groups and services isn't very forthcoming."

(Female, 45-54, Charnwood)

More support services needed

"At LRI there is a psycho-oncology service which deals with stress and psychological problems a cancer diagnosis can engender. It is run by a world-renowned psychiatrist. However, many GPs and even oncology consultants do NOT refer patients to it. Some do not even know it exists."

(Male, 65-74, Oadby & Wigston)

"Nobody co-ordinating the care to talk about the issues - no point of contact. There was an absence of support between diagnosis and start of treatment which was a very difficult time to cope with."

(Male, 45-54, Blaby)

"Ways of getting more monetary support as I have no employer, no job and savings have receded to a point that it now is harder to live and keep my head above water so to speak."

(Male, 55-64, Oadby & Wigston)



Lack of support

"I found out about Coping with Cancer Support group when I went to Helen Webb House for a craft sale. I had heard of the support group at the LRI but details were hard to access. Would have been great to talk to someone who had, had bowel cancer."

(Female, 65-74, Hinckley & Bosworth)

"I had to find out for myself what support was available. I was allocated a support nurse but she was of very little help to me so I didn't maintain contact with her though I felt I needed some help particularly at the beginning when I didn't know of Coping with Cancer."

(Female, 65-74, Charnwood)

"I would have liked to have telephone support when first diagnosed. I met nobody with my cancer until nearly 9 months after diagnosis. Very isolating."

(Female, 55-64, Blaby)

"The support from LOROS is spot on. I would like to see the same oncologist at the hospital as I've not seen the same one twice. I wasn't given any information about my cancer - what I've got is what I've learned myself. I would like the doctors to remember "I am not a statue - please put a smile on your face and remember I am human." More needs to be done to promote support groups."

(Female, 75-84, Blaby)





Recommendations

The patients that we spoke to all had mixed experiences throughout their cancer journey. It is clear that more needs to be done to ensure that patients are given relevant information at all stages of their treatments.

Patients told us that once they had completed their treatment it was at that point they needed the support of a group and have the opportunity to talk to those who had experienced what they had. Details of local services and groups available need to be provided to patients throughout their treatment. Patients told us that they have heard of CWC support groups through a friend, word of mouth or by chance. Some of the patients and carers wished they had known about the group sooner as they found the support offered very valuable.

Based on the findings from our survey and from speaking to patients directly, Healthwatch Leicestershire would recommend that the providers and commissioners of relevant services in Leicestershire consider the following:

Clinical Commissioning Groups (CCGs)

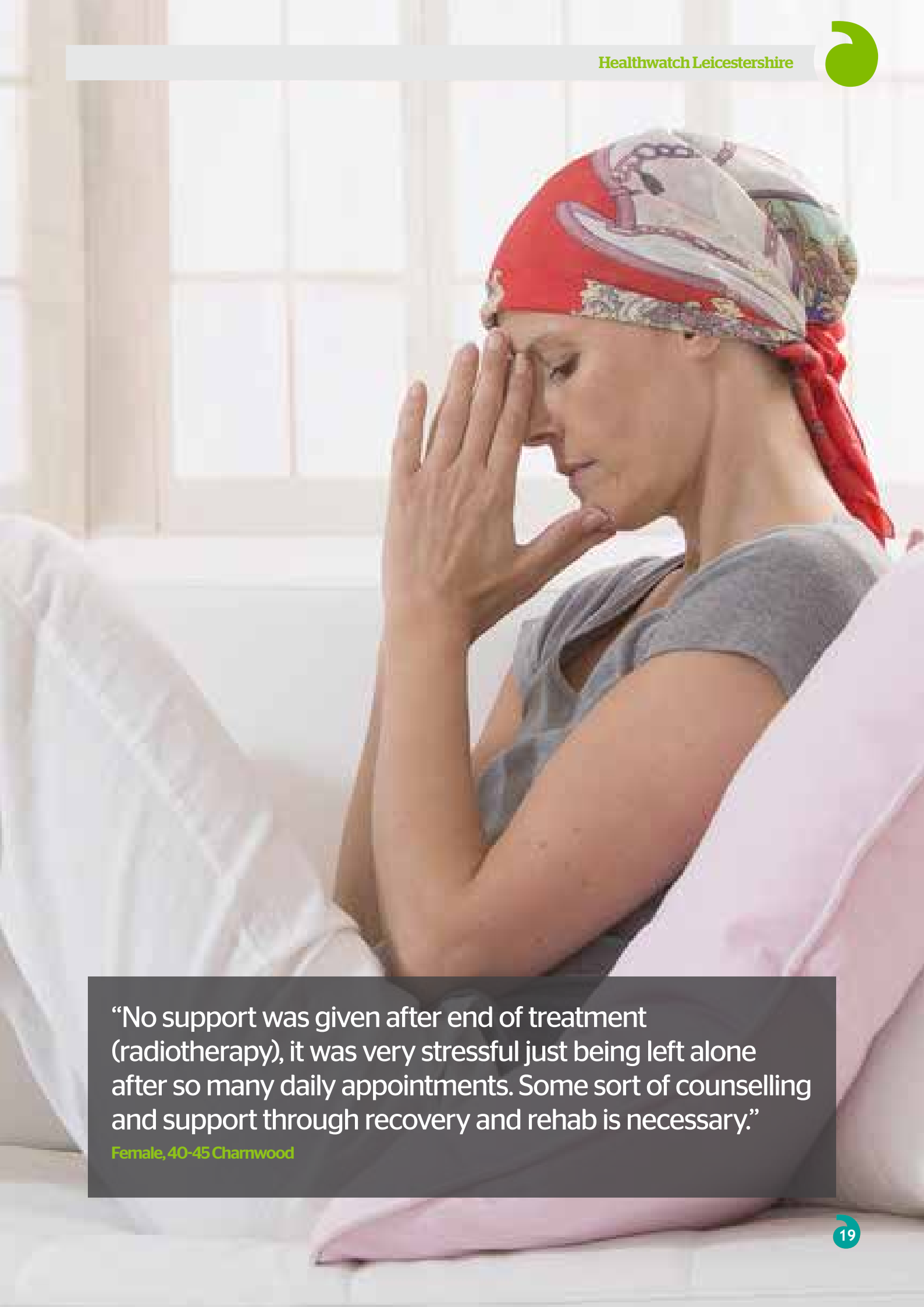
1. Newly diagnosed cancer patients, families and carers should receive information that helps them access support groups, advice and resources. It would also be beneficial if GPs had a list of local support groups for patients and carers as well as being available in the GP Practice.
2. Ensure that patients, families and carers are kept well informed of when they will be seen by a specialist once they have been referred by their GP. The creation of a 'services and support route map', alongside key questions to ask may be beneficial to patients, carers and families.
3. Training of GPs to include how to spot the early signs of cancer and diagnosing early cancer.
4. GPs to provide patients with an easy read timeline of what to expect when and provide a list of useful contact numbers for local support groups.

Service providers

1. Service providers should better advertise and actively promote support groups in specific areas.
2. Review the location of support groups and consider moving groups to more centralised areas in districts and boroughs for people to access more easily. It is important that support groups are accessible for all patients and include services which patients would find most useful.

All Stakeholders

1. Specific steps to be taken to ensure that information on support groups and signposting to other services is thorough and routinely updated, especially post treatment.



“No support was given after end of treatment (radiotherapy), it was very stressful just being left alone after so many daily appointments. Some sort of counselling and support through recovery and rehab is necessary.”

Female, 40-45 Charnwood



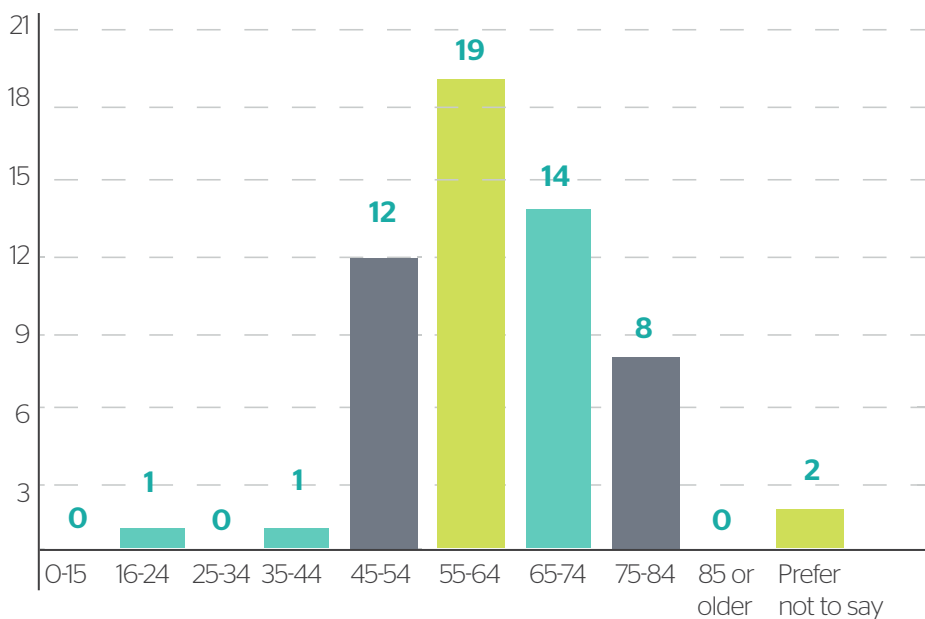
Demographics

As part of the survey we asked respondents for their gender, age and which district or borough they lived. The responses that we were given are as follows:

Gender

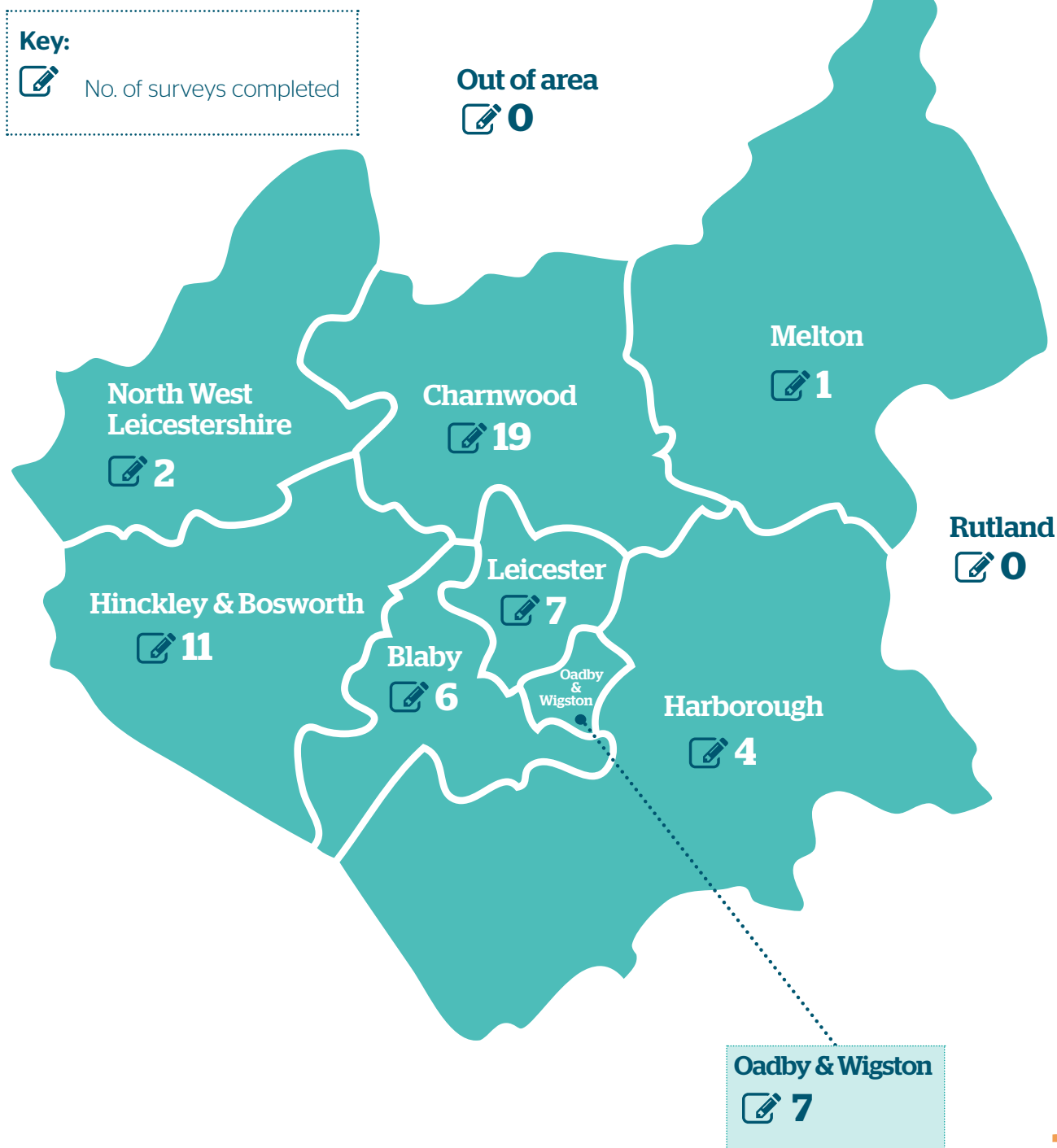


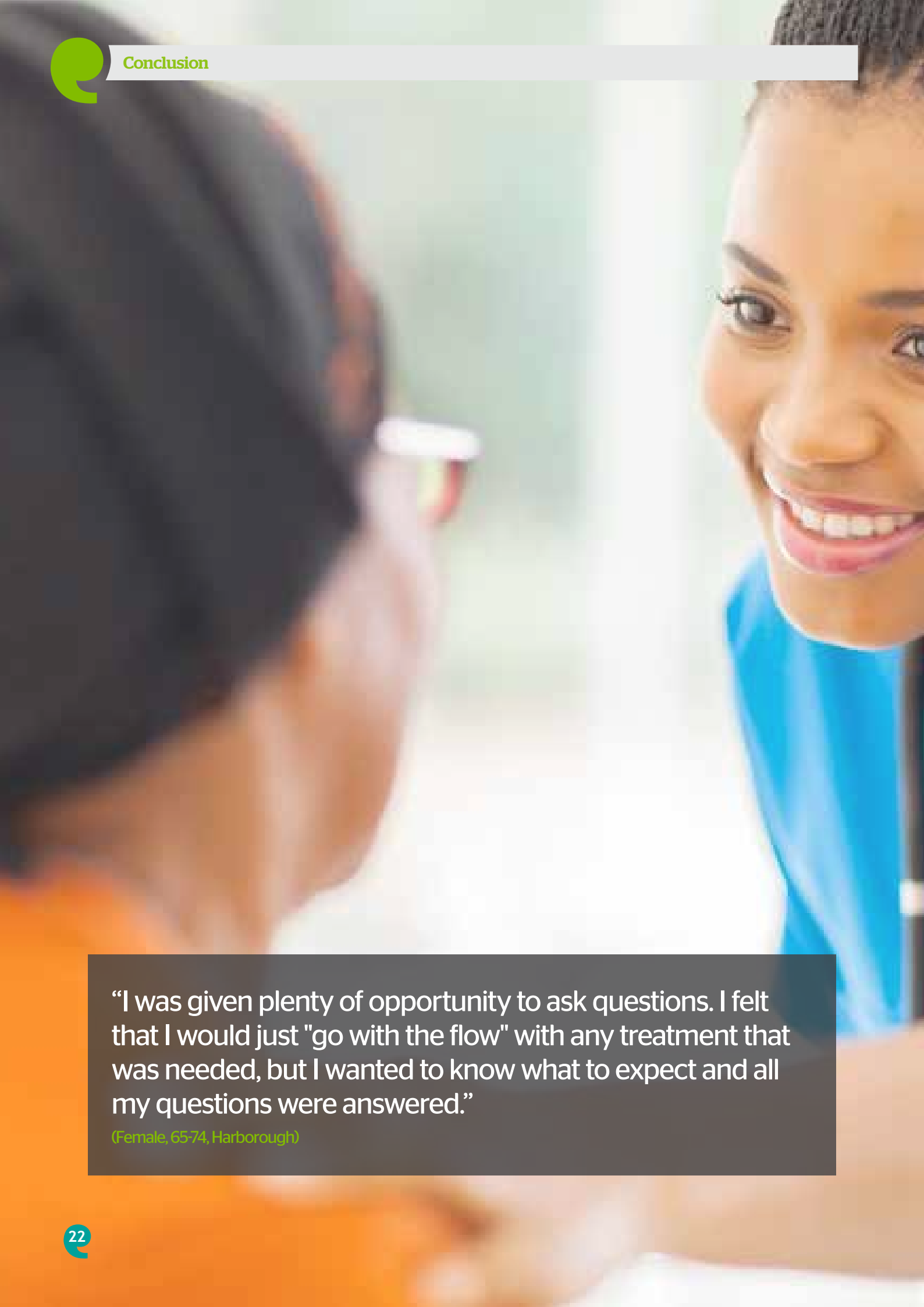
Age of respondent





Where do you live?





“I was given plenty of opportunity to ask questions. I felt that I would just “go with the flow” with any treatment that was needed, but I wanted to know what to expect and all my questions were answered.”

(Female, 65-74, Harborough)



Useful Contacts

Coping with Cancer in Leicestershire & Rutland

- ✉ Helen Webb House, 35 Westleigh Road, Leicester, LE3 0HH
- ☎ Telephone: 0116 223 0055
- @ info@c-w-c.org.uk
- 🌐 www.c-w-c.org.uk

LOROS

- ✉ Groby Road, Leicester, LE3 9QE
- ☎ 0116 231 3771
- @ info@loros.co.uk
- 🌐 www.loros.co.uk

Support for Carers - Leicestershire

- ✉ Torch House, Torch Way, Northampton Road, Market Harborough, LE16 9HL
- ☎ 0845 689 9510
- @ Maureen@supportforcarers.org
- 🌐 www.supportforcarers.org

CLASP - The Carers Centre

- ✉ Matrix House, Constitution Hill, Leicester, LE1 1PL
- ☎ 0116 251 0999
- @ enquiries@claspthe carerscentre.org.uk
- 🌐 www.claspthe carerscentre.org.uk

Together Against Cancer

- ✉ Unit S1, Troon Way Business Centre, Humberstone Lane, Leicester, LE4 9HA
- ☎ 0116 246 0195
- @ info@togetheragainstcancer.org.uk
- 🌐 www.togetheragainstcancer.org.uk

Leicestershire Advice Service for Social Care

- ✉ 5th Floor, St John's House, 30 East Street, Leicester, LE1 6NB
- ☎ 0116 222 9555
- @ advice@lcp-trust.org.uk
- 🌐 www.lcp-trust.org.uk

Macmillan Cancer Information and Support Centre

- ✉ Osborne Building, Leicester Royal Infirmary, Leicester, LE1 5WW
- ☎ 0116 258 6189
- @ cancerinfo@uhl-tr.nhs.uk

‘Where should I go?’

Healthwatch Leicestershire

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