

# **SAMueL2 PCI meeting**

27<sup>th</sup> October 2022

## **Attendees [initials]: Introduction**

Leon Farmer [LF]: Patient co-investigator,. Leading PCI involvement

Penny Thompson [PT]: A carer for her husband who had a massive bleed. Also part of the patient group with Leon.

Simon Douglas [SD]: Based in Oxford, a stroke survivor

John Williams [JW]: Had a TIA 4/5 years ago. Member of a support group that meets in Exeter every month.

David Burgess [DB]: Based in Newcastle. Involved in stroke research since 2012. On a number of projects.

Keira Pratt Boyden [KPB]: Joined SAMueL2 in spring. Qualitative researcher. Facilitate physicians to use the tool.

Michael Allen [MA]: Modeller

Anna Laws [AL]: Modeller. Started in May.

Iain Hancock [IH]: Had an ischaemic stroke 2 years ago (received IVT but it wasn't effective).

Nicky Hancock [NH]: Wife of Ian and an ex-healthcare professional

Lauren Asare [LA]: Started 3 weeks ago. PPI researcher.

Kerry Pearn [KP]: Modeller (note taker)

## **Actions from meeting**

### **Modelling**

- \* MA to find out about Alteplase (thrombolysis) dosing (is it fixed, or dependent on e.g. weight)
- \* MA to find out if there is data to show what proportions of patients do not benefit from thrombolysis
- \* MA/KP to review Stroke Association reports, and to look at what data they hold that may be useful to use (or request Stroke Association for more details).
- \* MA/KP - check proportion of known onset time by stroke severity (do we know the onset time more commonly for more severe strokes?)

### **Qualitative research**

- \* KPB to consider how to continue to involve Patient and Carers Involvement group in qualitative research planning.
- \* KPB: Can/should patients/carers be included in co-production workshops?
- \* KPB: Consider how to take patients wishes into account when performing observational work (including when patient may not have capacity to consent at the time).

## Summary notes

This section includes a summary of the questions raised and the discussions (please see the full notes at the end of this document that also included the information delivered during the presentations).

### Introduction to the modelling in SAMueL (1 and 2) [MA presentation]

**LF:** Is there a difference between ischaemia and infarction?

**MA:** No, it's just terminology (infarction = block, ischaemic = reduced flow)

**LF:** Is IVT more likely to cause a bleed if it is given later?

**MA:** No, the chance of bleed is constant with time. But the likelihood of a bleed is dependent on the severity of the stroke – the milder the stroke the less chance IVT will cause a bleed, the more severe the stroke the more chance IVT will cause a bleed. So we have the relationship that patients with a mild stroke will not benefit as much from IVT, but their risk is a lot lower. Conversely, patients with a severe stroke have the most benefit from IVT, but their risk is a lot higher.

**NH:** Is the IVT dose the same for all patients?

**MA:** Need to find out

**LF:** Are we addressing ascertaining stroke onset time

**SD:** why is it important?

**MA:** IVT offers little or no benefit after 4/5 hours, as it incurs more risk.

**SD:** Can you just try it?

**MA:** For most patients, after 4-5 hours of being starved from oxygen, most brain tissue has died. There's a new technique (a type of MRI) can detect whether enough of your brain is alive so that if we can remove the clot, that it would be useful. At the moment it is only being talked about for use with thrombectomy, and I'm not sure why it's not being talked about for being used for IVT.

**SD:** My experience, people at end of phone were called before the ambulance arrived, they were trying to get the onset time. I got an ambulance quickly as live near the hospital, why then is there a lag of information from the ambulance driver?

**MA:** You touch on important point. The hospital and ambulance don't use the same IT system, so information needs to be passed along and information can get lost between teams.

**NH:** My aunty died from a stroke. They were waiting 2 hours for an ambulance. Then took 1 hour journey going to the (not most local) hospital. If a bleed then taken to Plymouth. In this current climate (with long waits for an ambulance) is there any hope for anyone to have IVT in time?

**MA:** It is still better to call an ambulance, rather than to self present at ED. If turn up at ED then the hospital is not pre alerted. We are also going ask the question: "What if ambulances arrive sooner". Even before COVID the improvement in speed in hospitals were being cancelled out by slower ambulance time, so that overall time to treatment was not changing, even though the hospitals were improving. Everyone knows ambulances are a bit broken at the moment and it's hard to fix.

**NH:** When Ian had his stroke, it took 20mins to get to ambulance, met by registrar in emergency department, and they talked to ambulance crew and Nicky (wife) while Ian was in scanner. Talking to Nicky after the scanner. For any relative this is a scary time, there is lots of information to take on

board. Need to give time to speak to family members to make a decision. Give relatives time to think about what decision is the right one to take.

**MA:** Remember reading about Atal Gwande's experience. He is a physician, and his father was a physician in India. He talked about when his father was diagnosed with cancer. They went into a consultation, and neither of them could remember anything that was said in the consultation.

**MA:** SSNAP records if patient refuses IVT. This is almost never ticked. If that data is right, patients will trust the steer of the doctor. This fits with what we've heard anecdotally. Did you feel steered?

**NH:** Ian had a massive stroke and I was told that this will be the best help for him, but that there is a risk. I just thought that I've got to give it a go. What we didn't know at the time was that for Ian IVT was ineffective. After a scan the following morning we saw that the clot hadn't dispersed. At the time I felt what's the other choice. We took the risk.

**MA:** Were other people here offered IVT? Were they being asked to make choice, or to confirm what clinician recommended.

**SD:** Wife also a hospital nurse, and she said to go ahead.

**MA:** Do you know if she felt comfortable

**SD:** Think she felt confident but very scared.

**LF:** I had not realised that you could receive IVT and it doesn't work. How often does that occur?

**MA:** We only know what happens in clinical trial. Interesting to see that for Ian it was the next morning when they saw that the clot was still present. But Ian could have had a benefit from IVT in that it stopped the clot from getting bigger and worse.

**LF:** Do we need to look into this more. Is this why clinicians are hesitant to give it, if there's a risk and it also may not work. Interesting to know % of IVT not working.

**MA:** Really good question, I've 3 answers. 1) SAMueL2 getting outcome data. We can now get a better understanding of IVT and time. 2) Anna has coded up proportions of patients with different disability levels, this gives us a more fine detail. We have not yet though looked at what proportion of patients don't benefit at all 3) Dig back into literature, and ask Martin James. Are there studies looked at that compared clot size before and after IVT?

**LF:** Could it be related to blood type, or blood factors? Would a blood test at the time alleviate that discussion. If it's well known, if it is a factor in clinicians minds. Not accounted for it in the modelling to far.

**MA:** We will ask the clinicians this at the meeting on Wed 02 Nov 2022. Can you predict if a treatment is going to be useful or not. Or harmful or not?

**LF:** You've mentioned SSNAP. Please can you explain what this is in more detail?

**MA:** Sentential Stroke National Audit Programme. It's a national clinical audit for stroke patients. For every single emergency stroke patient admission, their data is collected in one place - in SSNAP. It contains data about the stroke pathway (now also tied to ambulance data), known stroke symptoms, other clinical data. It's a magnificent dataset that only the NHS can have.

**IH** Question for MA: Is there a correlation between a clinician who offers IVT and other physicians who offer thrombectomy. Is it related to if the clinician has training.

**MA:** We are collecting data for pilot work for thrombectomy. IVT activates the bodys natural mechanism for clot dissolving. Thrombectomy is mechanical removal of clot. They guide up (in a cath lab) a little mesh and they push it up into the right part of the brain (through blood vessels). At the clot they push the mesh up, and it can close around clot and pull it out. Thrombectomy can only be used when the clot is in a big vessel. It tends to be the worst strokes. It's easier to do this technique on them (than for a small clot). IVT is suitable for twice as many strokes. If a patient has

thrombectomy the patient will usually have IVT first (to stabilise the clot). There are 23 neuroscience centres in the country. We have done work with NHSE to look at how many and where to put a thrombectomy service. If they put them everywhere, then there are not enough patients to keep up the specialist skills of the clinicians (they will not do enough of them). Modelling on how many and where. We suggested that it went up to 40, more spread around country (there are currently 7 in London – this is too concentrated).

**SD:** Where and when is the treatment available?

**MA:** There is not much coverage overnight (there are fewer arrivals overnight). But there are as many strokes on a Sunday as on a Wednesday. The aim is to provide a 10 hours a day, 7 days week thrombectomy service. The people who can do thrombectomy are “neuroradiology interventionalists” – people know how work in cathlab, how to guide the mesh to the brain. They are also skilled to coil aneurysms. It’s a question about whether the same people who do heart attack stenting, can they do thrombectomy? There are more people who can do these, so then more people can be trained up.

**JW:** You have access to large dataset, but do we have a relationship with stroke association?

**MA:** Yes, a loose relationship. We’ve never asked the stroke association what data do you have. Maybe they have surveys, and yearly reports. We can easily look at the yearly Stroke Association reports and pull out any importance of IVT and thrombectomy from patients.

**NH:** They will have data on outcomes. The Stroke Association follow people after their stroke for longer. People progress and share information in patient groups, and the lady who runs our carers group will take our comments that we want to address to a meeting she attends on behalf of us.

**MA:** New dataset we’re asking for 6 month outcomes. These are missing in cases, and possibly a bias on the cases that are followed up. For longer term outcomes we tend to rely on the clinical trials. Anything that’s bigger and richer can help.

**LF:** Onset times interests me. In SAMueL1 we didn’t look into it too much. How are we going to effect the known onset times?

**MA:** How are we going to effect anything? Keira’s going to help us with this. We can model “If you determine more onset times, this would be the effect”, and we can ask “Does this look important in your hospital?”. The individual context is likely to be different in each hospital. As we knew the hospital we worked with before we could tell them that it’s because you’re too fast. It’s likely that each hospital will have it’s own story. What we learn for one hospital may not be applicable to another. We tend to say “Is it worth your hospitals looking into.... onset times” for example. Another interesting project is to delve into what are the individual hospital contexts on onset times. We will instead point hospitals in the direction of what aspect to focus on.

**JW:** If I have a stroke, I will phone for an ambulance. Won’t the phone call be a record of the stroke onset – or not?

**MA:** If you are awake then time of call is shortly after time of stroke. If wake up having the stroke then it is harder to determine the onset time. You don’t have to be sure of the exact time, you can estimate the onset time. This is a difference between clinicians whether they need precise or best guess onset time.

**ACTION:** Check proportion known onset time vs stroke severity.

**NH:** Are hospitals with a stroke nurse giving IVT more than hospitals without stroke nurse (their knowledge and presence could influence a new registrar/clinician, they can give them valuable support to help the new staff make that decision).

**MA:** Yes evidence having specialist stroke nurse have more and faster IVT (meet patient at hospital door and gets the patient through the messy hospital processes). If have boring science hat on – if you know that a relationship exists, but you are not sure if it's causal. Have to be aware that the reason there's a stroke nurse is because the hospital invests generally in their stroke pathway (so there could be other stuff going on at the same time to improve the IVT, and it is not just causal of the stroke nurse presence).

We have seen more and more that a stroke nurse is desirable. If want 24/7 and stroke nurse cover, can only have this at the big hospitals, and so not possible in the local hospitals. Trade-off, if have stroke at local hospitals

SSNAP one day a year, ask how many stroke physicians, stroke nurse, hours they are present.

**DB:** Ambulance decides which hospital take patient to

**MA:** Another project (OPTIMIST). Ambulances will decide where to take patients, and they will take them where they want irrespective of guidance. Have to persuade ambulance crew what we think is best. They can decide that I'll drive an extra 10mins to take them not to the local hospital as I know that their outcome at the other will be better.

## **Introduction to the qualitative research in SAMueL2 [KPB presentation]**

**LF:** How can PCI group be involved.

**KPB:** The questions that you have all already brought up in this meeting are useful to help me refine my questions and learn about the context in the different pathways. The question about stroke nurses is something I want to keep looking at. Find out if there are any staff members that are the most useful to learn our information (is it the stroke nurse, or is it the consultant?). Looking at the different dynamics and relationships on the ground may help us to work out the best way to present the findings. It is useful for me to get as much context as possible.

**LF:** For the clinician workshops, are they clinicians only, or can PCI be involved? If clinicians are rubbing shoulders with PCI then if majority of people say I'm prepared to take the risk, it may be useful for clinicians to know in order to take that decision in the future.

**KPB:** it's not just isolated clinicians, it's about everyone around and the patient and how they are communicating between them. I like the idea of PCI being involved in the workshops with clinicians.

**MA:** We should definitely do it. As we engage with hospitals it can be online, so it would be great to have a patients voice present. Clinician to hear a patient voice. It will help to validate to us modellers that when clinicians say they know what patients think, be good to have someone there to challenge or confirm it.

**DB:** For the observational study – are you going to be present during IVT delivered? Different clinicians may have different approaches.

**KPB:** I will spend 6 weeks in total (2 weeks at each of the 3 sites). This will help to get a few cases of IVT during that period. Important to see the differences on a weekend vs week day. That may help us to communicate machine learning findings in a way that takes this context into account. On a week day when more busy, or weekend when no consultant there.

**DB:** Lots of hospitals have installed machine learning for scan interpretation (Brainomix). Might be worth checking out what experience the hospital has of using machine learning and whether they are already using machine learning to interpret their scans.

**KPB:** Good point. I will find out what they are using already in each hospital. It might effect how they feel about the tool we want to develop. I have spoken to some registrars who use Brainomix (to determine clot or not). Some people made them feel more confident in their decisions, other were nervous about what if Brainomix is wrong. Who is to blame for following that decision?

**MA:** Have links with team in Glasgow/Edinburgh. Doing research into how physicians are with Brainomix.

**KPB:** Does anyone have any thoughts and feelings about having a researcher present during your time in the acute phase of your stroke pathway?. Were you noticing what was happening around you?

**DB:** If put to the family/patient (patient not usually in a place to make a decision) that you are a researcher looking to improve and understand the process and not clinically involved in any way, a researcher to make the system better. Most people will accept this.

**NH:** I wouldn't have minded. The families focus is on their loved one (are they going to live or die). As long as it's nothing intrusive, you are respectful, and emotions of family taken into consideration – researcher may need to leave in cases to not put further stress on the family. The way you put the situation forward.

**LF:** During that phase it's a mad world all around you - giving painkillers and looking at charts. I may not have noticed an observer standing in background. I agree that most would accept.

**SD:** I wouldn't like it. If I don't know where I was, and what's happening to me, but a lot of time I was out of it. I wouldn't like it.

**DB:** Framed as a way to improve the system as an attempt to make it better.

**SD:** I didn't have family with me (in lock down).

**KPB:** It might sound strange, but you could give permission to refuse after the date. Really helpful thank you.

## Upcoming availability

Some people are away in upcoming months:

6-20 Dec (Ian and Nicky)

11 Nov – 6 Dec (David)

## Full notes

### Introduction to the modelling in SAMueL (1 and 2) [MA presentation]

Going to give overall background to the project, show some of key things from SAMueL1, and talk about what we will do in SAMueL2. So this is a good lead into our next meeting when we will show you things from SAMueL2.

There are two types of stroke: 1) blood clot, infarction, ischaemic (4 out of 5 strokes) – this can be treated with IVT, to remove the clot or stop it growing. 2) a bleed, haemorrhage (1 out of 5 strokes) important not to give thrombolysis to these people.

Unfortunately there is a risk of IVT causing a bleed in ischaemic stroke, which can be lethal.

LF: Is there a difference between ischaemia and infarction?

MA: Infarction = block (this is a clot). Ischaemic = reduced flow (this is caused by the clot and the problem is less oxygen to the brain).

IVT breaks the clot down by activating the body's own clot breakdown mechanisms. Clots naturally form in the body, once the tissue is repaired then the body has a mechanism to naturally remove the clot by breaking it down.

What's the problem that we are addressing? Opinion leaders would say that 1/5 people should be receiving IVT, but only 1/9 are in England. So only half of the people that could receive the benefit, are. These are stable numbers - not improving the IVT rates in England in the last 10 years.

The aim is to look through the reasons why IVT rates aren't improving.

Tom Monks a while ago looked at this, and looked mainly at speed. In a follow on project we found that some hospitals were fast, but hospital IVT rate still lower than expected. This led us to find that some hospitals are not identifying the patients stroke onset time.

By talking to the stroke staff in some hospitals, they said it's the job of the ambulance service to find out the stroke onset time, and that if the ambulance crew don't find it out and write it down then we will not know it.

Another hospital may take a more proactive approach and quiz the ambulance team more and phone other people to try and find the stroke onset time out – they would treat it as an investigation to find the time out.

We also found that doctors would differ about their opinion about whether to give IVT. We gave lots of patient records to Dr James. He went through them and gave his clinical decision about whether he would give those patients IVT, and we found he would give more IVT than happened in real life in the other hospital that the patient attended. We can train a model to learn how Dr James makes decisions, and get the model to classify each patient record. Our ML part is learning how to make the clinical IVT decision.

We have data on the whole acute stroke pathway. A critical part of the pathway is for the patient to have a head scan (to determine if the stroke is being caused by a bleed or a clot).

LF: If IVT is more likely to cause a bleed, is it more likely to cause it if given later?

MA: No, the chance of bleed is constant with time (MA believes to be the case, from memory). But the likelihood of a bleed is dependent on the severity of the stroke – the milder the stroke the less chance IVT will cause a bleed, the more severe the stroke the more chance IVT will cause a bleed. So we have the relationship that patients with a mild stroke will not benefit as much from IVT, but their risk is a lot lower. Stroke clinicians know this, but if a medical (emergency) doctor is making the IVT decision, they may not be away of this relationship and so be extra cautious to give IVT if it's a mild stroke.

There is a higher risk of a bleed with more severe stroke, but those patients can receive the most benefit from IVT.

We can model the acute stroke pathway and we can model the effect of these type of questions:

“What if the pathway processes were faster?”

“What if we determine stroke onset time in more patients?”

“What if clinical decision making was like that of a benchmark hospital?”

We found that one of the hospitals had the fastest arrival to scan times in the country. Most patients were scanned 15 mins on arrival, but this hospital also had one of the lowest proportion of known onset times. If the ambulance crew suspected the patient to have a stroke, the ambulance crew would drop the stroke patient directly at the scan and leave, and this could be before the stroke team had arrived at the scanner (from the stroke ward) and had the opportunity to talk to the ambulance crew and ask the question. If the ambulance crew had not written the stroke onset time down, then that information was lost. Our recommendation to that hospital was to slow down and get the right information.

Machine learning (artificial intelligence) – people often make it sound more clever than it is. Basically the model is presented with lots of data on many historical patients, it is trained on these, so that when you give it a new patient, it can look at what has happened before to similar patients and make a prediction for the new patient based on this. They need huge datasets to train on, similar to how doctors learn by having a lot from experience, and exposure to a lot of previous patients.

We have a dataset containing  $\frac{1}{4}$  million patents, so our machines have a good basis on finding patients that were similar and what happened before.

There's a gap between what the clinicians think should happen, and what is happening.

Using our pathway simulation, we answer a series of “what if?” questions. What if...

- 1) arrival-to-treatment < 30mins (in Europe 15 mins can be achieved)
- 2) you can get towards being in the top tier in finding out the stroke onset time?
- 3) the top tier of hospitals made the clinical decisions?  
(we use the hospitals own patients)

By applying these What If questions to all of the hospitals in England, we found that making those three changes together across the whole country we got 18-19% IVT rate. We can look at which change is the most import for each hospital. We found that:

- 1) Speed is important, but was only a problem in 1/10 patients
- 2) Stroke onset time was a problem in 4/10 patients
- 3) Doctors choose not to give IVT, when another hospital would: 5/10.

Idea here is, if hospitals are given a target to give more IVT, the issue is not just speed, the focus overall needs to shift to also identify onset time, and for Doctors to make different decisions that another hospital would (they could lack confidence to give IVT to a particular patient group).

For an individual hospital, we can show the impact on IVT rates if make each of these three changes, and combinations of them. Helps the individual hospital know where to focus their efforts.

The questions that we are asking in SAMueL2:

- 1) Which patients do clinicians agree and disagree on, and why?
- 2) How do organisational factors (use of specialist stroke nurses) affect the IVT pathway and decision-making?
- 3) How best can we engage clinicians in our work, and prompt them to reconsider their IVT pathway and/or decision making?

LF – you are very good at explaining.

NH: Is the IVT dose the same for all patients?



MA: Good qus – I don't know the answer, expect it could be relative to the patients weight and height. But it could be a standard amount.

LF - Are we addressing ascertaining stroke onset time

SD: why is it important?

MA: IVT offers little or no benefit after 4/5 hours, as it incurs more risk.

SD: Can you say, try it?

MA: Do you know there's no effect after 4/5hour? There's technology being designed (a new way to scan the brain to see how dead the brain tissue is) that can help to inform whether it is worthwhile to pull a clot out. For most patients, after 4-5 hours of being starved from oxygen, most brain tissue has died. The new technique (a type of MRI) can detect whether enough of your brain is alive so that if we can remove the clot, that it would be useful. At the moment it is only being talked about for use with thrombectomy? Why it's not being used for IVT, I don't know.

SD: When I was in, people at end of phone were called before the ambulance arrived, they were trying to get the onset time. I got an ambulance quickly as live near the hospital, why then is there a lag for the ambulance driver. It couldn't I suppose all the information is at source.

MA: You touch on important point. Another project we work on is pre-hospital pathway. A problem is that the hospital and ambulance don't use the same IT system. If the ambulance call handler knows something, you can't be assured that it is known by the stroke team. The systems are not tied together, the information needs to be passed along and information can get lost. The ambulance crew may have known something, but if they have left before the stroke team comes to the patient then the stroke team can not necessarily have access to all of the information collected by the ambulance team.

NH – My aunty died from a stroke. They were waiting 2 hours for an ambulance. Then took 1 hour journey going to the (not most local) hospital. If a bleed then taken to Plymouth. In this current climate (with long waits for an ambulance) is there any hope for anyone to have IVT in time?

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MA: Remember reading about Atal Gwande's experience. He is a physician, and his father was a physician in India. He talked about when his father was diagnosed with cancer. They went into a consultation, and neither of them could remember anything that was said in the consultation.

MA: SSNAP records if patient refuses IVT. This is almost never ticked. If that data is right (it fits anecdotally) patients will trust the steer of the doctor. Did you feel steered?

NH: Had massive stroke and was told that this will be the best help for him, but that there is a risk. I just thought that I've got to give it a go. What we didn't know at the time was that for Ian IVT was ineffective. After a scan the following morning we saw that the clot hadn't dispersed. At the time I felt what's the other choice. We took the risk.

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MA: Do you know if she felt comfortable

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LF: Do we need to look into this more. Is this why clinicians are hesitant to give it, if there's a risk and it also may not work. Interesting to know % of IVT not working.

MA: Really good question, I've 3 answers. 1) SAMueL2 getting outcome data, we did not get this with SAMueL1 (we didn't give enough specific reasons as to why we wanted it last time). We can now get a better understanding of IVT and time. The tricky thing with observational studies of what treatment a patient receives is that it is hard to disentangle why the patient the treatment and the outcome. We can look at it, but need to be cautious to draw big conclusions on it. 2) Anna has coded up proportions of patients with different disability levels, this gives us a more fine detail. We have not yet though looked at what proportion of patients don't benefit at all 3) Dig back into literature, and ask Martin James. Are there studies looked at that compared clot size before and after IVT?

LF: Could it be related to blood type, or blood factors? Would a blood test at the time alleviate that discussion. If it's well known, if it is a factor in clinicians minds. Not accounted for it in the modelling to far.

MA: We will ask the clinicians this at the meeting on Wed 02 Nov 2022.

Can you predict if a treatment is going to be useful or not. Or harmful or not?

In Pharma world, if you give a patient your treatment and the drug is not successful (does nothing) then the pharma companies will still get paid. Drug companies do not want to give their drug to a person that will get harmed.

Richard Everson is creating a pair of Devil and Angel models: If I give this will it cause harm? If I give this will it have an effect?

LF: You've mentioned SSNAP. Please can you explain what this is in more detail?

MA: Sentential Stroke National Audit Programme. It's a national clinical audit for stroke patients. For every single emergency stroke patient admission, their data is collected in one place - in SSNAP. It contains data about the stroke pathway (now also tied to ambulance data), known stroke symptoms, other clinical data. It's a magnificent dataset that only the NHS can have. No other country can collect this nation-wide data.

Martin James (co-lead of this project) is also the clinical lead for SSNAP. Motivated to get SSNAP being used in more constructive ways.

<< Welcome to David >>

IH Question for MA: Is there a correlation between a clinician who offers IVT and other physicians who offer thrombectomy. Is it related to if the clinician has training.

MA: Collecting data for pilot work for thrombectomy. IVT activates the body's natural mechanism for clot dissolving. Thrombectomy is mechanical removal of clot. If you have a heart attack, under CT scanner in cathlab they can go in the vein in your leg, guide it up to the block in your heart and put a stent in to open the block in the heart up. Thrombectomy is similar. They guide up (in a cath lab) a little mesh and they push it up into the right part of the brain (through blood vessels). At the clot they push the mesh up, and it can close around clot and pull it out. Thrombectomy can only be used when the clot is in a big vessel. It tends to be the worst strokes. It's easier to do this technique on them (than for a small clot). IVT is suitable for twice as many strokes. If a patient has thrombectomy the patient will usually have IVT first (to stabilise the clot). There are 23 neuroscience centres in the country. We have done work with NHSE to look at how many and where to put a thrombectomy service. If they put them everywhere, then there are not enough patients to keep up the specialist skills of the clinicians (they will not do enough of them). Modelling on how many and where. We suggested that it went up to 40, more spread around country (there are currently 7 in London – this is too concentrated).

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It's a question about whether the same people who do heart attack stenting, can they do thrombectomy? There are more people who can do these, so then more people can be trained up.

JW – You have access to large dataset, but do we have a relationship with stroke association?

MA: Yes, a loose relationship. We don't know what data they have though. We did modelling on neonatal care, working with their equivalent charity (BLISS) and they have lots of data about what patients thought were important. We've never asked the stroke association what data do you have. Maybe they have surveys. BLISS gave us original dataset. Also got information from their yearly reports. We can easily look at Stroke Association reports that they do each year, pull out any importance of IVT and thrombectomy from patients.

NH: They will have data on outcomes? The Stroke Association follow people after their stroke for longer. People progress and share information in patient groups. The lady who runs our carers group very often take our comments that we want to address and take to a meeting she attends on behalf of us.

MA: New dataset we're asking for 6 month outcomes. These are missing in cases, and possibly a bias on the cases that are followed up. For longer term outcomes we tend to rely on the clinical trials. Anything that's bigger and richer can help.

LF: Onset times interests me. In SAMueL1 we didn't look into it too much. How are we going to effect the known onset times?

MA: How are we going to effect anything? Keira's going to help us with this. We can model "If you determine more onset times, this would be the effect", and we can ask "Does this look important in

your hospital?”. The individual context is likely to be different in each hospital. As we knew the hospital we worked with before we could tell them that it’s because you’re too fast. It’s likely that each hospital will have it’s own story. What we learn for one hospital may not be applicable to another. We tend to say “Is it worth your hospitals looking into....” Onset times for example. Another interesting project is to delve into what are the individual hospital contexts on onset times. We will instead point hospitals in the direction of what aspect to focus on.

JW: If I have a stroke, I will phone for an ambulance. Won’t the phone call be a record of the stroke onset – or not?

MA: If you are awake then time of call is shortly after time of stroke. If wake up having the stroke then it is harder to determine the onset time. You can ask your partner “Did the partner have the same number of wees in the night?”. You don’t have to be sure of the exact time, you can estimate the onset time. This is a difference between clinicians whether they need precise or best guess onset time. Other information may get lost between team – unless ambulance crew wrote down precise onset time (didn’t do any more investigations) then we will not give IVT – anecdotally,

ACTION: Check proportion known onset time vs stroke severity.

NH: Are hospitals with a stroke nurse giving IVT more than hospitals without stroke nurse (their knowledge and presence could influence a new registrar/clinician, they can give them valuable support to help the new staff make that decision).

MA: Yes evidence having specialist stroke nurse have more and faster IVT. If have boring science hat on – if you know that a relationship exists, but you are not sure if it’s causal. Have to be aware that the reason there’s a stroke nurse is because the hospital invests generally in their stroke pathway (so there could be other stuff going on at the same time to improve the IVT, and it is not just causal of the stroke nurse presence).

SSNAP one day a year, ask how many stroke physicians, stroke nurse, hours they are present.

Evidence suggests that stroke nurses are very good to have, they meet the patient at the door and get the patient through the messy hospital processes. Not all hospitals have them. For some hospitals the ED coordinate the patient. But we have seen more and more that a stroke nurse is desirable. If want 24/7 and stroke nurse cover, can only have this at the big hospitals, and so not possible in the local hospitals. Trade-off, if have stroke at local hospitals

One hospital we identified in Wales that if you have a stroke in their car park, it’s better to get an ambulance and go to another hospital

DB: Ambulance decides which hospital take patient to

MA: I work on another project (OPTIMIST). Ambulances will decide where to take patients, and they will take them where they want irrespective of guidance. Have to persuade ambulance crew what we think is best. They can decide that I’ll drive an extra 10mins to take them not to the local hospital as I know that their outcome at the other will be better. We have done geography modelling in Ireland. Ambulances were going by regions (republic or unionist), and they take the patient to a hospital of “your type of Ireland”. Sometimes may be better to go to the other hospital type.

## **Introduction to the qualitative research in SAMueL2 [KPB presentation]**

KPB: Thank you. I am really enjoying, and reminds us how appropriate this work is, Hearing your experiences is so valuable.

Talk about the qualitative research. Our key aim is to understand how we can use the machine learning findings, how can we support physicians to use a tool and use the findings.

Qualitative research is a way to speak to people and to get their everyday experiences, views and perceptions. We want to look holistically – for example when a patient arrives at the hospital, how are the physicians communicating and interacting. What influences are helping them to decide whether to give a patient IVT or not. Clearly there are cases where IVT could be used, but it's not currently.

The questions that we are asking in the qualitative research:

- \* How are they currently making decisions?
- \* What may help them make decisions? What would physicians find useful to change their practice?
- \* How aware are they of the SSNAP data?
- \* How do they feel about machine learning in healthcare? Do they trust it? Use it?
- \* What do they think about some of the findings that we are trying to communicate?
- \* Any barriers?
- \* Any practical problems – if the clinician is on the go, what technology will help you to make these decisions?

Three different research methods:

- 1) Focused observation in hospitals (aim to observe the pathway and speak to physicians and get their reflections on the ground)
- 2) Interviews (explore personal and individual attitudes and experiences, drill down a bit more, what might help them as individuals when they are not as influenced by what their colleagues are saying, gather focused data from an individual perspective)
- 3) Workshop (test ideas and get feedback about findings to get reactions and responses. Later in project get good example from physicians about what might help them to make decision about IVT)

Look in more detail about these 3 methods.

In the spring, I will go to the 3 hospital sites (high, mid and low IVT rate site, also cover a mix of urban-rural areas). You brought up issues about ambulance times so we want to capture the differences of practices.

I will spend 2 weeks at each site, with part of the focus of the observation and interviews to look at the kind of organisational culture and personal perspective around the pathway ( as well as machine learning).

Someone brought up the question that it might be in the back of a physicians minds that there's very negative effects of IVT - we will hopefully capture that in the interviews (and observation) so then we can make the tool to be more effective.

We can't answer all the questions and we can't know what's going on in every hospital but we will try and get a strong sense in a representative set of hospitals.

LF: How can PCI group be involved.

KPB: The questions that you have all already brought up in this meeting are useful to help me refine my questions and learn about the context in the different pathways. For me, the question about stroke nurses is something I want to keep looking at in this research. Are there any staff members that are the most useful to learn our information (is it the stroke nurse, or is it the consultant?). Looking at the different dynamics and relationships on the ground may help us to work out the best

way to present the findings. It is useful for me to get as much context as possible. We can always learn about more questions that we want to find answers to.

LF: For the clinician workshops, are they clinicians only, or can PCI be involved? If clinicians are rubbing shoulders with PCI then if majority of people say I'm prepared to take the risk, it may be useful for clinicians to know in order to take that decision in the future.

KPB: it's not just isolated clinicians, it's about everyone around and the patient and how they are communicating between them. I like the idea of PCI being involved in the workshops with clinicians. MA what are your thoughts about this? We have a pilot workshop next week to test out a workshop.

MA: We should definitely do it. As we engage with hospitals it can be online, so it would be great to have a patients voice present. Clinician to hear a patient voice. It will help to validate to us modellers that when clinicians say they know what patients think, be good to have someone there to challenge or confirm it.

DB: For the observational study – are you going to be present during IVT delivered? Different clinicians may have different approaches.

KPB: I'm still in design and pilot phase. I aim to start the observational study in spring, as I need to go through ethics first. I will spend 6 weeks in total (2 weeks at each of the 3 sites). This will help to get a few cases of IVT during that period. Important to see the differences on a weekend vs week day. That may help us to communicate machine learning findings in a way that takes this context into account. On a week day when more busy, or weekend when no consultant there.

DB: That was my reason for questioning of IVT over different periods. Lots of hospitals have installed machine learning for scan interpretation (Brainomix). Might be worth checking out what experience the hospital has of using machine learning and whether they are already using machine learning to interpret their scans.

KPB: Good point. You have reminded me to ask people to find out what they are using already in each hospital. It might effect how they feel about the tool we want to develop. I have spoken to some registrars who use Brainomix (to determine clot or not). Some people made them feel more confident in their decisions, other were nervous about what if Brainomix is wrong. Who is to blame for following that decision? This leads into our work.

MA: Have links with team in Glasgow/Edinburgh. Doing research into how physicians are with Brainomix.

KPB: I am currently thinking through my questions. We are putting our energy into collecting data from clinicians (unfortunately we do not have patient consent, and it is not the focus on this project sadly). Does anyone have any thoughts and feelings about having a researcher present during your time in the acute phase of your stroke pathway?. Were you noticing what was happening around you?

DB: If put to the family/patient (patient not usually in a place to make a decision) that you are a researcher looking to improve and understand the process and not clinically involved in any way, a researcher to make the system better. Most people will accept this.

NH: I wouldn't have minded. The families focus is on their loved one (are they going to live or die). As long as it's nothing intrusive, you are respectful, and emotions of family taken into consideration – researcher may need to leave in cases to not put further stress on the family. The way you put the situation forward.

LF: During that phase it's a mad world all around you - giving painkillers and looking at charts. I may not have noticed an observer standing in background. I agree that most would accept.

SD: I wouldn't like it. If I don't know where I was, and what's happening to me, but a lot of time I was out of it. I wouldn't like it.

DB: Framed as a way to improve the system as an attempt to make it better.

SD: I didn't have family with me (in lock down).

KPB: It might sound strange, but you could give permission to refuse after the date. Really helpful thank you.

## **Upcoming availability**

Some people are away in upcoming months:

6-20 Dec (Ian and Nicky)

11 Nov – 6 Dec (David)