**How are families and hospitals bringing the Generation Study to life?**

**Behind the Genes transcript**

**Jenna: Hi, and welcome to Behind the Genes.**

**Rachel:** I think if whole genome sequencing can help families get answers earlier, then from a parent perspective I think anything that reduces a long and potentially stressful journey to a diagnosis is really valuable. If a disease is picked up earlier and treatment can start sooner, then that could make a real difference to a child or even Amber’s health and development.

**Jenna: My name is Jenna Cusworth-Bulger and today I have the great pleasure to be your host. I’m a senior service designer at Genomics England specifically working with the hospitals involved in delivering the Generation Study. In March 2023 we started with our very first hospital, St. Michael’s in Bristol. I am today joined by Tracie Miles who I had the utter pleasure of working closely with when they were setting up. And we also have Rachel Peck, one of the mums who joined the study in Bristol. Regular listeners to this podcast may already be familiar with the Generation Study but for those who are not, the Generation Study is running in England and aims to sequence the genomes of 100,000 newborn babies from a cord blood sample taken at birth. The families consented to take part will have their babies screened for over 200 rare genetic conditions most of which are not normally tested for at birth. We expect only 1% of these babies to receive a condition suspected result, but for those 1,000 families that result could be utterly life changing as it could mean early treatment or support for that condition.**

**Would you like to introduce yourselves and tell us what it means to you to have been that first hospital open in this landmark study. Tracie, I’ll come to you first.**

**Tracie:** Hi Jenna, lovely to be with you all this morning. And for those who are listening it is early in the morning, we get up early in the morning because we never know when these babies are going to be born on the Generation Study and we have to be ready for them. So, my name is Tracie, I am the Co-Investigator with the wonderful Andrew Mumford, and we work together with a huge team bringing this study to life in Bristol. I am also the Associate Director of Nursing and Midwifery at the South West Genomic Medicine Service Alliance.

**Jenna: Thanks Tracie. We’re also joined today by Rachel. Would you like to introduce yourself and your baby, and tell me when you found out about the Generation Study?**

**Rachel:** Hi, thank you for inviting me. My name’s Rachel, I’m based in Bristol. My baby is Amber; she was born four months ago in St. Michael’s hospital in Bristol. I first heard about the Generation Study when I was going to one of my antenatal appointments and saw some of the posters in the waiting room. Amber is napping at the moment, so hopefully she’ll stay asleep for long enough for the recording.

**Jenna: Well done, that's the perfect mum skill to get a baby to nap whilst you’re busy doing something online. So, Rachel, you said you heard about the study from a poster. When you first saw that poster, what were your initial thoughts?**

**Rachel:** I thought it was really interesting, I haven’t come across anything like that before and I thought the ability to screen my unborn baby at the time’s whole genome sounded really appealing.

**Jenna: Fantastic. So, what happened after the poster?**

**Rachel:** If I remember correctly, I scanned the QR code on the poster which took me to the website. I filled out a few simple questions online and then I was contacted by one of the research team where I arranged a formal consent conversation. That was done by Zoom I think in the evening because I’ve already got a toddler at home so post bedtime works best for me. So, we had about a forty-minute conversation on the phone where I could ask all the questions that I needed to ask and if I was happy which I was. I then gave my consent and then I believe my maternity records were kind of highlighted to say that I signed up for the Generation Study and that when my baby was born then a sample was going to be taken, and I would be given the results in due course.

**Jenna: And did all that go smoothly, that you’re aware of?**

**Rachel:** Yeah, as far as I’m aware. It was genuinely really simple to do. After that initial consultation where I signed the consent form there wasn’t any follow-up appointments so the next thing I knew, I think it was just chance, but one of the research nurses actually came down to see me on the day which was really nice. Just to say, ‘Oh, just to let you know that the team are aware.’ And then, other than that, the next thing I knew was getting the results through by post.

**Jenna: Sure. So, behind the scenes your baby’s blood was collected from the umbilical cord, that would have been registered, packaged, sent off and went on a whole journey for you to ultimately get your result. It all sounds very simple, but I think we’re going to dig into a lot of the mechanisms that kind of went behind the scenes to make something that seems simple come to life. Tracie, we met in the summer of 2023 I believe. I came to St. Michaels with a suitcase full of our materials which we had started to bring to life, including that poster. We’ve sat together and we were trying to figure out exactly how this was going to come to life in our very first hospital and how, what Rachel described, was actually going to become real. Tracie, can you tell me what you remember about those conversations and the thinking that you did as a team ahead of getting that green light to go ahead and start recruiting?**

**Tracie:** Listeners, just to let you know that Rachel hasn’t been primed to say that it was a seamless journey from delivery to getting results. I’m delighted to hear that it was. And I think the reason that we’ve achieved that in Bristol and across England now with the other teams that Jenna and the team have helped roll out, is teamwork. And part of our team is our mum, in this case Rachel. If you hear me or Jenna describing our mums as "Mia", that's the name, the significant name or the identifier we give for our participant. So, yeah, Jenna, I think the thing was it was about those first conversations. It was about teamwork and who shall we involve? We involved everybody didn’t we, Jenna? So, I know that the team, by the time they came to us they'd already been planning for two years. So, in fact what came to us in Bristol was a wealth of work and information, and two years of behind the scenes of the team working. We involved every midwife. Now a midwife is a cover all term.

We involve community midwives, research midwives, antenatal midwives, post-natal midwives. They all do different things for the mum pathway. Not forgetting dad as well, he is involved in all of this and Rachel I’m sure will testify later to the fact that when she was offered the consent, her partner was offered to come along too. UHBW, that’s United Hospital Bristol and Western, that our maternity hospital as part of, have got a fantastic R&D department and they were on straightaway with the rule book checking that we knew what we were doing. So, for those of you that aren’t in the medical world, that's making sure we’ve got the right governance, that we’re doing things by the rule book. Andrew went out and spoke to lots of different clinicians that would be involved in the pathway after the results were back, for those babies where we found a condition suspected. So, essentially Jenna, I think the list that was fairly long, grew longer and longer.

**Jenna: I think that was something that I was really struck by when I came back and visited you repeatedly after that. You were particularly good at getting some of those staff members that you might not even think about involved in the study, like the receptionist on your sonography department who you had recruited to make sure that they gave out the leaflet and the participant information sheet to all the mums coming in for their twenty-week scans etc. All that thinking was really valuable and something that I’ve passed on and taken out on my trips to other hospitals along the way. We heard from Rachel that she heard about this study from the poster. Now that you’ve been going for just over a year, what are all the different ways that people hear about the study, is it just the poster?**

**Tracie:** No, it’s not just the poster. So, essentially when we first opened, we had lots of material. We had banners, we had posters. A short leaflet that you might often pick up at the GP, a little one that you can unfold into three pieces, and then a bigger patient information leaflet which actually described the whole study and also signposted the mums and dads to go and have a look on the website to hear more about it. What we did was we literally walked the mum’s journey as she came into the hospital through antenatal and placed those posters and leaflets in the places where we knew she would see them. Now we had to be very careful about that as well because we couldn't just distribute them everywhere, we wanted to make sure that mum was getting sight of them, or mum and dad if they were coming together, at a place where their pregnancy was in hopefully, a safe position. So, that's around about 20 weeks onwards.

We didn’t want to be giving that information out in the early days of pregnancy when actually mum and dad are getting flooded with lots of information, but we wanted them to feel secure in their pregnancy and for us to feel clinically secure. That worked really well and really effectively, but there's nothing like people pairing. So, in fact getting our ultra sonographers. So, for those of you that have been through pregnancy will remember at around about twenty weeks you have a scan, it’s often called a dating scan or an anomaly scan, and we would get our receptionist to physically hand out a leaflet then.

What we have evolved over the last year working with the team from Genomics England to make sure that we keep the wording right so that we can share with all the other sites across England, because it’s good to have consistency. And also, as this evolves if this becomes standard of care, if this proves that actually this is useful for future-proofing for all of us in the public, if this study becomes something in real clinical terms, we’ve actually started sending out what we call, a signposting email. So, this is an email that goes to all of our prospective parents at 20 weeks plus, once we’ve checked that the pregnancy is safe and healthy. That has absolutely paid dividend and actually plays into the NHS future promise of analogue to digital to using those quick smart ways of working to reach our families. So, that has created a huge influx of recruits for us, Jenna.

**Jenna: That’s really interesting. We’ve sort of observed that same sort of thing. As we go through the hospitals now there's kind of three main ways that people are finding out the study. We call it like the passive way. So, that's what Rachel did which is the posters, the banners, but that doesn’t work for everyone. In hospitals poster blindness is real. And also, you’re coming for your twenty-week scan, you’ve got other things on your mind. You’re not really looking around wanting to pick up leaflets and things and obviously we’ve also got to think about our non-English speakers. Or even an English speaker who sees the poster, but their literacy isn’t very high, or their health literacy isn’t very high. So, reading a message that says something about genomics and testing, it can be quite overwhelming for people and not something that they would respond to.**

**So, then we’re signposting as our other kind of keyway and that's trying to get exactly what Tracie described, all the different staff involved. Who could be physically putting this leaflet in somebody’s hand? Who could be mentioning it albeit briefly, just, you know, this is something you might like to consider. Rachel, I want to ask you what Tracie was describing there about the message kind of being better to be given later in pregnancy or after that 20-week scan point, because of all that information overload you get earlier in your pregnancy. Does that resonate with you?**

**Rachel**: Yeah, I think that sounds about right. For lots of people when there's so much uncertainty in early pregnancy and I think some people are quite almost superstitious and don't want to sign up for things that potentially might not happen. So, I think from a personal perspective and from other friends who haven’t been quite as fortunate, I think actually waiting until a little bit later when you’ve got a little bit more headspace and mental capacity for that sounds about right. I think there's too many things early on. It sounds like you’re aiming at the right spot.

**Jenna: Absolutely. I think one of the other interesting aspects of all of this is the fact that Amber’s cord blood was taken on the day that Amber was born, and I’m interested to understand a little bit about how that baton was passed from the moment that you consented, Rachel, to make sure that that sample was taken. I know it sounds like Rachel; you were in hospital at a point that the staff were there so they actually popped down to your bedside to see you but that doesn’t always happen. Our teams don’t work 24/7 and babies do get born at 2:00 a.m. over a bank holiday weekend. But Tracie, how do you make sure that that kind of message is passed through at St. Michaels, and what's worked well and what have the challenges been?**

**Tracie**: So, a bit like how did we get the message through, is there one way? And the answer is no. There are posters, there are emails, etc. What we do do is first and foremost we encourage our mum, like Rachel here, and the dad, it might be two mums coming in together, to advocate for themselves. To say, ‘I’m on the Generation Study.’ We don’t expect that to be the only signal however because if a mum is coming in in full labour having done that a couple of times myself, I might forget. Now Genomics England have made some great bag tags, some stickers, all sorts of different visual identifiers that some hospitals around England are using, some aren’t. We in fact actually don’t get our mums to carry them, that may change. There are lots of different ways of doing it and every hospital maternity unit will find their fit. So, visual clues that mum and dad, or mum and mum, advocating for themselves as they come in, but also making sure that we have spoken with the delivery suite midwives and the theatre midwives.

Because in our hospital, which it seems to be the same sort of ratio around the country, sometimes up to about 40% of deliveries are done in theatre. So, we need to make sure we talk to our theatre staff and the people there as much as our central delivery or labour ward, for listeners who aren’t familiar with the terms. So, we make sure that we went and walked the floor in the delivery labour ward and theatre on a regular basis. So, the task for us was to make sure that our midwives, all 200 of them know that if a mum is in the Generation Study and coming in for delivery, that they know that she’s on the study. So, ways we do that is research midwives are an absolute ally, they do walk the floor. They do pop down to delivery suite and they do alert the team that there is a potential that a mum might be coming in that week with a planned Caesarean section, that's one easy. That actually can be an email. But we still do that by word of mouth, or they have a big board up in the delivery suite, which I gather is quite often the way across a lot of the country.

Also, really, really key and this once again fits with our NHS plans, analogue to digital. The majority of our sites now are taking on electronic records. So, we put a key flag on the electronic record to say that this mum is on a research study. Staff are used to that because it’s not the only research study that is happening. Now it doesn’t have to just be an electronic note, it can be done on the retro paper notes as well. So, for those of you that have got paper notes or if we’ve got mums who are holding paper notes, fear not, there is an area on the notes where we can put that too. So, it’s basically anywhere where we know the delivery midwife has sight of the babies’ notes we will put a sticker, we will say something. So, it’s one size doesn’t fit all.

**Jenna: Yeah, what you’ve described there is just so lovely and so true about it’s got to be belt and braces. The research team, the study team and the hospital might be a small number of people working Monday to Friday. Your people you completely rely on are those huge numbers of delivery midwives that need to have that message transmitted to them potentially over a 20 week timespan from the time the consent has happened to that day that that baby is born. So, what was really key as my role as service designer was going to the sites. I’m still doing this to this day, onboarding new sites all the time. We go and we speak to the sites, help them envisage how they might deliver this, how it’s actually going to work. What’s the nitty-gritty of all that mechanism that’s going to happen but making sure that what they really understand is, what's the outcome? What do we want to happen? We want as many babies as possible to have those cord bloods taken and not missed.**

**How you actually send that message whether it’s through a paper note, a sticker on a paper note, giving a pack to the family to bring in so they’ve got something physical to hand over to their delivery midwife as a physical memento. Magnets that are put on the handover boards, or any or all of these things, in lots of ways the hospitals that have still got paper notes actually find it easier because that can staple a bag with the bottle that we use for our cord blood samples and this mum is part of the Generation Study to the front of the notes. It’s more obvious than it would be as a digital flag.**

**Tracie**: I totally agree with that, it’s all about that visual cue that we were talking about earlier. We actually fund a midwifery support worker, her name’s Lauren. Hello Lauren, if you’re listening. And what Lauren does is actually she makes sure that in all the rooms where women deliver that there are little set bags with all the equipment needed to take that cord blood. She also came up with a brilliant idea and again, a visual clue and Genomics England help us to design it, a poster. We would put on the outside of the door of mum and dad when they said they were on the study. So, if you’ve got a changeover of midwives then those midwives know that they’re going into a room to support and deliver a mum that's got a baby on the study.

**Jenna: And I think that's something that's really key is what you said there about Lauren and her bright idea to create that poster and things like that, and that's been really key to how we’ve worked from Genomics England as a kind of service design kind of wrapper if you like around all of these hospitals. I have taken on the role of chief pollinator, so I’ve flown from hospital to hospital taking all the best ideas. So, Lauren’s idea of the poster, I came along and I took a photograph of that poster. That poster is in a slide and that slide gets shown when I go and do onboarding and training sessions with future hospitals.**

**Bristol were really key because as our first site and as the first early days check in we did, the photographs I took at your hospital at Birmingham Women’s and at the Rosie in Cambridge which were the first three hospitals, you still to this day make up a large percentage of what we show because you were the first to have all those great ideas and we share those out. But we don’t go round all the other hospitals, and we have found new ideas all the time and they are put together in our service design manual which is all available for all the sites. Something that St. Michael’s can refer back to to see what new things they could be thinking about. But basically, raising up the best and allowing hospitals to borrow from each other. Before we just move on from how it all works, I just want to ask Rachel, did you notice any of that or were you very busy having a baby? And did you remember to kind of advocate to yourself and mention the study?**

**Rachel**: I did remember to advocate for myself, also it was one of the jobs that I allocated to my husband as well as a, well, if I forget which is likely, can you make sure that you mention to them. I had a caesarean section. For other people who have had caesarean sections, there's quite a lot of waiting round time. So, when we were in the theatre getting ready, having a chat with the anaesthetist it was a nice opportunity to be able to take my mind off the impending surgical procedure and just mention about the Generation Study. But incidentally, they knew about it anyway. I think I remember seeing some kind of sticker or maybe the blood tubes or something on my theatre records. But see them taking the sample, I wasn’t aware, I had other things on my mind at that point.

**Jenna: Absolutely. You were cuddling Amber for the first time probably.**

**One of the things that you touched on Tracie, was you had to go round all of your delivery suite midwives and make sure they all knew how much blood to take, what tube to put it in. The fact that they had to invert it 10 times, put it in a particular fridge so that you knew where to find it. All of those are really important training messages that you had to pass on. But for you to be able to pass them on, we had to train you in the first place. So, my memory was that we came down to you one cold December day and spent a whole day with you down at St. Michaels trying our best to train you as seamlessly as we could. My memory of that day is it wasn’t terribly slick because it was our first and we’re always learning. I’d like to think we’ve got it a lot more slick now, but what do you remember about that day? And just in general kind of learning what you needed to do on the study and what kind of worked well for you, and what worked less well?**

**Tracie**: I do remember that day, it was very cold. I think what's changed Jenna is on that December day the whole team felt that they were having to take on the whole of the journey. They now as the work has developed, realise and learn the part of the journey that they need to be involved in and don't have to be concerned about the rest of the journey.

**Jenna: I learnt an awful lot and I think it’s really true that it’s really important that people who are taking the samples, they just need to know their role. But they do need to know a little bit about what the study is, why it’s worthwhile, why this mum has signed up and what value it’s going to bring to that family. I think the other thing that we learnt when we came to your training as well was in the same way that we went a bit too deep for some people in their role, we didn’t go deep enough for your team that were actually going to be doing these consent conversations. At that, at end of that training day, you still felt trepidatious about doing those conversations and so we really took that on board and then developed our informed choice cards which are like scenario cards that allow teams to kind of practice, rehearse and think through how they’re going to answer those common questions.**

**And we’ve taken those into a session that allows people who are just doing the consent conversation to go even deeper, so we do that online in a webinar now which we run monthly and that allows any new members of staff to go that little bit deeper in terms of what is this consent conversation? What is it that I need to get people to understand and be fully informed about before they come into this study?**

**A key objective of the Generation Study which after all is a research study, is to understand if the NHS and families would benefit if screening for conditions via whole genome sequencing was something that became part of NHS standard care. Rachel, can I ask you as a mum, is that something that you’ve reflected on at all and how would you feel about it?**

**Rachel**: Yeah, I’ve thought about quite a bit. I think if whole genome sequencing can help families get answers earlier then from a parent perspective, I think anything that reduces a long and potentially stressful journey to a diagnosis is really valuable. If a disease is picked up earlier and treatment can start sooner, then that could make a real difference to a child or even Amber’s health and development. So, I think that would be potentially very advantageous. I guess in a resource limited NHS that we have, there are, you know, clear challenges in rolling out whole genome sequencing for everyone. But I’m guessing that the Generation Study will provide the evidence to help understand if this is feasible or worthwhile. And clearly the Generation Study needs to show that the screening of these 200 or so conditions is as good as the existing screening that already exists. From a parent perspective, if it’s shown to be equally as good at doing that, plus all these other disorders then it seems like a win-win.

I think for me the main advantage and the main reason why I was keen to enter for Amber was if she were at risk of getting one of these rare disorders then there's an advantage to picking that up earlier for her. Because I’m aware that lots of people if they have a rare disorder, it can take a long time to get to that diagnosis and that can be really stressful for you as the parent but also for the child. Anything I think to minimise their suffering is worthwhile. So, it sounds fantastic, if it works.

**Jenna: Absolutely and I think that's what’s really nice about being involved in something like this is that the study itself is set out to find out those things. It’s not set out to find out how we could do whole genome sequencing in the NHS, it’s whether we should. As part of the study, you also consented to have Amber’s data go through into the National Genomic Research Library which leads us to one of the secondary objectives of the Generation Study which is to understand the implications of keeping a baby’s genomic data over their childhood, or even over their lifetime.**

**Amber will be contacted when she is 16 by Genomics England to find out whether she herself is happy for her data to be kept. But keeping that data for that length of time offers up opportunities for further screening for other conditions later in Amber’s life. Or using that data with your consent of course, to do further research into genes and health. And so over the next few years you may be contacted by Genomics England to invite you to take part in future studies. And, I was just wondering about how much you have been told about the potential for that and again, how you feel about that kind of aspect of being part of this study.**

**Rachel**: Yeah, that was definitely discussed quite a lot in the consent conversation that I had with Siobhan, and we were told that Amber’s data would be stored long term and that there might be future opportunities for the team to kind of get in touch or do additional testing. And I think from a parent’s point of view I guess that's the hardest thing to consent for in terms of you having to make a decision on behalf of your unborn child. But I think why we thought that was worthwhile was that could potentially benefit Amber personally herself, or if not, there's a potential it could benefit other children. So, I think that whole kind of for the greater good, that kind of prevailed.

And I think the other, not concern as it were, but other thing we wanted to discuss with that consent was the security of that data. And certainly, when I was discussing it with my husband that was his kind of main point to kind of clarify, if the data is being stored long term and if that was safe. And in terms of the safety, thinking about could future employers or can insurance companies, you know, get hold of that data? As a parent, the last thing you want to do is accidentally prevent your daughter from getting a job that she wants to get. But it was all explained that that wouldn't happen, but I think that was something that was us for us personally important to clarify.

**Jenna: I think that's really where that depth of the consent conversation is so key and why we do that sort of additional training to allow staff who may be very used to doing research and doing research consent, but never before have done a genomic consent where it’s about keeping genomic data and the implications of keeping it for that really long time. What else do you remember about that consent conversation, Rachel? Is there anything else that kind of stands out that you had to sort of really dig into with Siobhan on that day?**

**Rachel**: I’m just trying to think back because it was a little while ago. The main kind of points that I want to discuss was the security of the data and then what would happen if for whatever reason the umbilical cord blood sample wasn’t taken and if that meant that we could still be part of the study or not. It was explained that yes, there is a way, they would do an initial heel prick blood sample. But that was reassuring to know that if for whatever reason if there was some kind of emergency and it didn’t happen the way we wanted. So, I think that was the other kind of practical thing that was discussed.

**Jenna: It sounds like Siobhan sort of had by that point all of the answers at her fingertips, but that kind of links back I guess to how important it is for all the training and all of the materials, because quite a lot of the answers to those questions are in the participant information sheet. Quite a few of them are covered in the participant video which is a sort of a four-minute-long video, it’s meant to make the understanding a little bit more accessible. But it’s not relying on one route of information, it’s the conversation and that face to face you have with someone. It’s the written information and it’s those videos and other materials.**

**So, we need to go as far as we can to kind of get the word out. One of the limitations that we had, certainly back in the day when we just had St. Michael’s and a couple of other hospitals on board was that trying to get the word out about the study widely was also going to disappoint quite a lot of people who weren’t able to take part because their hospital wasn’t in it. We’ve talked a lot about this consent conversation, and I think something that's really important, underpinning for the whole study is the ethics that’s been involved and all the work that's been done around that area.**

**As the study is free and optional and taking part involves a commitment from families to have babies’ data held for at least 16 years, the consent conversation and getting that right is so vital. We touched upon this in a previous episode with my colleague Mathilde Leblond where we talked about all the design research that our team did in the build up to launching this study, so that we could really deeply understand what families wanted and needed as part of their experience. So, Tracie, we’ve heard from Rachel the things that she was concerned around, but what were your reflections as a team in St. Michaels around the ethical aspects of the study? And what has been particularly tough about that in relation to you guys in Bristol?**

**Tracie**: I would say informed consent is something that we all take as healthcare professionals, and we all hold dearly the governance. So, I was mentioning earlier that actually consent may not be a one-off situation. So, for example, Rachel had forty minutes with Siobhan. That was the conversation that she had where Rachel felt that she was enabled and informed enough to take consent, and Siobhan listening to her having that conversation with Rachel felt that that was appropriate at the time. So, consent was achieved between the two of them. Now, that wasn’t the only part of Rachel’s consent is Rachel was telling us there's the patient information leaflet that she read, so that's also part of the informed consent. And we have to be sure that our mums and the other parent of the baby have read that information.

And one of the things that I was very worried especially about at the beginning was it’s a superb information leaflet, it’s quite long, it needs to be. It signposts the parents of the unborn baby to a website which is fantastic. Do they all look at it? Not always. Would I? Probably not. So, there's no criticism of the parents here. So, one of the things that I was really concerned about from the genomics perspective of this and the data protection because this is not a one-off, this is a longitudinal study. Amber when she’s 16 years old will decide whether or not she wants to continue, so it’s not a one-off moment that her lovely mum and dad have consented her for. There's a lot that’s been consented for. All great and all appropriate and all future-proofing for future Ambers. But my concern was actually, are we getting that information across to all the mums and dads as they sign up? So, it was really important that when we were training our midwives and our genomic practitioners, those that were consenting, to make sure that they were really cognisant of the enormity of the wealth of science we were signing our parents and their babies’ futures up to.

**Jenna: Indeed, and very well said and I think you touched on something that is really close to our hearts as well that we’ve thought a lot about but still continue to do work to get right, which is the patient information leaflet if you have the health literacy and written language literacy to be able to sit and read a 16-page document, great, but not everybody does. As I’ve gone place to place and hospital to hospital, I’m always struck by the different communities that surround different hospitals and the different challenges that they might have. So, if you compare somewhere like Royal London which is in the heart of Whitechapel, I think around 40% of their birthing parents there are first generation Bengali women who have little to no English. Also, whose health literacy is quite low as well. So, engaging them takes a very different approach to an approach you might take elsewhere. So, it’s definitely not a one size fits all. Tracie, how have you adapted some of your approaches to your local communities in Bristol?**

**Tracie**: So, we have a fairly diverse population, not as diverse as the Whitechapel example that you gave, but in fact we were aware, a bit like the team in London that we have a population of Somali potential birthing parents. What we’ve done is we’ve worked with community leaders and elders from the Somali population to develop a day, or it might be a couple of mornings, for us to talk about and workshop to explain about the study. So, we have all of the information. We have the translations that have been done by Genomics England. And hat we are doing is we are working with the community elders for them to tell us the right fit. Should it be a whole day? Probably not. Should it be a coffee morning or a tea morning? Probably. Should it be where we get a guest speaker in? That was their idea. What is the key condition suspected, one of those 200 conditions that the study is looking at that is prevalent in that community? Let’s ask the community elders what they think, and we’ll do what we’re told. So, it’s been fabulous actually doing that.

**Jenna: It’s really, really great to hear about that. I think we’ve got little pockets of work like that popping up all over the country now which is really exciting to start seeing. I think at first, we were very much about getting the study up running and out there. And now we’re starting to make sure we get that reach and we get that equity, and the opportunity for all pregnant people to decide whether this is right or wrong for their family. It’s about informed choice and you can’t make an informed choice whether that's an informed yes or an informed no if you don't have the information.**

**We are proud that we go further than most research studies in terms of our accessibility, in terms of translations and we know that not English speaking is not the only barrier to access, there's lots of cultural barriers as well. But with the translated materials we support 10 languages as far as our professionally translated participant information leaflet. I was also really pleased when I found out at first that our website team had built the website in such a way that it worked not only with screen readers. So, somebody with a visual impairment could ‘read’, in inverted commas, the website but that also it translates via Google into the 160 languages that Google support, which we know Google translations aren’t perfect but they’re better than nothing.**

**And going back to what Tracie sort of said, the website doesn’t have to do everything, it’s about a conversation at the end of the day. It’s a consent conversation that can be supported by a professional interpreter but it’s about getting that initial message out there so they even get as far as having that conversation with an interpreter.**

**We heard from Rachel around her reflections for the future, Tracie, about the study potentially becoming NHS standard care and about that potential of us having Amber and 99,999 other babies’ data in the National Genomic Research Library and the potential that gives us for further research. Or for potentially re-screening those children as they grow up. When you look to the future and think about the Generation Study and what it might pave the way for, what are your hopes or perhaps fears?**

**Tracie**: So, my belief working in the genomics field is genomics is everybody’s business. So, it’s the 3 of us talking today, we’re all very keen about genomics but there is a fear around genomics. Actually, I feel that this landmark study is absolutely fantastic. It makes genomics everybody’s business. And it actually helps the whole healthcare community looking after these parents and the unborn babies as they go through the journey learn about the positivity of genomics. I think this landmark study is an absolutely win-win. It speaks to the whole family.

**Jenna: Thank you, Tracie. I’m also particularly excited about what the future could hold. I think as the service designer that's been working so closely with the hospitals, I’m really excited around what we’ve learned through this study in terms of reaching families and getting genomic information and options out to them. As you say, it is everybody. I continue to enjoy meeting new hospitals and seeing their kind of innovative take on that and kind of pollinating that back to other trusts so that we can reach as many families as possible and get that equity of access for everybody. I’m also particularly excited that we’re moving into a phase where we’re going to be learning more from the parents themselves that are taking part.**

**So, I think we’ll wrap up there. Thank you to our guests Rachel, Tracie for joining me today as we discuss the rollout and impact of the Generation Study at St. Michael’s Hospital in Bristol. If you’d like to hear more about this, please subscribe to Behind the Genes on your favourite podcast app. Thank you for listening. I’ve been your host Jenna Cusworth-Bulger. This podcast was edited by Bill Griffin at Ventoux Digital and produced by Deanna Barac.**