Behind the Genes transcript

What can we learn from the Generation Study?

**Vivienne: Hello and welcome to Behind the Genes.**

“And this is quite an exciting shift in how we use whole genome sequencing, because what we are talking about is using it in a much more preventative way. Traditionally, where we’ve been using it is diagnostically where we know someone is sick and they’ve got symptoms of a rare condition, and we’re looking to see what they might have. What we’re actually talking about is screening babies from birth using their genome, to see if they are at risk of a particular condition, and what this means is this raising quite a lot of complex ethical, operational, and scientific and clinical questions.”

**Vivienne: My name’s Vivienne Parry, and I’m Head of Public Engagement here at Genomics England, and I’m your host on this episode of Behind the Genes.**

**Now, if you are a fan of this podcast, and of course you’re a fan of this podcast, you may have already heard us talking about the Generation Study, the very exciting Genomics England research project which aims to screen 100,000 newborn babies for over 200 genetic conditions using whole genome sequencing.**

**Well, we’ve got more on the study for you now. What we’re doing to make it both accessible and equitable for all parents-to-be, and our plans to ensure that we continue to listen to parents, and perhaps in future, the babies as they grow up. We’ll chat, too, about emerging challenges and how we might deal with them.**

**I’m joined in our studio by Alice Tuff-Lacey, the Programme Director for the Generation Study, and Dalia Kasperaviciute, Scientific Director for Human Genomics, both from Genomics England, and we’re delighted to welcome Kerry Leeson-Bevers, Chief Executive of Alström Syndrome UK. And I’m just going to quickly ask Kerry, just tell us about Alström Syndrome and how you’re involved.**

**Kerry:** Yes, so Alström Syndrome is an ultra-rare genetic condition. My son has the condition and that’s how I got involved. So, the charity has been around now since 1998, so quite a well-established charity, but as part of our work we developed Breaking Down Barriers, which is a network of organisations working to improving engagement and involvement from diverse, marginalised and under-served communities as well.

**Vivienne: And you wear another hat as well?**

**Kerry:** I do. So, I’m also a member of the research team working on the process and impact evaluation for the Generation Study. So, I’m Chair of the Patient and Public Involvement and Engagement Advisory Group there.

**Vivienne: Well, the multiply hatted Kerry, we’re delighted to welcome you. Thank you so much for being with us.**

**So, first of all, let’s just have a sense from Alice Tuff-Lacey about this project. In a nutshell, what’s it all about, Alice?**

**Alice:** Thanks Viv. So, I think in the last few years we’ve seen some really big advances in the diagnoses of rare diseases through things the Genomic Medicine Service. But we know it takes about 5 years often to diagnose most of these rare conditions. What we also know is that there are several hundred of them that are treatable, and actually there can be massive benefits to the child’s health from diagnosing and treating them earlier. I think a really good example of this which is often talked about is spinal muscular atrophy, which is a particular condition where there is a genetic treatment available and there is a really big difference in families from those babies where the condition was identified later on, versus their brothers and sisters where they were identified early because they knew there was a sibling that had it and they were given that treatment.

What we think there is a huge potential opportunity to identify these children from their genome before they get ill, and this is quite an exciting shift in how we use whole genome sequencing, because what we are talking about is using it in a much more preventative way. But this is a really different approach to how we’ve been using it so far, because traditionally where we have been using it is diagnostically where we know someone is sick and they’ve got symptoms of a rare condition and we are looking to see what they might have, what we are actually talking about is screening babies from birth using their genome to see if they are at risk of a particular condition. And what this means is, this raises quite a lot of complex ethical, operational and scientific and clinical questions.

So the aim of the Generation Study is really to understand if we can and should use whole genome sequencing in this way to screen for rare conditions in newborn babies. We’ve been funded by the Department of Health and Social Care to do this over the following years, and the way we’ll be doing this is by a national study across a network of trusts in England where we are aiming to recruit about 100,000 babies and screen them for rare treatable conditions that we know present in childhood. And really the aim of this is to understand if this will work and how it will work, and to generate the evidence to allow the NHS and the National Screening Committee to decide if this could become a clinical service, and that’s very much the primary goal of the study.

Beyond that, however, there are some other aims of the study, and we also consent mothers to ask permission to retain their genomic data and to link it to the baby’s clinical data over their childhood, and we’ll be providing access to this to researchers in the de-identified way in our trusted research environment. And this is to really understand if that data can also be used to further generate information around other discovery research, but also critically understand that the motivations for parents involved will be very different, and we need to think very carefully about how we engage and work with the parents of the babies going forward about how we use their data.

**Vivienne: And the super exciting thing is we’ve started recruiting. How many mothers have we recruited?**

**Alice:** So, we’ve recruited over 3,000 to date, and it’s building every day and every week really. And it’s really exciting because we see more and more trusts coming online and the study building and really starting to learn from the experience. And every week and every month, we’re learning much more about how this process works, what the impact it’s having, and kind of what we need to do over the coming few months and years to deliver it.

**Vivienne: And we did a huge about of work at Genomics England before the study even started, to try and find out what people wanted. So, we found out, for instance, that people didn’t want to know about late onset conditions, they did want to know about conditions where there was a treatment, and they wanted things that could be done for their babies in childhood. So, we had a really clear steer from the public about this project before we even started. So, how are we continuing to learn from the people who are involved in the study and the public? I mean Kerry, you’ve been involved in this aspect. We need to listen, don’t we, to find out what’s going on?**

**Kerry:** We do, we do, and I think it’s really encouraging to see the public dialogue and the amount of engagement work that was done there to kind of identify what some of those areas were, but it’s really important that we don’t stop that engagement there. It’s really important to continue that, and I know that we’ve got quite a diverse group for our Patient and Public Involvement Advisory Group and the Evaluation Team, and one of the things they’re really interested in is how we’re going out there to speak with communities. You know, we can’t just be reliant on the media, and press releases about the study. We need to actually go to communities and have these conversations so that people can have a conversation within an environment that they feel safe and confident with the people that they feel supported by as well.

So I think it’s really key that we continue to ask those questions but also learning from the evaluation and, as we go through the process, of speaking to the patient organisations as well who support families that suffer from some conditions that we plan to identify through this study, and learn what some of their challenges are as well. You know, do they feel equipped to be able to support parents that are getting a diagnosis? As well as obviously their participants and the general public, to make sure that we’re aware of attitudes and perceptions as the study goes along.

**Vivienne: Because there’s always a danger with this kind of study that it’s people who are health literate who end up being involved. Whereas some of the people on whom the burden of rare disease is greatest may not either feel that they can access, or would want to access, this study. So, what are we doing there? How are we listening to people?**

**Kerry:** When we are looking at recruitment as well, like you say, you know this is a research study and when we look at history and when we look at participants in research studies, we very rarely do you get a diverse representation of people in these types of studies. So, it’s really important that those extra efforts are made really in terms of recruitment to get the right sample of people involved. And I know at Genomics England, that they have invested their time and money in terms of interpreters and translating materials and things, but actually it’s the sites and recruiting people that need to be well resourced in order to use recruitment strategies, because if we’re just looking at posters in waiting rooms, for instance, you’re going to get a particular demographic of people that will respond to those kind of posters, such as people who don’t speak English as a first language, it would be really difficult sometimes to read those kinds of posters and then to ask questions about that.

We need skilled people within sites that are recruiting who have got cultural competence who can have those conversations, address some of those areas, some of those concerns so that we can get that diverse representation.

**Vivienne: So, there’s a whole piece about equity of access for everybody and Dalia, perhaps you can explain why this is so important, scientifically as well as ethically? There’s another piece about making sure that we get a full diversity represented.**

**Dalia:** We know that some of the conditions are more common in certain populations or certain communities. We also know that some of the conditions are caused by certain variants in one population but not in the others. And these genetic causes even of the same condition can vary between different communities and different genetic ancestors. On the other hand, our knowledge about the conditions and the genes, and the variants which cause them, come a lot from what we’ve seen before. Where we’ve seen those variants in the patients with the disease, and importantly where we’ve seen those variants in control populations where these individuals which don’t have conditions.

Therefore, if we lack the diversity in our datasets, we would not know about all the diverse reasons of why conditions can be caused, or how it progresses, or what it might mean for individuals. And we would not be able to have equitable testing, or we wouldn’t know whether the test works for everyone. If that happened, we might be in the territory where we can’t detect or don’t detect as well all the conditions across different individuals. But also, we may be having more false positive results and create more anxiety for families as well as burden for healthcare system.

**Vivienne: So, are you saying, Dalia, that actually sometimes we might get a false positive, or indeed a false negative, simply because in that person, the condition which we think is usually caused by a particular change, they’ve got a slightly different change and so therefore we’re not picking it up.**

**Dalia:** Indeed, but it’s one of the possibilities. If, let’s say, all our knowledge about certain genes came from a limited number of individuals, seeing a new variant in another individual might seem that it’s something really rare and never seen before and it’s potentially changes how the gene functions, we would say; “oh that’s maybe something which causes the disease,” when actually it can be that it is a benign variant, just a normal variation which is very common in another part of the world, it’s just that we don’t have enough data to know about it. So, we need to be aware of those risks and take it into account when we interpret the variants.

And, we also need to be transparent when operating in the environment. There was historical and investment in the diversity in research and our data sets still are not as diverse as we would like to be. It’s shifting, the balance is definitely shifting in the last few years. A lot of effort is being done but the only way to shift the balance forever and make that genomic medicine work for everyone is to really actively engage those individuals and involve them in the research, and taking all the effort that Kerry was talking about.

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**Vivienne: Alice, that goes back to this thing about holding the genomic data, because you need to hold the genomic data because the thing about genomics as always, you need to know what happens next. So, for instance, if somebody had a negative result and then later developed a condition, you need to be able to go back that data in order to find out what the problem was.**

**Kerry:** That’s right. You know, as Dalia talked about, we know that there is a risk within the study and we try and be clear about that in our participant information that there are some babies where they may have a genetic condition that we will need not find it, and others where we might find something that doesn’t go on to be the actual condition. And we need to kind of monitor those in different ways.

So in particular in the cases where, if we’ve returned a result where we don’t think we suspect a condition and a baby goes on to develop a condition, it’s quite complex how we monitor that, and we’re trying to go for a multi-track approach, and I think a lot of the benefits is some of the infrastructure that Genomic England already has that we can utilise. So, some of the foundational things we’ve put into the study to help support the approach are things like the ability to contact parents regularly so we can actually work with them to find out over time if their babies develop conditions.

As you say, ability and consent to access the clinical data about the baby so that we can then access national data sets, and then we can then potentially monitor to see if babies seem to be showing signs of developing a condition. And also, really continuing to work with a network of clinical specialists where we’ve work quite hard over the last couple of years to build that kind of network and engage with them about the study, because they’ll be the ones who the babies will come to if they develop those conditions. So, they are a really good route to us finding out, whether or not there are babies who have been part of the study who then go on to develop a condition.

And I think the reality is that this is a really complex process and it’s something that even traditional screening programmes really struggle with, and that’s why this multi-pronged approach is really important, and why also we see that this approach will evolve over time, and at the moment, the important thing is we’ve worked hard to put the right foundations in to allow us to do this type of monitoring, and to really evolve that approach as things develop and as more things come along potentially where we can invest in.

**Vivienne: So, it’s interesting, isn’t it, because I guess that some parents would think that if you get a false positive or false negative, that it means that the test is at fault. And actually the accuracy of the test is good, but what we may have an issue with is that there is something else causing the problem that we don’t yet know about. So, a big part of this project is giving much, much more information about the causes of conditions.**

**Alice:** Yes, and I think that’s also why the discovery research aspect is really important, the fact that we consent for that ability to hold the baby’s data. So not only will we want to use it for the evaluation, but as I mentioned at the beginning, we have asked for parents to be able to allow us to link it to clinical data which then allows us to track over time and find out more information, because it’s always the quality of the information we know that will help us in the future to identify these conditions, so the more we can generate potential information, you know, the more we will learn as a society.

And so it’s actually quite an altruistic thing we’re asking of parents, and that’s something we recognise and that’s why it’s also important we think about, how we continue to engage with the parents and the baby over their lifetime to remind them that we’re holding this data, but also to understand what their concerns and feelings are about us holding that data and how we’re using it for that broader research.

**Vivienne: And that’s very much what you’re involved in, isn’t it Kerry?**

**Kerry:** Yes, and I think sometimes in some ways that may offer some reassurance to parents as well, to know that’s there as a reference point if things do develop over time, but I know that one of the things we’re looking at as part of the evaluation, and the PPI Group we’re involved in, is looking at the experiences of patients through this journey because actually it will create quite a lot of uncertainty.

As a parent of a child with a genetic condition, that uncertainty really is one of the hardest things to learn to live with. So at that early stage, one of the things we’re looking at is that experience, how much support people have received, whether that has an impact on the parent and their child and their on bonding and their experiences and things like that, and I think it is important that we do that, but I think also having those references, where you’re able to go back and ask those questions, that’s really important that the support is in place, and that pathway really for parents to know where to go to. Because sometimes, although we may arrange to have calls at regular intervals and things, sometimes the questions of parents don’t necessarily come at the time when they are having a telephone call. They come really late at night when there’s nobody to pick up the phone, so having as much information as we can available, and those support structures in place, is really key.

**Vivienne: We all start off these projects thinking that they are going to go in a particular way, but actually there’s a lot of flexibility in this study, isn’t there, Alice? For instance, we will be looking at all those false positives, false negatives because we need to learn from that. We will be, perhaps, changing our approach as we go on if there is something that isn’t working out. Is that what we’re doing?**

**Alice:** Yes, I think what we have recognise is it is a study and therefore that involves learning by it’s very nature, and that’s why partly we’re working with external evaluation partners that Kerry’s involved with, but also why we invest in a lot of things internally. Like we do a lot of user research with our midwives and our participants, and also potential participants. Because, actually we don’t know the answer to this. No one’s done this before, and so this is about all of us really learning, and learning in the right way and continuing to do that throughout the study, but also more importantly capturing that information and making sure that at the end of it, we then have some understanding of if we were to see that it’s right to deliver this as a clinical service, what that might actually involve.

But also, even if we get to that point, I think beyond that we will still continue to learn over time and that’s again why that long enduring consent is quite important, because we can then continue to maintain that long term evaluation and continue to maintain that long term potential to help further further research. And so that’s the thing where actually we’ll be learning for the next 10-15 years, really what the Generational Study has learnt, and actually what we have achieved through it.

**Vivienne: I just want to move back to something that you mentioned, Kerry, about conditions that we’re looking for, and there were a lot of very specific things. I’ve said that what parents wanted, but there’s also some scientific things, and Dalia might want to come in here, that these are conditions that we pretty sure that if you’ve got the particular genetic change, that you will get the condition – something called penetrance. So, you know, we’re not leaving people with a lot of uncertainty. But, how will we go about assessing new conditions as part of this study, or are we just on the ones that we’re on at the moment?**

**Dalia:** So, we started from the things we understand the best and we know how to detect them and we know how to confirm them because the tests that we are doing in Genomics England is a screening test, it will not be a definitive answer whether you have or you don’t have a condition. Anyone which will get a positive result will be referred to an NHS specialist clinician for further assessment. And some of those positive results turn out not to have the conditions and some of them will have, and they will have their treatment pathways. So, we’re started to very cautiously, and that’s what came from public dialogue, everyone was saying that; “you need to be really cautious, we need to see that it works for the conditions that we understand well”.

But as a starting point, as we learn more, we’re learning of how could we expand that list. What would be acceptable for public. Maybe some conditions will have an experimental treatment, which currently would not be included in screening but as treatments evolve, at some stages maybe there will be opportunities to include some conditions in the future.

As our science evolves, we keep assessing the new conditions and seeing can we include them, would it be acceptable to parents, would it be acceptable to the healthcare system, and one of the things about screening it’s really important not to cause harm. There are a lot of benefits in screening but if we didn’t do it cautiously, it also has some risks, and we need to be very careful about it.

**Vivienne: Now Kerry, there are lots of parent groups who will come along to us and say; “oh you must include this condition,” but perhaps there isn’t yet a treatment, or there isn’t a pathway in the NHS that will help people get what they need. And I guess if we try to include too many conditions, we would actually undermine trust.**

**Kerry:** So, the patient organisation, our condition, Alström Syndrome, isn’t included in the list. For our condition, there is no specific treatment although we do have a highly specialised service, and it is very important to get early diagnosis because children can develop heart failure and there are symptom-specific treatments available there. But I get the reasoning why there needs to be a specific treatment and the need to include just a smaller group at the beginning, but our hope as with I’m sure a lot of other patient organisations, is that our condition will be added at a later time if it is found that this is something that would be acceptable in routine care.

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**Vivienne: Let me move on to another aspect of this study. These are babies, and we are holding their genomic information but at 16, they will be able to decide whether they want us to continue holding their genomic information. Alice, is that very much part of this programme to think about what we’re going to say and how we’re going to engage those 16-year-olds?**

**Alice:** Yes, it very much is. What I always say, because I get asked this question a lot, is that I don’t think we can pre-judge what that looks like. Because I look at my children, and certainly their lives are very different from my childhood, and I don’t think we can imagine exactly what our babies will look in 16 years and what that world looks like. I think the important thing is many of things we are trying to do is that we lay the right foundations in place, and part of that is ensuring that we continue to think about how we engage with young people as the study evolves and over time, so that we understand what the world is looking like from their perspective.

But also, how do we equip the parents to talk about the fact that these babies are part of the study to them? What does that look like? How can we support them? And that’s very much something we want to be looking at in the next year, really working with parents from the Generation Study to understand how best we can do that so that they can have some of that conversation for themselves as well. I think we can’t pre-judge exactly how we need to talk about them and also not think it’s just one thing. We need to evolve and work with the children as they grow up, and work with their parents to equip them because, as I said, we don’t really know how they’re going to access information in the future. You know certainly TikTok didn’t exist when I was a child, and so that’s what we’ve got to think about is what’s the best avenues or forums to really engage properly with them as they grow.

**Vivienne: Kerry, what other concerns to parents have that we’re learning now?**

**Kerry:** I think the concern is that when treatments are being developed, that they are not necessarily being developed for the whole population. They’re often being developed for sub-sets of population because we don’t have a complete dataset. And when you think about people being involved in research, people feel that they are being left behind because their data is not necessarily represented within there, it doesn’t reflect their community, and it’s not being discussed within communities, the different research opportunities and things have been available, I think it’s the fact that we’re not investing enough in community engagement and dialogue to explain more about genetics.

I think technology has advanced at pace. As a parent of a child with a genetic condition, that is very encouraging to see that, but I think sometimes the support and the information is not necessarily keeping up, so we’re not having those open conversations really about genetics and genomics, and I think that’s one of the things I hope that this study will really lead to, that it will now become much more part of everyday conversation.

Because often, when you have a child with a genetic condition, you first hear about a condition, the way you take in that information and ask questions is very different than having a conversation with the general public about genetics. When you’re concerned that your child may have a condition or you may have a condition yourself, you’re in a completely different mindset. So, the hope is that that dialogue will open so that people will be able to ask questions to learn more about the projects and things that are out there and available so that people are included and can take part in research if they want to. But it’s important to remember that not everybody will want to. It’s about being given informed choices and to do that we need to make sure that the support and the information is appropriate, inclusive and accessible.

**Vivienne: We always have to remember, don’t we, that if people say no to these things, it’s not a failure to on our part, or a failure on their part. It’s just something they’ve thought** **about and they don’t want to do, and for all sorts of different reasons. And the other reflection I have about different communities is the ‘different’ bit, is that what approach works for one community may not work for another, and I think that that’s something that’s going to have to evolve over length of the study, is finding the things that are the right way, the most helpful way to approach people.**

**Kerry**: I completely agree. I think it’s like you say, if people say no, that is completely their right to do so as long as they’re saying no when they’ve been given the information to be able to really take that on board, think through, consider it and then make an informed decision. I think often people say no because they’ve not been given the right information to be able to understand what is expected, so they’ve not necessarily been given the opportunity. And I think we all want good outcomes for everybody. That doesn’t mean delivering the services in the same way. Sometimes we need to deliver services in different ways because often services aren’t very accessible for some communities to be able to access. So sometimes we need to make changes, adapt, to make sure that everybody has the same opportunities to the same outcomes.

**Vivienne: We are constantly re-evaluating, rethinking, re-engaging to try and make it the best we can. Whether it’s with different communities and different approaches. Whether it’s with constantly assessing people who’ve had false positives, false negatives and finding out why that is the case. And in the future, I think this will have some really major effect. Dalia, you’re the scientist amongst us today. Tell us what you’re hoping for from this study in science terms.**

**Dalia**: So, first of all, we want to find the babies which we can treat before we develop symptoms, before we get ill, so that we can have more fulfilling lives. That’s the bottom line. But we’re doing that, we also will learn about the conditions. We’ll learn a lot about the natural history of the conditions. What happens when you detect it before baby gets ill, then you start treatment, and how does it work in the diverse communities and diverse populations that we’ve talked about. Are there are any differences based on people’s ancestry, but not just ancestry, about their lifestyle, about anything else which can affect how disease develops, or how the care or treatment goes.

So, that’s kind of the bottom line. The top line and now our ultimate aim, probably many years from now, would be that we can detect variants of genes or conditions before they develop, and we can create treatments for them before our children get their conditions. That’s something that the science community is very excited about. I think we’re quite a few years from that, but that’s where we hope all this will be heading in the future.

**Vivienne: It’s really becoming a possibility, but the science is only the first part of it. It’s the human interaction. It’s the how it lands with people. It’s how they feel about it. It’s how they trust it. And these are all the things that we’re really working on at Genomics England to make this study not just a scientific success, not just a success for the NHS, but also something that is really meaningful and important and valuable and trusted for people having babies. Would you agree?**

**Alice:** Yes, 100%. I think, just to come in there, Viv, I think we’ve talked a bit about the importance of public trust and being the foundations of what we do, and I think that’s something that Genomics England’s always held true to itself, but I think for the purpose of the Generation Study, it’s been one of kind of the foundational principles from the beginning, and I think Kerry and you have touched upon some really important themes today about how it’s not a ‘one size fits all’ approach. And I think very much that piece that we touched on a bit about, kind of, how do we make this accessible to everybody, we see it very much as not a ‘one size fits all’, and so we’ve been trying lots of different things to really tackle that, and evolving the approaches which, as you said, that’s where the flexibility comes in.

My hope for the next 12 months is that we can really, now that we’ve got the study up and running, work a lot with the some of the regional networks, the Genomic Medicine Service alliances who are working at the regional level, and the recruiting trusts, to really explore different approaches and work out how we can support them to engage with the communities in their areas, because they’re the ones who will understand who they are, and our role is to really try and provide, as Kerry highlighted, the tools of support to allow them to do that, and to try and make sure that we can make this as equitable as possible in terms of people being able to at least understand the studies here, get the information in the appropriate way, and then as we have also talked about, making their own minds up about whether this is the right thing for them to be part of.

**Vivienne: So, the final question for you all is if I’m a mother-to-be, where can I find out more information. Let’s start with you, Kerry.**

**Kerry:** Well, from the Generation Study website, there’s information there. Midwives, GP practices, obviously they’re often going to be your first port of call, so I’m hoping that they feel equipped to be able to answer those questions and to signpost people to one of the trusts that are involved.

**Vivienne: And we’ve also got a Genomics 101 episode where we answer some of the frequently asked questions, and I think there are at least 2 or if not 3 separate episodes from Behind the Genes, which people can look for which look at different aspects of the project. Anything else, Alice, that we need to know?**

**Alice:** So, Kerry highlighted it, the Generation Study website is a really good starting point, but that’s a good place to also find out what trusts are involved because it’s also important to know that this is not available in all trusts in England at the moment. We have a network and it’s growing, and it is all around England, but the first place to start is, kind of, is it in your local trust? And then from there, it’s then engaging with your trust and hospitals where there will be information, and the midwives are prepared to kind of talk to people. So those are, kind of, the good first places to start.

**Vivienne: Well, we’re going to wrap up there. It’s been so good talking to you all. So, thank you to our guests Alice Tuff-Lacey, Kerry Leeson-Bevers, and Dalia Kasperaviciute for joining me as we talked through how the Generation Study is continuing to evolve as it responds to emerging challenges.**

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**I’ve been your host, Vivienne Parry. The podcast was edited by Bill Griffin at Ventoux Digital, and produced by Naimah Callachand at Genomics England.**

**Thank you so much for listening**. **Bye for now.**