**Behind the Genes Transcript**

**How do people feel about using genomic data to guide health across a lifetime?**

**Harriet: Welcome to Behind the Genes.**

**Suzalee:** I have come to terms with the thought that life is unpredictable and I have already begun to accept any health condition that comes my way. Believe you me, I have been through the stage of denial, and yes, I have frozen upon hearing health diagnoses in the past but now I believe that I am a bit wiser to accept the things that I cannot change and to prepare to face the symptoms of whatever illness I am to be dealt with or to be dealt to me. If the analysis of my genome can help me to prepare, then yes, I am going to welcome this programme with open arms.

**Harriet: My name is Harriet Etheredge, and I am the Ethics Lead on the Newborn Genomes Programme here at Genomic England. On today’s episode I’m joined by 3 really special guests, Suzalee Blair and Gordon Bedford, who are members of Genomics England’s Public Standing Group on Lifetime Genomes, and Suzannah Kinsella, Senior Associate at Hopkins Van Mil, a social sciences research agency that has helped us to facilitate this work.**

**Today we’ll be discussing the concept of the lifetime genome. What do we mean when we say, ‘lifetime genome’? How can we realise the promise of the lifetime genome to benefit people’s healthcare whilst at the same time really appreciating and understanding the very real risks associated? How do we collectively navigate ethical issues emerging at this genomic frontier?**

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**Let’s get on with the show. I’ll start off by asking our guests to please introduce yourselves. Suzalee, over to you.**

**Suzalee:** Thanks, Harriet. So I am a proud mum of two kids, teacher of computing at one of the best academic trusts in the UK, and I am also a sickler, and for those who don’t know what that means, I am living with sickle cell disease.

**Harriet: Thank you so much, Suzalee. Gordon, over to you.**

**Gordon:** I’m Gordon Bedford, I’m a pharmacist based in The Midlands. I’ve worked in hospital and community pharmacy. I have a genetic condition, which I won’t disclose on the podcast but that was my sort of position coming into this as I’m not a parent of children, but it was coming in from my perspective as a pharmacist professional and as a member of society as well.

**Harriet: Thank you so much, Gordon. And, last but certainly not least, Suzannah.**

**Suzannah:** So, yes, Suzannah Kinsella. I am a social researcher at Hopkins Van Mil, and I had the pleasure of facilitating all of the workshops where we gathered together the Public Standing Group and working on reporting the outcome from our discussions, so delighted to be coming in from South London.

**Harriet: Thank you so much, everyone, and it’s such a pleasure to have you here today. So, many regular listeners to Behind the Genes will now that Genomics England is currently undertaking the Generation Study. I’m not going to speak about it in much detail because the Generation Study has already been the subject of several Behind the Genes podcasts and we’ll put some links to these in the show notes for this episode. But briefly, the Generation Study aims to analyse whole genomes of 100,000 newborn babies across England, looking for 250 rare conditions. We have a view to getting these children onto treatments earlier and potentially enhancing their lives.**

**The Generation Study is a research project because we don’t know if the application of this technology will work. And as a research project we can also answer other important questions, such as questions about a lifetime genome. When we invite parents to consent to the Generation Study on behalf of their newborn babies, we ask to store babies’ genomic data and linked healthcare data in our trusted research environment. This helps us to further research into genes and health.**

**But a critical question is ‘what do we do with these data long term?’ And one of the potential long-term uses of the data is to revisit it and re-analyse it over a person’s lifetime. We could do this at critical transition points in life, like adolescence, early adulthood or older age, with the aim of using the genomic data to really enhance people’s health. But this is a very new concept. There’s been little work on it internationally, however I am pleased to say that interest seems to be picking up.**

**In the Generation Study, whilst we are at the present time doing no lifetime genomes work, we are looking to explore the benefits, risks and potential uses of the lifetime genome. This Public Standing Group on lifetime genomes was our first foray into this area. So, I’d like to start off by inviting Suzannah to please explain a bit more about what the Public Standing Group is, why it was created and how a group like this helps us to generate early deliberation and insight.**

**Suzannah:** So, the first thing I should talk about is who were these 26 people that formed part of this group, and the first thing to say is that they were a wide range of ages and backgrounds from across England, so some from Newcastle, some from London and everywhere in between. And these 26 people all had one thing in common, which is they had all taken part in a previous Genomics England public dialogue, either the whole genome sequencing for newborn screening which took place in 2021, or in a more recent one in about 2022/23 which was looking at what should Genomics England think about in terms of research access to data that’s drawn from the Generation Study.

So, the great thing was that everybody had already some previous knowledge around genomics, but the concept of a lifetime genome was completely new. So these 26 people met on 5 occasions over the period of 2024, mostly meeting face to face, and really the task that they were given was to look at the lifetime genome and look at it from every angle; consent, use, information sharing and all sorts of other aspects as well.

**Harriet: Gordon and Suzalee, you were participants in our Public Standing Group, I’d love to hear from you what your roles in the Standing Group were and what you found most interesting, but also for** **you which bits were the most challenging. Suzalee, shall we start with you?**

**Suzalee:** For me the most interesting bits were being able to learn about one’s genome and, through Genomics England and their possible use of pharmacogenetics, could determine the specific medication that could be prescribed for a new health condition instead of expensive and possibly tonnes of adverse side effects trial and error medications.

Additionally, as a person living with sickle cell disease, I got the chance to share my story and to give voice to people living with the same condition or similar to myself, and how the potential of the genomics newborn programme could help our future generation.

There were some tricky bits, and the most challenging bit was to initially discuss and think about the idea of whether or not a parent might choose to know or not to know the potential of their newborn developing or prone to develop a certain condition based on the data received from the programme. My thought went back to when I gave birth to my first child 16 years ago and I was adamant to know if my child would inherit the sickle cell disease, what type, if it would be the trait. In my mind I knew the result, as my haemoglobin is SC and their dad is normal, but I wanted to be sure of my child’s specific trait. But then I asked myself, “What if my child was part of the Newborn Genomes Programme, then the possibility exists that other health conditions could be detected through the deep analysis of my child’s genome. Would I really want to know then? What would be the psychological effect or, in some cases, the social impact of what I have to learn?”

**Harriet: Thank you so much, Suzalee. And I think it’s just wonderful to hear about the personal impacts that this kind of work can have and thank you for bringing that to us. Gordon, I’ll hand over to you. I’d be really interested in your thoughts on this.**

**Gordon:** So my role in the Public Standing Group was to give my section of society my experiences in life to bring them together with other people, so experiences like Suzalee and the 24 other people that joined us on the study, to bring our opinions together, to bring our wide knowledge and group experiences of life. And it’s important to have a wide group, because it forces us to wrestle with differences of opinion. Not everybody thinks like I do. As a pharmacist, I can see the practical side of genomics, like pharmacogenomics, where we could use a baby’s genome to predict how they’ll respond to drugs over their lifetime. That’s a game-changer for avoiding adverse reactions or ineffective treatments, but not everybody’s sold on it.

Some in our group worried about privacy, who gets this data, or ethics, like whether it’s fair to sequence a baby who can’t say yes or no. I get that. I don’t have children, but I hear those things clearly. The most interesting bits for me, the pharmacogenomics discussion in meeting two stood out, everyone could see the tangible benefits of tailoring medicines to a person’s genome, making treatments more effective, and in Meeting 5 designing our own lifetime genome resource was also fascinating. Ideas like it for public health research showed how far-reaching this could be. Some of the challenging sides of things that I came across, the toughest part was grappling with unknowns in Meeting 4, like how to share genetic info with your family without damaging relationships. Those risks felt real, and it was hard to balance them against the benefits, especially when trust from groups like minority ethnic communities is at stake.

**Harriet: Thank you so much, Gordon. I think from you and Suzalee it’s so fascinating to hear how you were grappling, I think, with some of your personal and professional feelings about this and your deeply-held personal views and bringing those first of all out into the open, which is something that is very brave and we really respect and admire you doing that, and also then understanding that people do hold very different views about these issues. And that’s why bring these issues to an engagement forum because it’s important for us to hear those views and to really understand how people are considering these really tricky ethical issues.**

**So, Suzalee, I’m wondering from your perspective how do you feel we can really be respectful towards other people’s points of view?**

**Suzalee:** Yes, Harriet. In spite of the fact that we had different viewpoints on some topics discussed, every member, researcher, presenter and guests were respectful of each other’s point of view. We all listened to each other with keen eyes, or sometime squinted eyes, with a hand on the chin which showed that what was being said was being processed or interpreted. All our views were recorded by our researchers for further discussion and analysis, therefore I felt heard, and I believe we all felt heard.

**Harriet: Do you have any examples that you can recall from the groups where there were differing points of view and how we navigated those?**

**Gordon:** Where we had screening at age 5, but we agreed on an opt-out model, because it could help spot issues early. But some worried - psychological impacts, knowing too much too soon. But we looked at an opt-out model rather than an opt-in model because it’s easier to say to somebody, “If you don’t want to continue with this, opt out” rather than trying to get everybody opting in at every different age range. So, as we reach the age of 5, 10, 15, 20, whatever, it’s easier to get people to opt out if they no longer want to be part of that rather than trying to get them to opt in at each stage throughout their life.

**Harriet: Suzannah, do you have anything to add there as a facilitator? How did you feel about bringing these different points of view together?**

**Suzannah:** Yeah, you asked about where are the tensions, where do people maybe agree a bit less or agree and hold different views, and I think what stands out is particularly… There was an idea floated by one of the speakers about you could have your DNA data on an NHS app and then, let’s say if you’re in an emergency, a paramedic could have access to it or others. And that really I think brought out quite a wide range of perspectives of some in the group feeling, “You know what, anyone who has an interest, anyone that can help my health, let them have access to it as and when, completely fine,” and others took a more cautious approach saying, “This is my DNA, this is who I am, this is unique to me, my goodness, if someone, some rogue agent manages to crash the system and get hold if it goodness knows what nightmare scenario it could result in,” and so had a much more keep it locked down, keep it very limited approach to having access to your lifetime genome data and so on. So that was a really interesting example of people going, “Yep, make it free” and others going, “No, just for very specific NHS roles,” which I thought was fascinating.

**Harriet: Yeah, thank you so much, Suzannah. And I think it’s a real tangible challenge that those of us working in this area are trying to grapple with, is finding the middle ground here with all of the challenges that this involves, for instance, our data infrastructure and the locations at which data are held.**

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**Harriet: I think this brings us really nicely onto looking at some of the ethical, legal and social issues that we need to think through when we’re considering the lifetime genome. I’m wondering if we can expand on some of these and the importance of addressing them. Gordon, would you like to give us your thoughts?**

**Gordon:** Sure, thank you. Our job was to dig into how a baby’s genome could be used over the lifetime, think pharmacogenetics for better drugs, early childhood screening for conditions or carrier testing to inform family planning. We saw huge potential for individual health like catching diseases early, but also broader impacts like reducing NHS costs through prevention. Weighing the risks and benefits. The benefits like earlier diagnosis or research breakthroughs grew clearer over time with ratings rising from 4.1 to 4.7 - that’s out of, I believe, a figure of 5, but risks like data breaches and family tensions over shared genetics stayed significant. We agreed the benefits could outweigh the risks but only with mitigations like transparent governance and strong security. And what are the global implications moving forward? What we discussed isn’t just for the UK, it’s feeding into the global conversation about newborns in genomic research. That responsibility made us think hard about equity, access, and how to build public trust.

**Harriet: Thank you, Gordon, I think there’s so much there to unpack. And one point I think in particular that you’ve mentioned, and this came out really strongly as one of our main findings from these groups, was the way that a lifetime genome and the way that we might deliver that information could really impact family dynamics in ways that we might not have really thought of before or in ways that we really have to unpack further. And, Suzalee, I’d love to hear from you about this, how might diverse family dynamics need to be considered?**

**Suzalee:** Harriet, as it relates to diverse family dynamics a burning legal issue, which is then triangulated into being considered an ethical issue as well as a social issue, was the question can siblings of sperm donors be informed of life-threatening genomic discoveries? Whose responsibility is it? Will policies now have to be changed or implemented by donor banks to take into consideration the possibility of families being part of the new genomes programme?

**Harriet: Yeah, thank you, Suzalee. I think there’s so much there that we have to unpack and in the Generation Study we’re starting to look at some of those questions, but going forward into potential risks, benefits and uses of the lifetime genome, all of these new technologies around human reproduction are things that we’re going to have to consider really, really carefully through an ethical and legal lens. Suzannah, I wondered if you have anything to add to these as major ethical issues that came out in these groups.**

**Suzannah:** I think, as you say, people were so fascinated by the idea of this information landing in a family, and where do you stop? Do you stop at your siblings, your direct family, the brothers and sisters of a child? Do you go to the cousins? Do you go to the second cousins? It’s this idea of where does family stop. And then people were really interested in thinking about who does the telling, whose job is it? And we had this fascinating conversation – I think it was in Workshop 3 – where this very stark fact was shared, which is the NHS doesn’t know who your mother or your father or your siblings are; your NHS records are not linked in that way.

And so that presented people with this challenge or concern that “Actually, if I get quite a serious genetic condition diagnosed in my family whose job is it to share that information, what support is there to do that and how far do we go?” So, I think people were really fascinated and hopeful that Genomics England will really be at the vanguard of saying, “How do we as we move into an era of more genetic data being used in our healthcare, how’s that managed and how’s it shared?”

**Harriet: Yeah, thank you so much, Suzannah. So I think that what’s coming out through everything that you’re all saying is the huge breadth of issues that came up here. And of course we’re seeing, very encouragingly, so many nods to the potential benefits, especially around things like pharmacogenomics, but we are seeing some risks. Gordon, I wondered if you’d like to elaborate a bit further.**

**Gordon:** So, something that came up, and it divided the group quite considerably, carrier status divided us. Some saw it as reducing disease prevalence and others feared it could fuel anxiety or stigma amongst the family or other families. It showed how personal these choices are and why families need control over what they learn.

**Harriet: Yeah, it’s a very good point, and carrier status is something that could be a conceivable use of our lifetime genome record. Suzannah?**

**Suzannah:** Just building off what Gordon was talking about, I remember there were also discussions around are we getting into a state where this is about eradication of so many different conditions, and actually how does that sit with a society that is more embracing, accommodating and supportive of people with different health needs. So, I think that was quite a big ethical discussion that was had, is, and particularly where we think about what we screen for in the future over time and so forth, people really being conscious that “Actually, where are we going with this? Are we risking demonising certain conditions and saying we don’t want them on the planet anymore and what are the consequences of that?”

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**Harriet: And I think came to a point in our final meeting where we were asking our participants, so Suzalee and Gordon and everybody else in the room, whether you might consider having a lifetime genome for yourself and what that would look like. We’d love to share your views about that, and Suzalee, I’m wondering if you can share your thoughts on that with us first.**

**Suzalee:** Definitely. I would wholeheartedly be interested in the lifetime genome programme if it was offered to me right now. I believe that the pros for me are phenomenal. I have come to terms with the thought that life is unpredictable and I have already begun to accept any health condition that comes my way. Believe you me, I have been through the stage of denial, and yes, I have frozen upon hearing health diagnoses in the past but now I believe that I am a bit wiser to accept the things that I cannot change and to prepare to face the symptoms of whatever illness I am to be dealt with or to be dealt to me. If the analysis of my genome can help me to prepare, then yes, I am going to welcome this programme with open arms.

**Harriet: Thank you, Suzalee. And, Gordon, how did you feel about it?**

**Gordon:** Being part of the group showed me how genomics is both thrilling and daunting. I’d lean towards ‘yes’ for a lifetime genome resource for the chance to detect conditions early, but I get why some people may say ‘no’ over the data fears or ethical lines. This isn’t just a science project, it’s about designing a future where everyone feels included and protected. We need more voices, parents, young people, underrepresented communities, to keep shaping it in the right direction. Laws would have to be enacted regarding the storage, use and availability of genetic data. We haven’t yet seen as well, how AI’s complete benefits in medicine will develop over time.

**Harriet: Thank you so much, Gordon and Suzalee, for sharing that. And, Suzannah, I know that at the end of the Public Standing Group we generally asked all of our participants whether they would choose to have a lifetime genome, the same sort of question I’ve just asked Suzalee and Gordon. I wondered if you could just briefly give us an overall sense of how the Public Standing Group participants felt about that.**

**Suzannah:** Yes, so it’s interesting to see that actually not everyone said, despite spending a year or almost a year discussing this, not everyone said, “Sign me up,” 6 said, “No” or “Maybe.” And the reasons they gave, this idea, “Well, all this data, could a government sell it off? What guarantees have we got?” So that was a reason. Somewhat of a concern also about breaches but also this idea of “What do I really want to know? Do I want to have a lifetime resource that can tell me what’s going to happen next in my health?” and some say, “Let me deal with it when the symptoms start coming and that’s the way I want to handle it.” So, yeah, about 20 said, “I’d be really interested,” similar to Suzalee and Gordon, 6 on the fence or firmly, “No thanks.”

**Harriet: Thank you so much, Suzannah. I think your point about uncertainty there is so relevant and important to us. We see uncertainty across genomics and we’re layering that here with uncertainty about futures, we’re layering that with uncertainty about health. And I hope that this has served to really illustrate the magnitude of the challenge we’re looking at here and I think also why for us as Genomics England this is just something we’re exploring. There’s so much to unpack, there’s so much still to be done.**

**In terms of our next steps for Genomics England, it feels like we could speak about this for a week but I’m going to have to wrap it up here. So, for us what are our next steps? We hope really that as we publicise the findings of this Public Standing Group and when we start combining some of our work and looking at it in harmonisation with the work that others are doing across the world, we might be better positioned to understand the potential future directions that a lifetime genome could take.**

**That’s obviously very, very exciting because we expect to see this area of enquiry expanding significantly over the coming years. And we’re already hearing about a number of other countries who are also doing birth cohort studies like we are who might hope to use similar applications of the lifetime genome going forward. So, there’s a real opportunity for us here to collaborate and it’s really heart-warming that the voices of our participants in this Public Standing Group can be used to facilitate that level of engagement. For us at the Generation Study, we’re already looking at the next iteration of our lifetime genomes work and we’re being led by the findings of this Public Standing Group as we move forward, specifically in that we’re going to be starting to take some of these emerging themes to the parents of our Generation Study babies to really find out how they would feel about them.**

**Harriet: I’d like to extend my sincere gratitude to all for being my guests today, Suzannah Kinsella, Suzalee Blair and Gordon Bedford. Thank you so much for your time and joining me in this discussion of the lifetime genome. If you’d like to hear more content like this, which I am sure you would, please subscribe to Behind the Genes on your favourite podcast app. Thank you so much for listening. I’ve been your host, Dr Harriet Etheredge. This podcast was edited by Bill Griffin at Ventoux Digital and produced by Deanna Barac for Genomics England.**