**Behind the Genes transcript**

**How can we enable ethical and inclusive research to thrive?**

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

**Bobbie:** In an earlier conversation with Paul, he used the word ‘extractive,’ and he said that he’s been involved in research before, and looking back on it he had felt at times it could be a little bit extractive. You come in, you ask questions, you take the data away and analyse it, and it might only be by chance that the participants ever know what became of things next. One of the real principles of this project was always going to be co-production and true collaboration with our participants. Our participants now have a variety of ways in which they can transport their voices into spaces that they previously found maybe alienating, challenging, and not particularly welcoming.

**Natalie: My name is Natalie Banner, I’m the Director of Ethics at Genomics England and your host on today’s episode of Behind the Genes. Today I’ll be joined by Paul Arvidson, a member of the participant panel at Genomics England, Professor Bobbie Farsides, Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School, and Dr Rich Gorman, Senior Research Fellow, also at Bright and Sussex Medical School.**

**Today, we’ll be exploring the ethical preparedness in genomic medicine or EPPiGen Project. This project examined how the promise and challenges of genomic medicine are understood and experienced by the people at the heart of it, both the clinicians providing care and the patients and families involved. A big part of the EPPiGen Project explored using creative methods of storytelling and poetry to explore the experiences of parents of children with rare genetic conditions. We’ll discuss why the idea of ethical preparedness is crucial in genomic medicine to acknowledge the challenges and uncertainties that often accompany the search for knowledge and treatment in genomic healthcare, and to help professionals develop the skills to navigate the complex ethical considerations.**

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**So, I’m going to ask our fantastic guests to introduce themselves. Paul, would you like to go first?**

**Paul:** Hi, I’m Paul Arvidson. As well as my Genomics England hat, I’ve got a SWAN hat as well, I’m the dads’ rep for SWAN UK, and I’m on the poets from the EPPiGen Project.

**Natalie: Brilliant to have you hear today. Thanks, Paul. Rich?**

**Rich:** Hi, I’m Rich Gorman, I’m a Senior Research Fellow at Brighton and Sussex Medical School and I’ve been working on some of the research on the EPPiGen Project that looks at people’s social and ethical experiences of genomic medicine, and particularly families’ lived experiences of genomics.

**Natalie: Brilliant. Really looking forward to hearing from you. And Bobbie?**

**Bobbie:** Hello, I’m Bobbie Farsides, I’m Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School and co-PI with Professor Anneke Lucasson of the Wellcome Trust funded EPPiGen Project, and it’s been my pleasure and privilege to be involved in the work that we’re going to talk about today.

**Natalie: Really fantastic to have the 3 of you here today. So, we’re going to take a slightly unusual approach to starting the podcast today and we’re going to begin with Paul who’s going to read us a poem from the book Helix of Love. Paul, over to you.**

**Paul:** This is called ‘Tap, Tap, Tap’.

‘Tap, tap, tap, I hold the egg to my ear. There it is again, tap, tap, tap. Run to get a torch and light through the shell, to see who’s tapping from within. Chicken’s home from work these days just for fun and the odd egg. Market stalls swapped for medicines, cash boxes for cough machines. We kept the apron though. Profound learning disability is our life now, most of it, learning about it, learning from it, surviving with it, despite. It’s a subtle egg though, this. The shell is there, invisible, but there’s a person inside, tap, tap, tap. What are you trying to tell us about what the world’s like for you? Are you bored? Do you hurt? Is your sister a love or a pain? Tap, tap, tap. I wish I could set you free.’

**Natalie: Thank you, Paul. Such beautiful and powerful words. I wonder if you wouldn’t mind telling us a little bit about that poem and your journey and maybe touch on what the EPPiGen Project has meant for you.**

**Paul:** Wow, that’s a lot to unpack in one go. I suppose the oddness of the metaphor is probably worth a mention. The way the project worked is that Bobbie and Rich collected together a proper poet, Dawn Gorman, and she led us through the process of kind of, she basically taught us all to be poets from scratch, it was… When you say it like that it was a hugely audacious project really to just collect all these randoms together in a room and throw a poet at them and see what happened.

And they trusted us, I suppose, and trusted Dawn that there was going to be something came out of this. But one of Dawn’s techniques was that like each week we did… I think we did… Did we do 6 weeks, chaps? Which felt like a huge amount of time, but it went in milliseconds. But what she did every week was that she gave us either a poetic form to work with, like, you know, “This week we’re going to learn how to do a haiku, or a sonnet,” or whatever, or she’d gone away and thought of a particular poem that she thought might resonate with us and then she’d bring that to the session. And she’d read a poem out and then say, “Right, what did you make of this? Go away and write what it inspires you to write.”

So, the poem that I wrote was, the inspiration for that session was a poem called The Egg by Richard Skinner. His poem was more about the form of the object itself, so, although that sounds really abstract, it really, really helped. So, every week it would be like Dawn threw this object into the group and said, “Right, okay, here’s your new prompt, bosh, off you go.” And although that sounds like the most obscure way to deal with anything, because you get a structure around which to organise your thoughts it was just this like hugely powerful thing for everybody.

And so, the thing that came to mind for me was the metaphor of the egg rather than the egg itself and it just kind of chimed with all of us. Like we used to run the egg stall in Minehead farmers’ market and so, I married into a country girl and so she had like 200 laying hens at one point, and so we had this whole market stall antics but also it spoke to so many things in one hit. So we gave up that part of our lives as our daughter Nenah’s condition became more and more complex.

She was always, once we knew what her genetic condition was one of the few things that we knew from the get-go was that it was progressive. So we knew in advance that that was the case, but we didn’t know what that meant. And so slowly but surely one of the things we had to do was give up our working life, you know, one week and one hour at a time, it felt. So part of the poem’s about that as well, the shift in the poem from the comedy bit to the beginning to the more serious bits at the end, and it kind of felt like we gave those things up day by day but the poem kind of got to speak to that.

And then there’s also the metaphor. Once you’ve got a good metaphor it’s always good to run with it, you know? And so the idea of the metaphor of somebody who’s got profound learning disabilities and can’t speak being inside this shell and as parents you’re always kind of peeking in from the outside to see what’s going on within or to try and find ways, the idea of when you’re checking to see if you’ve got a chick inside your shell, and you do this thing called ‘candle’ where you hold the light to it, that I describe in the poem, and you like hold it to your ear and hear if there’s movement going on inside. And you kind of, I don’t know, I felt with a profoundly learning-disabled child that you always feel like you’re doing that as a parent as well to see if what you’re doing is, you know, if you’re still communicating while you’re trying to be a parent.

**Natalie: Fantastic. Thank you so much for sharing that with us, Paul, both the poem and also your exploration of how you got to that point in writing that poem. Tremendously powerful to kind of understand and hear about that experience. Bobbie, if I can come to you. Paul referred to that project as kind of audacious, can you tell us a little bit about the origins of the Helix of Love but also why storytelling, especially through poetry, was so important for the EPPiGen Project?**

**Bobbie:** Yes, of course, Natalie. But can I start by saying I was so pleased that you got Paul to speak for a while after because I always have to compose myself after hearing these poems because they really do hit so powerfully, however many times you hear them. And I think that is part of what we wanted to achieve with this project, we wanted to use innovative research methods, we wanted to be… I love the word ‘audacious’; I’m going to borrow that. We wanted to be audacious; we wanted to be courageous, and let me tell you, our Ethics Committee were a little bit worried about the sorts of things we told them we wanted to do. But we knew because we live and work in Brighton that the world is full of creative people and we’d already had such wonderful partnerships with people over the years, we knew that we could draw people into this project who would help us to work with this fabulous group of parents ,in a way that would give them, as Paul says, an opportunity to explore their own feelings and their own experience and share it as they wished.

In an earlier conversation with Paul, which he might find surprising that it’s stuck with me so much, he used the word ‘extractive’ and he said that he’d been involved in research before and looking back on it he had felt at times it could be a little bit extractive. You come in, you ask questions, you take the data away and analyse it and it might only be by chance that the participants ever know what became of things next. One of the real principles of this project was always going to be co-production and true collaboration with our participants, and the poetry project probably wouldn’t have come about if it hadn’t been for the passion of one of our participants who was sort of finding a love for poetry herself and said, “Can we try this next?” So, you know, it means so much to Rich and I that we ended up with this amazing book, but it’s not our book, it’s our poets’, as we like to refer to them, book.

So, one of the things that we are so pleased about in this project is that our participants now have a variety of ways in which they can transport their voices into spaces that they previously found maybe alienating, challenging, and not particularly welcoming. And I think another wonderful upshot from this project has been how receptive people have been to the work. And it’s a sort of commonly held myth that your average philosophy article has a readership of 3.4 people. Rich created a wonderful map to show how Helix has travelled round the world and touched thousands of people – I don’t think that’s an exaggeration – and we couldn’t be more grateful for that as researchers because we feel as passionately about these subjects as our participants and it is they who have really got this project on the map. Paul, you were going to come in, I hope.

**Paul:** I feel like the one thing that this project really did was, I know PPIE is a phrase that’s bandied round but this project kind of stripped that theme apart and took the ‘I’ bit, this project is like built around inclusion and because it felt like, if we’d have just been jumping in a room with Dawn and told to get on with it, I don’t think it would’ve worked as well. The idea that it was kind of curated by Bobbie and Rich, we very much felt like our hands were held through the process, and after them having had to kick down doors in the Ethics Department to be able to get the project through at all, it’s like “What are you going to do to these poor parents?” having gone through that process themselves behind the scenes, then to kind of feel like we were guided through this process. And we were guided and held, and they were super-aware of all of us. And the fact that every time you tell these stories as a parent who’s gone through them there’s a cost. And we’ve had this discussion with the panel before and the communication group, about the fact that every time you come to a parent and say, “Tell us your story” there’s a cost.

And so, they were aware of that, and they held that in both of their hands and so it couldn’t have been anything other than this collaborative project by the time we’d finished.

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**Natalie: We’re going to hear a clip from Lisa Beaton, a member of the participant panel at Genomics England, who shares what it has meant for her to take part in the project.**

**Lisa:** It was an amazing opportunity. I had a huge sense of imposter syndrome actually when I as invited to join, because I was aware of some of the people who’d already taken part in the project and although I can bring lived experience to the table I don’t really consider myself as a creative writer or anything like that, although I do enjoy it. When I first started in the group, we were just doing free-flowing writing. It was really cathartic, and I didn’t expect that in any way, shape or form. To put pen to paper without necessarily having any strategy in mind, just letting the thoughts come out and ramble away, I didn’t really know what was going to come blurting out onto my notepad, and reading some of it back was moving but it was frustrating. It was moving, it was everything really, that opportunity just as a safe space, knowing I didn’t have to share it with anybody if I didn’t want to but I could, and I could just, I suppose I would call it almost like a brain fart, it just rambled away and maybe it was a way of downloading some of the emotions that I was carrying.

As the project went on and we explored different creative mediums I really enjoyed that and found different skills that I wouldn’t have thought about. And it was very thought-provoking, being able to go back and think about some of our very early experiences, which is, not that I’ve buried them but it’s just you move on to deal with the here and now, and it brought me back to some of those very raw emotions of the first days which I think are, I hope, helpful to certainly the medical community in terms of thinking about how they talk to new parents going through similar situations. I was very grateful.

**Natalie: Rich, I’d like to come to you now. As Bobbie and Paul have both mentioned, the outputs for this project have really spread far and wide and maybe beyond the kind of academic circles that you might typically think. I’d really like to hear from you about how you think the project has helped healthcare professionals, particularly really enabling them to understand a little bit more about what it means to be part of a genomic healthcare service and the journey that patients and families go through. Would you share a little bit about your experience in the project, particularly for healthcare professionals?**

**Rich:** Yeah, I mean, that was one of the things that when Bobbie and I set out to do this, that was one of the real aims, was to sort of help healthcare professionals have a bit more of an insight into what it means to access genomic medicine services from a patient or family perspective. And, as Bobbie said, there were 2 ways we could have gone and done this; we could’ve done some sort of conventional social science interviews, written that up in a lovely social science or philosophy journal article and no one would’ve probably read it, but instead we thought about the power of the arts to actually change in terms of how we were sort of collecting and collating people’s stories and then how we were sharing and disseminating those stories as well. And I think the medium by which stories are told affect the kind of stories that get told, as Paul was sort of hinting at earlier.

When we ask patients to tell us their story, you know, there’s a level of expectation there about what people are being asked to say in a form in a way, and certainly we didn’t get people in a room and say, “You must write about genomics.” So many of the poems in the collection aren’t really about sequencing or big data, they’re about these kind of much wider themes of everyday life. And I think that’s been really powerful in allowing healthcare professionals to sort of understand for patients obviously genomics is really important but it’s not the be all and end all of everything that’s going on in their lives, you know, there are so many other pressures, so many other hopes and desires, and people want an opportunity to express some of those positive aspects of their life with their loved ones and it not just be medicalised all of the time.

Again, as Bobbie said, it’s also opened up our research travelling really well and just become something that’s really accessible for people to pick up and read through, and I’ve had conversations with healthcare professionals that have said, “Oh I read through the book of poetry and it’s made me realise all of these things.” Language particularly has been a really prominent theme that people have reported, telling us they’ve learnt a lot about it, and thinking about how they write their letters and how they communicate with people. And obviously this isn’t new, you know, bioethicists for years have been talking about the need to communicate very carefully, very precisely and in a caring way, but I think there’s something about communicating those messages through a really powerful art form like poetry through patients’ own words that allows clinicians and healthcare professionals to sort of really get the impact of that in a very, very powerful way.

**Natalie: Thanks, Rich, really helpful insights there. I really want to pick up on your point about language and come back to Paul on that because I know that’s a topic area that can often be, you know, hugely sensitive to families that the medicalisation, the terminology that’s used, especially, you know, complex areas like genomics, coming back to this term we mentioned earlier about being sort of alienating. How have you found that the work through the EpiGen project and Helix of Love, has it potentially helped the way that families can think about the right sorts of language and enable health professionals to sort of approach some of these questions in a slightly more human way?**

**Paul:** Difficult to say. It’s a very, very live topic all the time. There’s like a backchat communications channel with the Genomics England panel where, because we all go along and do this thing, but we all share that genomics common threat in our lives. One parent was breaking their heart about the fact that they’d had sight of genetic science reports that basically described their child, and children like them as ‘lumped together’ in a project, and she was gutted about it. And we all were as well, and we were all open-mouthed about it. The whole idea of kind of separating the science and the science language out from the people who are involved, it is our job, isn’t it, you know, our job as the panel members is to remind people that those are people, not statistics. But it’s a really live subject and the more people, the more professionals who can be reminded of that on a daily basis and the more we can find kind and open ways to deliver that message to professionals, and every single day that we do that makes a difference, I think. If one parent has to get less of a letter like that or one professional thinks more carefully about how they phrase stuff before it goes out the door, then that’s one less parent who’s got to go through that.

**Natalie: Absolutely. And I’m thinking about that insight. I suppose the anticipation and the realisation to healthcare professionals about the impact of the way they approach things, the language they use, the kind of mindset they might adopt with parents and families, one really important aspect of the project was to do sort of preparedness and the idea that you should be able to anticipate and plan for and acknowledge some of the ethical challenges that might come through when you’re dealing with questions of genomic healthcare where there may be lots of uncertainty, there may be a long journey to go through.**

**Bobbie, can I come to you to help us unpack this notion of ethical preparedness as a core theme for EPPiGen? Help us understand what that means in kind of simple terms and why does it matter for those who are working in the genomic medicine and healthcare space.**

**Bobbie:** I think the way in which most people will have heard of this concept of preparedness is in relation to disaster planning. We know that some of the good things we try and do in life are also potentially fraught with challenges and difficulties just because of their complexity and because of the wide range of people and organisations that will be involved. Can we take this idea of preparedness and almost say, “You have a moral responsibility to be ethically prepared when, for example, you embark upon a really dramatic change in healthcare delivery or an introduction of fantastic new healthcare innovation”?

And genomics seemed to be the perfect case study for this. We then had to say, “What does that actually mean in practice?” And I think here we wanted to move away from the idea that you can ethically prepare people by putting a small albeit very expert and clever group of people in a room to write guidance and regulations, those things are needed and they’re useful. But it’s actually much more important to almost recruit everybody, to bring everybody up to speed, so that the ethical challenges aren’t a complete shock to those who are delivering the service in the frontline, so that those who plan systems actually think whilst doing so of the ethical challenges that can be posed by the tasks they’re attempting to achieve.

And I was a sort of founder member of the Ethics Advisory Committee at Genomics England, and it was so interesting in those early days because there were no patients, there were no participants. We were sitting alongside people whilst they designed and put in place basic processes, strategies and ethics was a part of that. And a really important part of that to me, at those meetings, was hearing what the potential participants had to say about it because, again, the Participant Panel was involved. And I found that those were my people, those were the people who were worrying about, concerned about the same things as I was.

So, I think to be prepared we have to take on the responsibility of giving people who work in ethically challenging areas opportunities to come together to acknowledge the complexity of the task, to share strategies and tools, but also, very importantly, to not become divorced from the people that they are attempting to serve, because in fact we feel that this part of our project, and our project is much bigger than this and we’ve done some fantastic things working with healthcare professionals, medical scientists, etc, etc, but this part of the project is an attempt to say, “We can better prepare families as well by ensuring that we tell them that their voices are valuable, that they’re important, and they help rather than hinder healthcare professionals in doing their jobs.”

**Natalie: That’s a really important point around the idea that this approach can help, can be positive. Because I think sometimes you think about preparedness and, and quite often with ethics it’s about risk, it’s about, you know, “How do we avoid the risks?” but there’s a very positive story to tell about taking a more preparedness-type approach to thinking through ethical complexities, challenges and so on, both for health professionals and, as you say, for families. I wonder if you could just talk a little bit more about the kind of positive aspects that that can bring to everyone in that genomics healthcare journey, both the health professionals and the families. Because I think sometimes it’s easy just to think that it’s mostly about sort of avoiding the risks and the pitfalls, and that might be harder to engage with people if you take that sort of risk-based approach.**

**Bobbie:** Yeah, it’s an interesting one. I think the ability to confront risk and uncertainty is a sign of maturity. And we find medical students, for example, hate any sense of uncertainty; they want to be told how to do something and they want to know that they’ll be able to do that thing and get it right. And our job is often to say, “Well it’s not going to be as easy as that, in fact it might be impossible, and here’s what you have to do instead and here’s how you allow yourself to fail or to not achieve in the way that you want but still do something really meaningful for the people that you’re caring for.”

So, I think there’s that aspect of saying, “It’s part of medical education, it’s part of how we should think in organisations that wherever you take risks, wherever you try to push frontiers, blur boundaries…” I mean, genomic medicine has done something really interesting in terms of blurring the boundary between scientific research and clinical care. Wherever you do these things there are going to be challenges but those challenges, they’re fascinating, they’re interesting, they can bring us together. If we’ve got a shared will to get through them, you know, to make things work, then it’s enlivens what you’re doing; it’s not a barrier.

I sort of began teaching and working in the space of bioethics right back in the ‘80s, which is a shock to you, I’m sure, but in those days I’m afraid that ethics was seen as a block, a barrier, a hurdle that people had to get over or through. And I think there’s still a sensitivity, and certainly, I myself have been sort of challenged on critiques that I have offered to say, “Oh that’s a bit harsh.” But I think what ethics attempts to do now, and certainly through really putting a positive spin on this idea of working together to establish ethical preparedness in important spaces, is to show that actually ethics can be very facilitative, it can be very supportive, and it can help people. It’s not a surveillance mechanism, it’s actually another clinical tool and something that, you know, people should seek support around.

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**Natalie: Rich, if I could come to you thinking about that reframing, I suppose, in your own research practice as an early career researcher, whether you’re seeing that maturity in approach in thinking about some of these really complex, knotty ethical questions in genomics, are you seeing a greater appreciation for those? And where do you think you’re going to take your research as a result of this project in that space?**

**Rich:** Yeah, thanks, that’s a great question. Yeah, I think so, and I think one of the things that’s really been revealing in this is the appetite for this kind of work in the sort of genomics sector, an appetite for thinking about the sort of complex ethical issues, for engaging with kind of arts-based research, for sort of finding new language and new spaces to involve patient and family perspectives and stories and think about how we can learn from them.

I think in the highly scientific, highly technical space of genomics we often assume that everyone wants numbers and hard data but actually I think the way that this work has travelled, the amount of invitations we’ve had to sort of exhibit this work and talk to healthcare professionals and scientists about this work shows that there’s this really rich appetite for thinking about this complexity and doing that work of ethical preparedness, as Bobbie’s talked about, and I think it’s fascinating. And I know a lot of the participants who joined in our project have also sort of had opportunities from being involved in our work and found that there are people that want to listen to their voices and hear from them and learn from them as well. So that’s been really exciting, and I hope it will continue and I hope there’s opportunities for much more interdisciplinary collaboration in the genomics space with philosophers, with social scientists with ethicists, with artists and, importantly, with patients.

**Paul:** You mentioned the idea that certainly the poetry at the very least has allowed those voices to get into different spaces, and I think when those things first started happening it was when we at least as the people who’d written the poems felt that there was a huge big impact from this stuff. And I wasn’t the first one to read one of these poems out loud, and in a way the collection of poetry became bigger than the sum of its parts in a funny kind of a way. And I can’t remember but somebody read one of the poems at a conference somewhere and they said at the end of it that you could’ve heard a pin drop, and it was just that thought that actually with a big audience expecting kind of quite dry subject matter about genetics, to have felt that moment where the poem got launched off the stage and then it impacted on the audience and then, the way they described it, you could almost kind of feel them describing the ripples of the poem just like spreading out amongst this kind of silent audience and everyone kind of taking this kind of mental sigh of like “Oh that’s what it feels like.” And the idea of that happening was when, for me anyway, when we knew that what we’d created was bigger than the sum of its parts and had its own legs, Bobbie and Rich had been the Dr Frankensteins of this kind of amazing, beautiful monster.

**Natalie: Obviously the poetry’s got into your soul, Paul, the metaphors are fantastic. But just to make sure we bring in even more participant voices and perspectives into this we’re just going to hear now from Jo Wright, who’s another member of the participant panel, who’s going to share what the project and the participant in it has meant for her.**

**Jo:** So being part of the EPPiGen Project, it helped me to find my voice in an area that was relatively new to me, and also it was a way to take control of my own experiences rather than feel like I’m being swept along by a lot of systems.

And there were things that I really value that I thought contributed to making the project so successful. One was that they asked the question “What is this experience like for you, the experience of being part of a research project, the 100,000 Genomes experience of waiting, the experience of having your data in the library?” And no one had asked that before. You go to your appointments and you’re in the system and, you know, it’s kind of, everyone was finding their way to some extent because it was new for all the clinicians as well, but the fact that they asked, because no one asked that before, I don’t have an outlet for that.

And then the other thing was that it was completely open so there was no research interview or questionnaire to answer, no expectation about what it was going to look like at the end. And I think working that way really strengthened the connection between us as parents of children with rare conditions and then also our relationships with Bobbie and Rich as the researchers and with the wider clinical community when they started to see our work and respond to it. So it was a way to understand people’s individual experiences but it also made us feel connected and empowered through sort of like shared human experience, and that could be between us as the participants but also shared experiences between us and the researchers or us and clinicians and scientists that were looking at what we’ve done.

**Natalie: So we’ve heard lots about the experience of participating in this fantastic EPPiGen Project, the kind of creative storytelling methods, the audacious methods that have been used, and some fantastic impacts beyond the kind of typical what could be quite dry sort of academic circles that this kind of work has spread out to. I’d be really interested to hear from each of you about the takeaways, what you’ve learned, what’s changed for you and what you’d like our listeners to really understand about this project and the work, and the sort of outputs from it and the ways it might continue to have resonance and impact going into the future, so whether people are patients, families, clinicians, researchers. What would you like people to remember and what’s affected you most about the project?**

**Bobbie, I might start with you.**

**Bobbie:** I think we have to always be very careful when we get excited about something - and the ‘we’ here are the people in the health community, the education community, etc - to remember. As Rich said earlier, that this is only ever going to be quite a small part of other people’s lives. You know, we’ve all devoted big parts of our careers, our enthusiasm, to thinking about genomics, to working in this space. I would really like people to pick up the book and work to understand a bit better about the everyday lives, the hopes, the expectations, the fears of the families who may or may not get a diagnosis, may or may not get on a good treatment path, all of whom want the best for themselves and everybody else from this venture.

But, as Paul knows better than most, it won’t come to everybody, and we don’t want anybody to be forgotten along the way. The people that signed up for Genomics England as participants were pioneers alongside medics and the scientists, and in these early years we want their experience to be recognised, and their experience goes much beyond their interaction with Genomics England and, unfortunately, all the work that we’ve produced shows how many challenges families have to face to secure a good life for their children, and I just want us all to just keep that in mind.

**Natalie: Incredibly important to maintain that focus, that awareness. And, as you say, Bobbie, there’s an interesting balance where there is a need for the drive and the innovation and the ambition to help ensure that we are pushing at the forefront of medical research but not leaving people behind and not ever forgetting, as you say, the experience of people who are actually at the forefront of this research and of genomic healthcare.**

**Paul, could I ask for your perspectives on this, and particularly how you see patient voices being involved in the future of genomic medicine, especially in light of your experience in the EPPiGen Project?**

**Paul:** I think the biggest surprise and biggest takeaway for me was the project gave me, I mean, I can’t speak necessarily for all the other poets, but you only need the evidence in the book itself. They gave us the tools, the project gave us the tools to find a different way to get at all of those things inside of all of us who were going through that experience. So it gave us a way to talk about all of those things and a way that was I suppose slightly removed to start with. It’s almost like a different lens or a different filter to give us a way to look at all those things, almost like a magnifying lens; you can either hold it really close to your eye and it gives you like a blurry view of the world that goes on and you can relax behind that and find a way to explore things in a funny way or an interesting way, but you can also go really close into the subject and then you’ve got to deal with the things that are painful and the things that are difficult and the things that have had an impact.

But, because you’ve got that tool and you’re used to using it or you’re familiar with using it, it then gives you that safety. That’s how I felt about it anyway, it was a massive tool to be able to get behind all of these things that I didn’t even know I was feeling, or I knew they were making me uncomfortable, but I didn’t know what they were or what name to give them. So the poetry gave us a chance to get behind all of that. Having read the poems, it feels like it’s that for everybody but obviously you’d have to speak to them to know, but it certainly felt like that for me.

**Natalie: And, Rich, your perspective. What are you taking forward from the project, so what would your sort of key takeaway be?**

**Rich:** I think it shows what is possible under that PPIE acronym. And there are many ways to do that involvement and engagement, it doesn’t have to be a sort of dry tick-box exercise, there are much more creative ways to bring people’s lived experiences and perspectives into conversations with genomics. So really, I suppose it’s a call for other people to explore working in this way as well and think about what other kind of creative outputs could work here. I mean, we’ve had huge success, and I think a really interesting impact from working in this way.

And certainly as an early career researcher it’s been really formative in my sort of academic journey, you know, reaffirmed that this is the kind of work that I want to do, working in this really co-productive way. And I think it’s possible, it can be done, and, you know, ultimately it’s just been a real privilege to do this kind of research, to sort of be trusted to sort of hold a space together for sharing people’s stories and give people a platform to share some really powerful profound stories. And going back to what Paul was saying earlier, I think he hit the nail on the head, as he very often does, this is about evoking people’s experiences, not just explaining people’s experiences, and allowing those stories to travel. And we don’t know where stories will travel, we don’t know how stories will travel, we don’t know how stories will be received, but we know that they do sort of travel and they do have legacy and they stay memorable to people, they have emotional resonance. So, the impact of this work can often be hard to sort of pin down really specifically, but we know those stories are out there and people are listening and changing their practice as a result.

**Natalie: We’ll wrap up there. I’d like to thank our guests, Paul Arvidson, Professor Bobbie Farsides and Dr Rich Gorman, for joining me today as we discuss the EPPiGen Project. We heard some powerful insights from patients and families about their experiences, and why ethical preparedness is so important in the context of genomic medicine. If you would like to hear more like this, please subscribe to Behind the Genes on your favourite podcast app. Thank you for listening. I’ve been your host, Natalie Banner. This podcast was edited by Bill Griffin at Ventoux Digital and produced by Naimah Callachand.**