**Behind the genes transcript: Why are ethical considerations crucial in genomics research and clinical practice?**

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

**Jonathan:** The first difference is that the model we’ve traditionally had around clinical ethics, which sort of assumes all focus is around the patient individually, is not enough to deal with the

challenges that we have, because we also have to understand how we support families to

take decisions. Families differ enormously, some families are united, some families have

very different needs amongst them, and we have to recognise that our ethical approaches to genomic issues must respect everybody in that.

**Natalie:** My name is Natalie Banner and I’m the Director of Ethics here at Genomics

England. On today’s episode, I’m joined by Chair of our Ethics Advisory Committee,

Professor Sir Jonathan Montgomery and Dr Latha Chandramouli, member of the Ethics

Advisory Committee and the Participant Panel, who’s also a community paediatrician

working with children with complex needs.

Today we’ll be discussing why ethical considerations are crucial in genomics research and

clinical practice and what consent means in the context of genomics. If you enjoy today’s episode, we’d love your support. Please like, share and rate us wherever you listen to your podcasts.

At Genomics England, we have an Ethics Advisory Committee, which exists to promote a strong ethical foundation for all of our programmes, our processes, and our partnerships. This can mean things like acting as a critical friend, an external group of experts to consult. It can mean ensuring Genomics England is being reflective and responsive to emerging ethical questions, especially those that arise as we work with this really complex technology of genomics that sits right at the intersection of clinical care and advancing research. And it can also ensure that we are bringing participant voices to the fore in all of the work that we’re doing.

I’m really delighted today to welcome two of our esteemed members of the ethics advisory committee to the podcast. Professor Sir Jonathan Montgomery, our Chair, and Dr Latha Chandramouli, member of our Participant Panel. So, Jonathan, if I could start with you, could you tell us a little bit about your background and what you see as the role of the ethics advisory committee for us at Genomics England?

**Jonathan:** Thanks very much, Natalie. My background professionally is I’m an academic, I’m a professor at University College London, and I profess healthcare law the subject that I’ve sort of had technical skills in. But I’ve also spent many years involved in the governance of the National Health Service, so I currently chair the board of the Oxford University Hospital’s NHS Foundation Trust.

I’ve spent quite a lot of time on bodies trying to take sensible decisions on behalf of the public around difficult ethical issues. The most relevant one to Genomics England is I chaired the Human Genetics Commission for three years which was a really interesting group of people from many backgrounds. The commission itself primarily combined academics in ethics, law and in clinical areas, and there was a separate panel of citizens think grappling with things that are really important. Genomics England has a bit of that pattern, but it’s really important that the ethics advisory committee brings people together to do that.

You asked why ethics is important and how it operates, I suppose the main thing for me is that these are tricky questions, and you need all the voices, all the perspectives, all the experience in the room working through at the same time. You don’t want to have separate discussions of things. My aim as Chair of the advisory committee is essentially to try and reassure myself that we’ve heard all the things that we need to hear and we’ve had a chance to discuss with each other as equals what it is that that leads us to think, and then to think about how to advise within Genomics England or other people on what we’ve learnt from those processes.

**Natalie:** Fantastic. Thank you, Jonathan. And as you mentioned, the necessity of multiple different perspectives, this brings me to Latha. You have lots of different hats that you bring to the Ethics Advisory Committee, could you tell us a little bit about those?

**Latha:** Thank you, Natalie, for that introduction. I’m Latha Chandramouli, I’m a Consultant Community Paediatrician and I’m based in Bristol employed by Siron Care & Health. I’m a parent of twins and from my personal journey, which is how I got involved, my twins are now 21 so doing alright, we had a very, very stormy difficult time when they were growing up with our daughter having epilepsy, which just seemed to happen quite out of the blue sometimes. It started to increase in frequency the year of GCSE, to the point that she would just fall anywhere with no warnings and hurt herself. This was difficult for me because as a clinician, I was also treating patients with epilepsy. I also was looking at the journeys of other people and was able to resonate with the anxiety as a parent. Worry about sudden death in epilepsy, for example, at night, these were the kind of difficult conversations I was having with parents, and I was now on the other side of the consultation table.

I was also doing neurology in those jobs in a unit where there was epilepsy surgery happening, so it was, in very simple terms, very close to home. It was quite hard to process, but equally my job I felt was I should not separate myself as a parent but also as a clinician because I had information, I had knowledge, and we had conversations with my daughter’s clinician.

We were then recruited into the 100,000 Genomes Project which had just started, so we were just a year after it had started. That was an interesting experience. We were in a tertiary centre with a lovely clinical geneticist team, we had the metabolic team, we had loads of teams involved in our daughter’s care. We could understand as a clinician, but there was also my husband, although a clinician, not into paediatrics and was in a different field. It was important that it was the whole family getting recruited into the journey. My daughter also was quite young, so obviously we have parenting responsibility, but we were very keen to make sure they knew exactly what they were getting into in terms of the long-term issues. Despite being informed, at times there were things that we went in with without understanding the full implications because life happens in that odyssey.

I think that was my biggest learning from those exercises when I began to question certain other things because I then had a breast cancer journey, but obviously I was not recruited as part of that process for the 100k. Those were kind of some of the questions coming in my head, how does the dynamic information sharing happen, and that’s how I got involved, found out a bit more about the participant panel, and that’s how I got involved from 2018 which has been an interesting experience.

Firstly, I think with Genomics England they are probably one of the groups of organisations having a big panel of people, genuinely interested in wanting to make a difference and represent thousands of participants who have got their data saved in the research library, recruited under the two broad arms of cancer and rare disease. We were under the rare disease arm, although I could resonate with the cancer arm because of my own experience.

At various times there were lots of opportunities to think about how data is accessed, are we getting more diverse access to data, all those different issues. At various points we have been involved in asking those questions. We all have different skillsets, you see, in our group. Some have got information governance hats; some have got data hats and PR hats. I’ve got a clinical hat and a clinical educator hat. I am a paediatrician, so I have recruited people for the same, for the DDD, for CGH etc, and I’ve always gone through the principles of consenting, confidentiality, the ethics. I also work in a field, Natalie, where there is a huge, as you are aware with the NHS resource issues, there’s huge gaps and waiting lists, so it’s trying to make sense of what is the best thing to do for that patient or that family at that point in life. Are we obsessed by a diagnostic label? Are we going down a needs-based approach? It’s having always those pragmatic decisions to be made. That’s one of my clinical hats.

I also am an educator so I’m very keen that young medical students, be it nursing students, everybody understands genomics and they’re signing up to it so that we can mainstream genomics. Those are some of my alternative hats which kind of kick in a bit.

**Natalie:** Fantastic, thank you, Latha. As you say, there are so many different perspectives there. You talk about kind of the role of the whole family as part of the journey. You talked about consent, confidentiality, data access issues, lots of questions of uncertainty. Perhaps, Jonathan, I can come to you first to talk a little bit about what is it about the ethical issues in genomics that may feel a little different. Are they unique or are they the same sorts of ethical issues that come across in other areas of clinical practice and research? Is there something particularly challenging in the area of genomics from an ethical perspective?

**Jonathan:** Thanks, Natalie. I think all interesting ethical issues are challenging, but they’re challenging in different ways. I’m always nervous about saying that it’s unique to genomics because there are overlaps with other areas. But I do think there are some distinctive features about the challenges in genomics and I suppose I would say they probably fall in three groups of things that we should think about. The first you’ve touched on which is that information about our genomics is important not just for the individual person where you generate that data but it’s important for their families as well. I think the first difference is that the model we’ve traditionally had around clinical ethics, which sort of assumes it all focuses around the patient individual, is not enough to deal with the challenges that we have, because we also have to understand how we support families to take decisions and families differ enormously. Some families are united, some families have very different needs amongst them, and we have to recognise that our ethical approach is genomic issues must respect everybody in that, so I think that’s the first difference.

I think the second difference is that the type of uncertainty involved in genomics extends much further than many other areas. We’re talking about the impact on people’s whole lives and it’s not like a decision about a particular medication for a problem we have now or an operation. We’re having to help people think about the impact it has on their sense of identity, on things that are going to happen sometime in the future.

And then thirdly, I think the level of uncertainty is different in genomics from other areas of medicine, and the particular thing I think is different that we have to work out how to address is that we can’t really explain now all the things that are going to happen in the future, because we don’t know. But we do know that as we research the area, we’re going to find out more. So, what are our obligations to go back to people and say, “we worked with you before and you helped us out giving data into the studies. We couldn’t tell you anything then that would be useful to you, but actually we can now.”. Now, that’s different. That continuity sometimes talked about, you know, what are our obligations to recontact people after a study. You don’t usually have those in the ethical areas we’re familiar with; you’re usually able to deal with things in a much more focused way.

I think those differences, that it’s not just the individual, it’s the family, that it’s not just about a specific intervention but it’s about an impact on people’s lives and that we will need to think about what we had to do in the future as well as what we do immediately. They make it different in genomics. Some areas of healthcare have those as well, but I’m not aware of anywhere that has all of that in the same position.

**Natalie:** Latha, I’m wondering if that kind of resonates with your experience, particularly the navigating of uncertainty over time?

**Latha:** Yes. I would say that’s exactly what you’ve said, Jonathan. I think it’s the whole process of consenting with the view that you do not know much more beyond what you know about the situation here and now. Part of that is like any other situation, that’s why we have evolved from I would say penicillin to the SMA gene therapy. If we did not do this, we wouldn’t reach frontiers of medicine and kind of that’s how I explained to families when I’m recruiting and I’m also very clear that it’s not all about research but it’s combination of the tool and focusing on your, but it’s also helpful for research even if you do not get answers. I think it’s very important at that stage, Natalie, that we have to be clear we may not get many answers at the very outset and also when do we really look at data, do we have that kind of realistic pragmatic resources to be able to relook every time? Is there a method of dynamically having that information from our NHS spine if somebody of the trio has contracted a condition, would that be fed in.

Those are the kind of questions parents and families ask. I cannot honestly answer that, and I often say that is optimal plan. If things go to plan, that will be the area we’d be heading towards, but currently I can’t give you timelines. I think it’s important we are honest at the outset and manage expectations. That’s how you engage families and, in my case, it’s more these children and families, so engaging is crucial. As you mentioned, it’s also the question that gets asked is very simply in my mind, you know, sometimes there is that conflict because of my own personal recruitment to the 100k project, I have an interest in genomics and, therefore, I would be very keen to embark on that journey and I feel that is the way forward.

I also understand as a member of my clinical team, for example, where I know there’s a huge waiting list, how am I best using the taxpayers’ money that’s been entrusted to us. If I think the waiting list is so high, can I see two further patients in that time that I’m using to consent which is not going to add much more to that child’s journey, for example, with autism or ADHD. It’s trying to be careful where is the ethics in doing an investigation, and that’s like in any situation as a clinician. I think that’s not much different, but it is kind of similar, but it opens up a huge area of uncertainty. As you would with any investigations, if you just went and did scans on everybody, you might pick things up which you don’t need to do anything about. It’s being sensible and being honest.

**Jonathan:** And for me, Latha, that raises two areas which I think are really interesting about genomics. The first of those is the language we’ve tended to use about consent I don’t think captures all the ethical issues that we raise, because we’ve tended to think about consent of something that happens once and then gives people permission to do things. Whereas what you’ve described, and what we find ourselves often thinking about, is that we have to get a respectful relationship with people, so the consent is not to doing certain things, it’s to agree to part of what I think about as a common enterprise. So, patients and families are partners with the clinicians and the researchers, and it’s not that they sign a form and then the consent issue goes away, which is how lawyers tend to think about it, it’s that we’re starting something together and then we need to think about how do we keep the conversation going with mutual respect to make sure that everybody’s values are there.

I think the second thing you picked up is a sense of the need for a better explanation of how research and care interact with each other. Because the care we get now is built on the evidence that people have contributed to in the past, so we’re benefitting from our predecessors, and we want to contribute to our successors and our family getting better care in the future. I think one of the things about genomics is that the gap between those two things is really non-existent in genomics, whereas if you take a medicine, the research that’s been done to make sure that medicine is safe and effective will have been done on a group of people some time in the past that I’ll never meet, whereas in genomics I’m part of the production of that. I may get some benefit now, my friends or family may get some benefit, but there isn’t this sort of separation between the care and the research bit that we’re used to being able to think about. This is a much more mutual exercise and the stakes that we all have in it are therefore intertwined much more closely than they are in some areas of medicine.

**Latha:** I agree totally. In our case, for example, I went in in thinking we might get a targeted medication. I know there are certain levels of epilepsy medications anyway, so in principle it wouldn’t have mattered a lot. However, it was important to know what the outcome was going to be because we had various labels, potential mitochondrial disease, potentially some susceptibility disorder, so we were on a spectrum from something very minimal to the other end on neurodegenerative situation. We were left dangling and we thought it would be good to embark on this journey, at least there’ll be some outcome, some prognostic outcome, and more importantly we don’t have any answers, but we actually can be a hopeful story for someone else in that same position, and I think that’s how we’ve embarked on it. That’s kind of my personal experience.

But in just harking back to some of the ethical issues, it’s again very clear educating the clinicians, as you said, it’s that relationship; it’s not just a piece of paper, it’s that development of relationship with your families, some of whom have got very complex issues going on in their lives themselves. I work in a very, very deprived part of Bristol, which is the highest deprivation index, so they have got lots of intergenerational things going on, there is poverty, there is learning issues and crime, lots of things going on. You’ve got to time it right, what is important for this family here and now, and then work on it.

There’s also the other issue that we may not continue to remain their clinicians after recruiting. I think that’s so important to recognise because the results might come back but you kind of discharge them and it may take a few years by the time the results come. How do you then cross that bridge if some unexpected results come, which then means contacting various other extended family members. I think that’s the bit we all do because that’s part of the journey we’ve embarked on, but it’s also thinking is there someone else who’s probably better placed, like a GP or a primary care person who’s actually holding the entire family and not just one person, not just the adult who has been the index patient. It’s just trying to think the ethics of it because it’s all about engagement and being transparent with families.

**Jonathan:** I think you’ve put your finger on another element that’s really important about the ethics. In the same way as in relation to the position of the individual patient, and we need to see them in families, which doesn’t fit very easily with lots of the clinical ethics that we’ve been used to. It’s also the case that a lot of the traditional clinical ethics has focused on the individual responsibilities of clinicians, whereas what you’ve just described is that we have to work out what the system’s responsibilities are, because it may not be the same clinician who is enabling good ethical practice to be pursued. These are both ways in which our paradigm of ethics has to be expanded from other areas of medicine.

**Latha:** Yes, I agree. And the other bit I think we can probably reassure quite nicely is about the ethics about information governance and we as data custodians storing information, how do we give with great ethics and discussion the access to research and being mindful that it is again thinking along the same principles GMC kind of had about the good for the common good and using resources equitably, but again being sensible with equality issues that a single condition doesn’t get forgotten. It’s that right balance that whilst we are doing common good, we might have a condition which might have a treatable medication, but we have to focus on that as well as research. I think it’s interwoven, all these ethical questions.

**Jonathan:** I completely agree, Latha. That interwoven bit is something where we need to be able to think through, “what is the role of Genomics England to improving that?”. I think we’ve got issues around the good stewardship of information which can’t be left with an individual clinician, they can only do that effectively if the system supports them and their colleagues in doing that. But we’ve also got to be proactive, we’ve got to recognise the limitations of the system, so one of the really important initiatives from Genomics England is the Diverse Data initiative because we know that without aiming to solve the problem, we will get a skewed dataset and clinicians can’t properly look after people. That tells us that the ethics in this area has to do more than avoid things going wrong, it also has to work out what it means to do things right, and what systems we have to put in place to do that. I think that’s a particular example of a shift we need to do across our ethics around healthcare.

If speak to the sort of things that lawyers have got wrong around this in the past and some of our history, we focused a lot of our effort on stopping things going wrong. That has meant that we haven’t spent as much time as we need to on thinking about how to make things go right, because stopping things going wrong is almost always too late. What we have to do if we’re being proactive is work out how to set things up in a way that will make sure that the chances of it going wrong are quite small and the chances of doing good are much increased. I think that’s one of the key challenges that we have in Genomics England and as an Ethics Advisory Committee. The things we’ve inherited tell us quite a lot about things that have gone wrong, but actually what we’re trying to do is to get our heads around what could go right and how to make sure it does.

**Latha:** Also, you mentioned about Diverse Data, I think that’s another important thing as we noticed in COVID as well. There were lots of disparities in the social model and the inequalities that have resulted in death, but also potentially HLA or epigenetic issues which could have contributed. We do have the COVID-19 genomic datasets, but it’s again important to make sure that we don’t perceive certain ethnic minority populations. Just not accessing or considering them to be hard to reach, I would say for them Genomics England is hard to reach. It’s looking at it slightly differently and thinking, “how can we reach them? how do we maybe use community workers and maybe even clinicians?”, I think they’ve got the best trusting relationships with their clinicians and using them to recruit. As you say, even before things get more complicated, you recruit them earlier so that you’d go down the prevention route rather than the gone wrong route and then look for answers later.

**Jonathan:** Latha, I think you put your finger on something really challenging for a group like the Ethics Advisory Committee at Genomics England, which is that however hard we try to get a range of experiences and voices, that’s not a substitute for getting out and hearing from people in real world situations. I think one of the things I’ve learnt over the years from my national health service work is that you cannot expect people to come to you, you need to go to them. In COVID when we were trying to understand why some groups were more reluctant to take up vaccines than others, there was no point in doing that sitting in your own places, you had to listen to people’s concerns and understand why they were there. One of the things we’re going to have to be able to do as the Ethics Advisory Committee is work out when we need to hear more from people outside of the Genomics England system, and I’m a great believer that if it’s right that we need to go where people are, you have to try not to reinvent mechanisms to do that. You have to try and learn where are people already talking about it and go and listen to them there.

**Latha:** Absolutely, yeah. I think they listen because I do work as a paediatrician with a safeguarding hat, and I think the same principles resonate in child death work. For example, simple messages about cot deaths, you would think that if a professional tells the same message to a parent or a carer it’s better received if it’s another family, a younger person, another layperson giving the same message. It comes back to who’s more receptive. It could be a community worker.

As you mentioned about vaccination, during the vaccination initiative I decided early on that I’m probably not going to do a lot because I’m not an intensivist, how do I do my bit in the pandemic. I decided to become a vaccinator and I thought with my ethnic minority hat on, if I went out there to the mass centres and actually vaccinated there or in mosques or wherever else, without even saying a word I’m giving the message, aren’t I, that, look, I’m fearlessly coming and getting vaccinated and vaccinating others, so please come. I think that has helped to some extent, just trying to reach out. Other than saying these people are not reaching us, it’s got to be the other way around.

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**Natalie:** I’m really enjoying this conversation. In part because I think it highlights just how valuable it is to sort of think about ethics a little bit differently. Historically, and certainly I think within the research community, ethics can just be associated with consent. Consent is the ethics issue and if you solve for consent, then you don’t have any other issues to think through. I think what this conversation is really highlighting is just how much broader the ethical considerations are. Beyond that, it’s still very important that consent can be that sort of anchor point for communication and engagement, but it’s not simply a one-off. And to be able to think through ethics not just in terms of risk or moving forward when things have gone wrong in the past, there is actually a really positive aspect to it which I think is critically important.

It’s great to hear your thoughts about that different approach to ethics that I think does embed it much more in community thinking, in questions of equity; it’s not just the individual. I want to follow-up by just asking where do you think the future lies in thinking about ethics both for Genomics England and the Ethics Advisory Committee, but in the space of genomic research and medicine more broadly, given that it sits in this kind of very interesting and quite complex space between research and care in the clinic.

**Jonathan:** I mentioned earlier in the conversation I think about this as a common enterprise that we have shared stakes in. Academic researchers have a stake in trying to build a better more robust evidence base, clinicians have a stake in being able to offer something to the people that they’re looking after. Families have stakes not just in their own immediate care, but they worry about their siblings, they worry about their children, their grandchildren. There are also of course industrial players, so people trying to build a business out of making better medicines in the future. There are government players trying to use public resources more effectively. I think what we have to try to create is a mutual process where we recognise that everybody has overlapping but slightly different values that they’re pursuing and trying to get out of it, and how can we make sure that we govern our work in a way that reflects all of those stakeholders and recognises the respect that’s due to them. I think this is more like a sort of membership of a common project. And the problem with consent is it risks us saying you can be a member of this club but only if you accept the terms and conditions that the committee has decided is there. That’s not going to be adequate going forward.

I think we need to make sure that everybody feels that they are respected, that they feel they can place their trust in the system that we’re designing. As an Ethics Advisory Committee, we have to ask ourselves what justifies us suggesting to people that this is trustworthy. We need to make sure we have good information governance that people are not going to expose themselves to breaches of privacy if they take part in this. But we also need to make sure that we don’t waste people’s efforts. If people are prepared to be part of the research project, we shouldn’t have rules coming down on the data usage that say that we’re going to reduce the value of that contribution by saying it can only be used for one project and can’t be used for others, because actually that would not respect properly people’s contribution to the process.

We need to ask ourselves not just about the protective element of trustworthiness but that element that says we will make sure that you get as much as we can design of the things that you think are important from this project. They won’t be identical for each group, and they won’t be identical within each group. Different family members of participants will have different balances, but they all have to believe that this is a good club to be part of and that they have been part of agreeing ways of working that they think will produce a better future that they want to be part of and that they want to be proud of saying we have helped create this future.

**Latha:** I kind of agree with all that you’ve said. I think it’s most important not to forget because I’m also a participant, like my trio sample is there in the pipeline, and I know my data is sitting there. I also have trust that there is good information governance, the data is secure, so it’s reinforcing that, but it’s also being very honest that it’s obviously the data is there, but we can’t forget the person or the persons at the centre of it, so it’s not just alphabets or sequences of alphabets, but it is that whole person, and that person represents a group of individuals, family members, different generations, and they have embarked on it. Even if they know they may not get hope they might provide hope for others. It’s being therefore respectful.

I think that is the first thing I think is the principle of it and if you respect. If you think it could be the same principle that we use in clinical practice, the friends and family test, because I’ve been on both sides of the consultation table, I think I’ve become a better doctor because I’ve been an anxious mum, and my anxieties were dismissed as being an anxious mum and I don’t care. As far as my child is concerned, my anxiety was valid and so I would do everything to reach an outcome as to what’s best for that person. It’s made me a better doctor because I can see it from both the perspectives. Most of us are human beings, apart from AI technology looking at the dataset, so we all have conditions ourselves, we’ve got doctors with health conditions, we’ve got clinicians, academics, technicians, nurses everybody who’s got a friend or a family member or themselves having a health condition. I think its fundamental principle is that friends and family test. How would I like my data stored? How would I like my data analysed? Could it do this, could it give me some information on how I would get cured or treated or be managed? How would it affect my insurance, or will it find out data about who’s the father of this child, for example? It’s being honest and being honest about the uncertainties as well.

When I’m recruiting, I’m very clear that these are what I know that I can tell you about the risks. But then there may be other risks that I do not know about. If you’re honest about it and acknowledge what is the limit of the knowledge of science at this point in time, because you said there are so many stakeholders, there are researchers and academics who’ve got interest in some areas, it could have developed because of a family member having that problem, but whatever it is that is a great interest because that intelligent mind is thinking ahead and we need to encourage that. It could be for writing up papers, it doesn’t matter. Whatever be the reason, if it’s for the common good, that’s fine. It’s also thinking how are we keeping our families in the loop, so you have newborns, you’ve got young people sometimes with significant disabilities so they are relying on a parent or a carer to consent for them, but some are not so disabled but they have needs, they’ve got rare conditions, but they can make their consenting issues known when they turn 16, for example. It’s the changing policies and they can withdraw at some point in life or there may be a member of the family who doesn’t want to be part of that journey anymore. It’s allowing that to happen.

**Jonathan:** I think that’s a really interesting example you’ve just touched on, Latha, where I may diverge a bit in terms of what I think is the key issue. The right to withdraw I think is a really interesting challenge for us going forward, because we developed the right to withdraw in the ethics of research studies that had physical interventions. It’s really clear that someone who is being put to discomfort and is having things done to her body, if she wants to stop that, we can’t justify continuing on the basis of it being a research project. But I’m less clear whether that applies to withdrawing data from data pools. I think there are a few dimensions to that which I hope as an Ethics Advisory Committee we’ll have a chance to think through a bit more. One is the mutual obligations that we owe to each other. I’m not in these particular studies but I do try and take part in research studies when I’m eligible and invited to because I think research is important. When I take part in things and when our participants have taken part, they’re doing something in which they rely on other people participating because the aggregation of the data is what makes it power.

One of the things we have to be honest about is what are our mutual expectations of each other, so I think we absolutely have to hold on to the fact that people should be able to withdraw from further interventions, but I’m not convinced that you should have the right to say the data I’ve previously contributed that other people have relied on can suddenly be sucked out and taken out of it, because I think it’s reasonable for us to say if this is a sort of part of an enterprise. While you’re part of it, you’ve made some commitments as well as, and that’s part of the mutuality of the respect. I think I personally would want to argue you can withdraw from new things, but provided that your privacy is not intruded on, so we’re talking about data health anonymously, you shouldn’t be able to say don’t process it anymore.

**Latha:** No, no, no. What I meant was from my perspective I would like to be constantly involved and get information through trickling. I don’t know what my daughter feels years down the line, she might say I’m happy for my data to be used for research, but I don’t want to know anymore. There are two aspects of that, and I think if we are clear with that and say continue with my data being used for research, but I don’t want to get anymore letters. I think those are the kind of questions I face when I tell them families that these are the uncertainties, you can have your blood stored, you may not be approached again for a resampling unless you have some other issues, but are we happy with this? I think that’s what I understand, and I try and recruit with that intention.

**Jonathan:** And that makes lots of sense to me. As you say, you probably can’t speak for your daughters now, and you certainly can’t speak for them when they become parents for themselves and those things, but we do need to create an ethical framework which recognises that people will change their mind on things and people will vary about what they want to do. But because we have mutual obligations, what that means and the control we can give, we have to be open and honest about what choices we can give people without undermining the enterprise and what choices we say, “you don’t have to do this, but if you want to be part of it, there are some common mutual obligations that are intrinsic”, and that’s true of researchers, it’s true of clinicians, it’s true of anyone who works in Genomics England or the NHS.

But I don’t think we’ve been very good at explaining to people that there’s an element of this which is a package. A bit like when I bank, I allow the bank to track my transactions and to call me if they see something that looks out of the ordinary as a part of the protections from me. I can’t opt out of that bit. I can opt out of them sending me letters and just say do it by email or whatever and I have some choices, but there’s an infrastructure of the system which is helping it to function well and do the things it’s able to do. I don’t think we’ve been very good at explaining that to people, because we’ve tended to say, “as long as you’ve signed the consent form at the beginning of the process, it doesn’t really matter what happens after that, you’ve been told.”. That’s not enough I think for good ethics.

**Latha:** And I think that comes back to the other issue about training those who are consenting. I speak from personal experience within my own teams I can see somebody might say, “I don’t do whole genomic sequencing consenting; I don’t have the time for it.”. I might even have my organisational lead saying when we had a letter come through to say now we’re no longer doing this, we’re going to be doing this test for everybody, there’s a whole gasp because it’s at least two hours’ worth of time and how are we going to generate that time with the best of intentions. I think that’s where I think the vision and the pragmatic, you know, the grounding, those two should somehow link with each other. The vision of Genomics England with working with NHS England and with the future, Health Education England arm that is not amalgamated with NHS England, is trying to see how do we train our future clinicians who will hopefully consider it as part of their embedded working thinking and analysis, but also, how do we change the here and the now?

The more senior conservative thinking people, who are worried about how do they have to generate time to manage, we’re probably already a bit burnt out or burning out, how do they generate time? If you then discover new conditions whether there is already bottleneck in various pathways, how are we ethically managing the new diagnosis and how will they fit in in the waiting list criteria of those people on the journey who are symptomatic. I find that bottleneck when I have conversations with colleagues is the anxiety, how is that going to be addressed.

**Jonathan:** Latha, you’ve sort of taken us around in a circle. We started off thinking what was special about genomics, and we’ve reflected on ‘we have to solve the problems of the health service’. I think that there’s some wisdom in that, because we are learning how to do things that are not unique to genomics, but there’s an opportunity in genomics to do it better and an opportunity for us to help other areas of the health service do better, too. I think we’ve come around in full circle in a sense.

**Natalie:** Which feels like a lovely way to wrap up our conversation. I feel like we’ve gone into some of the deep ethical principles but also really shown how they can be brought into the practice, into the clinic and brought to bear the thinking and the feelings, the hopes the anxieties of participants. There’s a very, very important range of different voices so a very rich discussion.

I’d just like to thank you both very much for joining us on the podcast. Thank you to our guests, Professor Sir Jonathan Montgomery and Dr Latha Chandramouli for joining me today as we discussed ethics in genomics research and practice. 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.