**Bridging the gap between diverse communities**

**Behind the Genes Transcript**

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

**Aman:** It’s really important to engage community leaders who are really well embedded within the communities, who are attached to organisations or institutions which are well trusted in the community as well, so that we can get a wider perspective of how communities feel about genomic medicine and accessing services that we want people to engage with.

**Naimah: My name is Naimah Callachand and I’m Head of Product Engagement and Growth at Genomics England. On today’s episode, I’m going to be joined by Anna Smith, child and adolescent integrative psychotherapist for Rare Minds, Aman Ali, a community ambassador for Genomics England, and Moestak Hussein, community coordinator at Bristol City Council. Today, we’ll be discussing the disparities in access to genomic medicine amongst diverse communities. If you enjoy today’s episode, we’d love your support. Please like, share and rate us on wherever you listen to your podcasts.**

**Aman:** Hi, my name’s Aman Ali, I am an ambassador at Genomics England, a person very passionate about health research and ensuring that diverse communities are involved in health research, and I work as a community engagement manager at Our Future Health.

**Anna:** My name’s Anna Smith, I’m a psychotherapist. I work in private practice and also with Rare Minds, who are a company who provide therapy to people with rare and genetic conditions.

**Moestak:** Hi, my name is Moestak Hussein and I have a background in community development, and I’m passionate about tackling health inequalities, and building social justice and inclusive approaches to address health inequalities. I work at Bristol City Council in the public health team, and I’ve participated in the Bristol workshops around equity in research in genomics.

**Naimah: So, let’s jump in and first of all I want to talk about barriers to access for diverse communities. I want to talk about how there are language barriers, cultural differences and socioeconomic factors that impact access to genomic medicine for marginalised communities. Anna, I wonder if you maybe could talk to me a bit about this.**

**Anna:** Yeah. So, I’m talking about the traveller community, and we refer to this community as a GRT community, which is Gypsy, Romany and Traveller, so it encompasses people in the UK, people living in Ireland as well. And some of the barriers to accessing healthcare are a lack of understanding of culture. There’s been studies done where it says that people from GRT communities show up lower on all markers for poor healthcare and poor mental healthcare, and part of the reason for that is things like illiteracy. You know, you’re dealing with people who can’t read or write. They can’t read appointment times. They don’t have access to public transport. A lot of women don’t drive in this community, and also women are not very well supported within the community by the people who can drive and who can get them places, because it’s not seen as something that they need access to. Because the community is so closed, everything sort of takes place within the community.

In terms of genomic healthcare, access right from the start of life, if people are not accessing healthcare right from birth, they’re not getting the genetic testing that’s needed, so then a lot of these things don’t even show up until the illness presents itself, and then accessing healthcare from there is really difficult. You know, it’s something that – it doesn’t happen a lot. Only 67 percent of people from the GRT community were able to get a doctor’s appointment when they needed it, compared to nearly 90 percent from other communities, and that’s through things like not having a fixed address. Lots of GPs don’t offer temporary registration, which means that if you are travelling, you do not have access to a GP, which is your first port of call if you need any access to healthcare. So, many people from the GRT communities are using A&E services in order to get healthcare, which – you know, they are not set up for dealing with long-term life changing conditions. They’re there to deal with what’s right in front of them and then they move on. There’s no sort of continuity of care.

**Naimah: Thanks Anna, that’s really highlighted a lot of barriers for the GRT community. And I wonder, Aman, if you want to come in now and maybe discuss some of the barriers that maybe the Muslim community might experience.**

**Aman:** Yeah, I think anyone involved in medicine or anyone who’s a doctor is really well respected in the Muslim community. That profession is something that every parent aspires for their children to get involved in. They at least want one of their children to be a doctor. Having said that, there’s this willingness to engage with the space, but there’s a lack of knowledge, which is a huge issue here. People don’t know what the word genomics means or genes, or understand DNA. Some of this language is a huge barrier to understanding and then eventually accessing some of the services that could be available to people from Muslim communities. Because when we speak about Muslim communities, we’re talking about a huge, diverse group of people from South Asia, from North Africa, from the Middle East, and they all have their nuances and different cultural experiences as well.

Just to kind of point out maybe one or two, most people in the UK have grown up in the UK, where access to healthcare is free, whereas this is quite a strange phenomenon for people who may have not been born in the UK and then access healthcare services in the UK. And the context being here is usually they pay for healthcare in other countries, and whenever any public or free healthcare is provided, it’s usually seen as kind of not very good or suboptimum, or yeah, it’s not going to be very helpful for us. So, when they see free healthcare in the UK, there’s that kind of apprehension, “Actually, is this going to be worthwhile? I’m not paying for this, so it’s not going to be very much good for me.” So, those are some of the cultural nuances that certain communities where healthcare is not for free in certain countries that poses a barrier.

Language in terms of speaking and reading is an issue. So, a lot of people, they may speak a language, but they don’t know how to read a language. So, even when services are translated – I, for example, can speak Bangla, but I can’t read or write Bangla, and not a word of Bangla at all. So for my parents, who can speak Bangla very well, their reading level is actually quite good, but I know that many within the community, they didn’t get education back home, and therefore reading and writing is a challenge as well. And then you have the issue of dialects. There’s so many dialects within so many different communities, so when a language is spoken or written in a particular way, if that dialect isn’t your mother tongue or a dialect that you’re familiar with, then that causes challenges to access as well.

**Naimah: Moestak, how do cultural beliefs and values influence attitudes towards genomic medicine within each of these different cultural communities?**

**Moestak:** I think Aman and Anna touched on it a lot, and it’s about communities being able to coproduce that historically hasn’t been there. The supremacy of certain communities to have a voice and be able to express how they would like to shape their healthcare, but also access to healthcare barriers have been part of having a barrier in access. And I think Aman touched on like even the term genomics, I don’t think it exists in particularly my community. I come from the Somali community, and I’ve tried to look at historical kind of words and terms. I mean, our language only got developed in 1973, the written language, so you can imagine that there’s a lot of gaps or there’s other terminologies.

So, the cultural beliefs and values is also communities’ recognition to be driving their own health needs and priorities is not valued within those sectors such as healthcare. I mean, we’re still talking about holistic medicine. People go to their faith leaders in the first instance to have support around prayer. That’s not necessarily recognised by mainstream health provision. And I think it’s about how do we build on those strengths and how do we recognise that that is a really great part of communities. And it’s also tradition and customs within childbirth, from birth, understanding what children and young people and families will need. I know there’s customs and traditions for women to stay at home, for example, for 40 days, and those are the kind of traditions that could be built on. And I think it’s about making sure that the child doesn’t pick up bacteria or things like that.

So, there is an understanding and knowledge within communities of genomics. It’s the awareness and the training around patient centred approaches are still missing, in my opinion. And I think that influences how people view genomic medicine. It goes back to the lack of trust and historic past abuses and cases, that communities has resulted in lower participation and a reluctancy to be part of genomic testing, but also that lack of understanding.

**Naimah: Anna, did you have something you wanted to add in there?**

**Anna:** What you were just saying about keeping it within the community, that’s something that we see with the GRT community massively is everything is handled within the family, and I think that’s not necessarily valued outside of that community. If you arrange an appointment with someone and the whole family turns up, it’s like, “Woah, what’s going on here? You know, how is this managed?” And it becomes a safeguarding issue, when actually that is how it's managed, and very often you need to get the whole family on board before you can start working with an individual. Because within the GRT communities, individuals do not exist outside of their families. Even what we’re saying about language, a lot of the GRT community who live in England now speak English, but the words that they use for mental health are very different.

You talk about mental ill health, that translates as psychosis in the GRT community, whereas if you’re talking about depression and anxiety, somebody might say that they’ve got bad nerves. So, if you come up and say, “We’re dealing with mental health now,” people would say, “Well, I don’t have psychosis, I don’t have that, this is not an issue for me.” And it’s like you’re speaking different languages even though you’re using the same words.

**Naimah: From what all of you have said as well, it does sound like there are a lot of similarities in the barriers in each of the different cultural communities.**

**I wanted to move on to ask about what strategies have been effective at engaging these diverse communities in healthcare research and decision making processes.**

**Aman:** There are a number of ways I’ve seen best practice take place in regards to kind of community engagement. The approaches have been one of two approaches. One, either inviting the community to come to your spaces, i.e. organising events or having opportunities where people can engage with your service. Or the alternative approach, which I think is actually more effective, is actually going to the spaces where communities are most familiar with. So, whether that’s holding a focus group at a community centre, at a church or at a mosque, or engaging in coproduction with a community organisation, to come together, to come up with an idea of how to best engage communities. And I also feel like there’s a difference between PPI, patient and public involvement, versus community engagement.

And those are the two major approaches that I’ve seen when it comes to community engagement, and I’m a big advocate of community engagement, because you’re going into spaces which are authentic to the very communities that we are hoping to engage, but you’re going into an unfamiliar environment as opposed to bringing that community into an unfamiliar environment, where they might be a bit guarded with what they want to share and how comfortable they feel. So, those are some reflections on good practices in community engagement.

And I think one of the key things that we need to do is understand who are the key community leaders within that community, ‘cos it’s one thing being within that community, and being able to speak about that community are two different things altogether. So just to articulate what I mean by that, I live in Luton, but I’ve just moved to Luton two months ago, so if you ask me about what life is like in Luton, I’ll be able to speak about my experience, but if I was to live here for 20, 30 years then I’d be in a better position to speak about how people in Luton live and what their experiences are like, and that’s two different perspectives you’re going to get. So, it’s really important to engage community leaders who are really well embedded within the communities, who are attached to organisations or institutions which are well trusted in the community as well, so that we can get a wider perspective of how communities feel about genomic medicine and accessing services that we want people to engage with.

**Naimah: Thanks Aman. I think you made a couple of really good points there, and I think you kind of have this overarching feeling of building trust, which is what Moestak mentioned in the previous question as well. I thought maybe now would be a good time to discuss your first responders project, Aman, if you could tell us a bit about that. It’d be good to hear the kind of developments from that community work.**

**Aman:** Yeah, so one of the ideas that came about from engagement actually that we had with some community leaders within the Muslim community, primarily some imams, they heard about the work of Genomics England, they heard about the work of research in particular, and they were really keen to get involved even further, but they were honest in saying that, “I know very little about this space. And it’s one thing for me not to know much, but then if I don’t know anything then I’m not able to then advocate for this within the community. So, two things you need to help me with. One, help me understand this space, but also allow me to then be able to advocate for services or information that my community can benefit from.”

So, that’s where the inception of this first responders idea came about. The idea being that community engagement happened with some imams from all across the country, where we trained them to understand a bit more about genomics, and genomic healthcare and medicine, but also to be able to navigate a number of scenarios that they may face in the community. For example, there’s a mother who has been recommended by their GP to go see a genetic counsellor, but they’re really worried about broaching that conversation with their husband or their family, because of the challenges that they may face. So, how would you support someone in the community when that scenario comes up? Or for example, someone like Genomics England or Our Future Health or another organisation has approached you about a research study, and they want to engage your community, how would you have that conversation with that particular organisation, advocate for those health programmes within your community?

So, we just presented a number of scenarios. But I think the main thing that we ended with was giving the imams in this particular incident the ability to signpost to services, be it helplines that are available for communities to access more information, or websites that people can access in order to understand more information about different issues to do with health conditions, or whether it be better understanding issues like cousin marriages or kind of accessing genetic testing.

**Naimah: That sounds like you’re empowering the leaders to advocate for healthcare and share this with their communities through this work. I wonder, Anna, is that something that you could do in the GRT community as well, like empower the leaders of the family to disseminate these healthcare messages, and how would we do that?**

**Anna:** Yeah, I think so. I think a lot of it would need to be outreach, and there are people out there who can help bridge that gap. For example, there’s a great team called Family Friends & Travellers, and if you get in contact with them and let them know which community you’d like to go into, they can help arrange, or they will come with you to go into that community. Because the GRT community, you know, is very mistrustful of anyone coming in, and rightly so. It was only in 2011 that they were included on the national census as an option to say you’re from that community, so I think there’s massive mistrust there of anyone coming into the community.

So, if you want to engage the leaders of the families or of the communities, you’re going into a settled traveller site, there will usually be somebody who is in charge of that site, not officially, but maybe their family might be the biggest family or they might be the most important family. And there are people out there who will allow you to start to engage with that person, who can then disseminate the information. But it needs to be outreach care, and the information that you disseminate, it needs to be tailored to people who have left school at primary age, who don’t have the skills to read or write, or to manage appointments or read prescriptions, or have access to that type of healthcare. That’s where it really needs to be tailored.

And I think confidentiality as well needs to be tailored a lot, because gossip and reputation and shame is huge in the GRT community, and if you are seen to be engaging with someone outside of the community, that is something that can bring a lot of shame to you and your family, so it needs to be handled really, really carefully.

**Naimah: Just to kind of go along with this theme of trust that you’ve all now mentioned, Moestak, I wonder if you could maybe comment on what strategies can healthcare organisations and researchers employ to build trust with these communities who have historically been underserved or mistreated?**

**Moestak:** Yeah, I think I mentioned earlier about the hierarchy of power around superiority and also mistrust of medical professional generally, and I touched there on how safeguarding concerns are triggered on not understanding cultural norms and practices within communities, and misconstruing that with safeguarding. There is generally that mistrust is there. And I think what Aman touched on there is really the importance of asset based approaches, and really building on transparent and really embedding transparent and inclusive practices from the onset. I mean, if we talk about coproduction, true coproduction is really creating a power balance where there’s no hierarchy. It’s an empowering model. It empowers both the researchers or the person that comes in, but also the communities that participate, and you all start on the same level, on the same outcomes and the same goals and aims that you want to achieve.

And I think it’s important to embed those kind of approaches, and it’s Covid-19 – I mean, we took part in Bristol in King’s Fund research around the community champions model. It’s exactly that, about engagement, about community driving their own solutions, and being able to collectively collaborate, drive their health piece forward, but also increase the capacity of communities. We worked with clinicians who come from those communities, and it’s no surprise that the uptake of covid-19 vaccine increased as a result of working with those trusted voices.

Quite often, those really effective programmes and engagement often are not funded adequately. They’re not sustained. And what happens is that we constantly are having to rebuild and restart, and that really does affect trust as well with communities. And when something works, why not build on it? And even now with that Covid-19 learning from the community champion model, the resource is not there anymore. It’s not valued anymore, sadly. That in itself is a risk, I think, in building the trust, but also the strength to continue that work and adapt in other ways around genomic medicine, and even increasing and diversifying the genomics data pool, helping communities understand and drive that. And that first responders project, communities being trained to capacity build and then being able to drive that within their communities, that’s the only way that we’re going to have effective strategies.

**Aman:** I think adding onto what’s been mentioned, with regards to building trust, it’s really important to understand the motivations of communities, and to understand what messaging is going to resonate with different communities, and it’s going to be a different message for each community. You can’t have the same approach for all communities. A recurrent theme that I’ve come across when engaging different communities is this difference between messaging which is individualistic and then messaging which is about the community and more the collective message, and how that resonates a lot more with certain communities that I’ve engaged with, particularly within Muslim communities. And that’s something that I think is a bit untapped in regards to kind of any materials that are created, be it posters or videos or any content looking to reach out to communities.

When we did some focus groups with some communities in Watford, who are primarily from the Pakistani community but also other parts of Asia in that region, the biggest response or biggest positive response that we got was when we posed the question, “If you were to know that people who look like you, from wherever your parents are, family may be from, would you be motivated to take part in that research?” And the biggest yes came on the back of that question. And that speaks to the fact that, “If I know that my family or my community, not just in the UK but abroad can benefit, then that would really motivate me and build trust that actually you’re not just here to benefit me as an individual, but you’re here to benefit my community as a whole, and therefore, yes, I’m going to be more trusting of this programme and be more motivated to take part.”

**Naimah: I just wanted to go briefly back, Moestak, you mentioned cultural norms, and I wanted to talk about the cultural norm in societies where maybe people may marry someone from the same ancestor, and what the societal fallout from these practices might be.**

**Moestak:** The stigma and the stereotypes often for communities comes from those beliefs and messages that are often sometimes not even backed up with scientific evidence. It can be seen as Islamophobic sometimes of Muslim communities that practice that. But also I think what’s important to understand is that concept around hereditary conditions and how that can determine one’s health, and it’s not really fully appreciated or desired. And so as a result, for example, a lot of people refuse to even have those early onset maternal testing for the foetus. My personal experience, I have three children, teenagers now, and I refused those tests as well, because my belief and my religious beliefs would kind of not align with being able to terminate a foetus if there were some genetic conditions. And so I think that is often not understood and made very clear to communities, and build on their beliefs and attitudes and values. And so those are the kind of cultural norms that are not fully understood.

But also the opposite side of that actually around being able to prevent a good life for somebody or a bad life for somebody, and being able to prevent genetic conditions is also part of the religion on the flipside, but again it’s not creating that link. That cultural beliefs is not understood. I think also the community implications around the stigma. I mean, autism’s a big issue in the Samali community, and I remember years ago when I was working in education, we had a big issue around even acknowledgement of diagnosis and referrals, and it’s because of the stigma. Those perceptions do exist within communities that if someone has a genetic condition or ill health or a disease, it’s almost like being a black sheep in the community. And so it’s being able to build on those desires of the community wanting to be healthy and well, I think is not often understood.

**Naimah: And do you think it’s partly as well education of healthcare professionals to communicate in a really culturally sensitive way?**

**Moestak:** Yes, exactly, that’s exactly what it is. It’s missed opportunities really that we can build on. In that particular example of autism within the community, I was able to do a really positive piece of work with the community, and building on their interest and their skills, but using my own lived experience and understanding and knowledge, and being able to inform that within education sector but also the health sector, and providing that training and upskilling. And there is unfortunately a lack of diversity within the workforce if you look at the NHS. The lower level kind of cleaning and porter staff are ethnic minorities. And so it is about using those clinicians, as I mentioned earlier, that are coming from those communities are the forefront.

We’ve recently had a really positive piece of work in Bristol around let’s talk about MMR, and we had a cohort of unvaccinated community, a Somali community, young people between the age of 16 to 25, and we worked with a Somali clinician, who led on that piece of work, and it was absolutely amazing. The young people as a result trusted her information and took up – but again also another thing that’s important is that a lot of data in the medical system is missing. I for one migrated here from the Netherlands, where I came there as a refugee at the age of three years old. My medical history is completely missing in both the UK records but also in the Netherlands, so I didn’t know if I had MMR vaccine. So, it’s a lot of gaps in information that people have, newly arrived communities that still need to constantly be updated and informed and education awareness raised with those communities.

**Naimah: Anna, I wonder if you wanted to add anything onto that point.**

**Anna:** It’s really difficult with that mistrust and sort of how closed the GRT community is to getting that information in, and I think to getting that information understood as well and to make it seem like it’s important. Because family is the most important thing, people are accepted the way that they are. You know, if we’re talking about autism, people are accepted the way that they are, and it is a bit like, you know, “There’s nothing wrong with my child, how dare you suggest that there is?” That testing isn’t done because the access to healthcare is so difficult, because people can’t register with GPs, because they can’t access maternity care, they can’t access postnatal care. Because they can’t register with the GP, they’re not on the system, and then the records don’t exist. Still now there’s birth records and death records that do not exist for these people within the communities, never mind medical history throughout their lives.

**Naimah: I think it really highlights a lot of gaps, doesn’t it? Aman, do you want to add anything to that question?**

**Anna:** Your opening remarks is that it’s a cultural norm in all societies, and we see even within the royal family in the UK, that it seems to be that any disparaging comments are targeted towards certain communities, and even then unfairly. I mean, often it’s associated with Muslim communities, but I would say the majority of Muslim communities don’t practice marrying someone from within the same ancestor. It’s certain cultural communities who do practice this. Having said that, even that practice shouldn’t be seen in a disparaging way, because it’s how those communities live their lives, and so we should be respectful of that and not speak in any way disparaging towards that community. And I think we have responsibility – ‘cos obviously nationally the conversation then moves onto increased risks of genetic disorders, and so we should be very matter of fact about what the percentage increase is when it comes to the likelihood of genetic disorders within families who marry with the same ancestor.

Because what happens is, if we’re not very clear with what the actual facts are with regards to the increased risk of genetic order then even within the community which practices marrying someone from the same ancestor, that figure can be inflated, and so this perpetuates fear and perpetuates the stigma even more. Whereas if we are just matter of fact, “This is the increased risk of genetic disorders,” and leave it there, then the communities can decide and they’ll have a more informed position. I think the figures are an increase from two to six percent increase, but if you were to ask people within the community, “What’s the increase of genetic disorders if you’re marrying someone from the same ancestor?” they might think it’s 40 percent or 50 percent or a really high figure. So, that’s something that we need to work towards better understanding, which will lead to removal of that stigma as well.

**Anna:** Again, that’s something that we see in the GRT community as well, there’s been research done by a woman called Sally Anne Lynch into cousin marriage within the Irish travelling community, and when they tested people, they found more than 90 genetic conditions that are present within people’s DNA within that community that just aren’t tested at birth. And I think, you know, you’re right, it’s something that is not talked about, because outside of these communities it’s seen as wrong and it’s not seen as something that’s normal. It’s seen as abnormal. But within this community, it is very normal and it’s very accepted. But then the testing isn’t done because of the access to healthcare.

**Naimah: I think it just seems like it does kind of boil down to education and educating healthcare professionals that it is kind of normal practices. Aman, did you want to add something else?**

**Aman:** Yeah, Anna made a really good point about testing. I think there’s something that is a gap in the service that we probably don’t provide more widely is that, when it comes to people who practice marriage within the same ancestor in other countries, testing is very normal. So, I know there’s many countries around the world where it’s very standard practice and even a requirement in certain countries that you must be tested before you get married, and so maybe that’s something that we can learn from in the UK.

**Moestak:** I think it’s important to understand that some communities, decision making of consent is sometimes done by the head of the family, and I think that that is not fully understood as well, and often can be a barrier to participation. And I think that there’s an element of empowerness that is needed, particularly around women that need that empowerment model around consent of decision making around their testing and genetic testing, and just medical consent.

**Naimah: That’s an excellent point as well, thanks Moestak.**

**Naimah: So, I know we’ve touched on aspects of this already, but I wanted to finish on this question, how can meaningful community engagement foster trust and collaboration in genomic research and healthcare initiatives?**

**Aman:** I think one of the things that I would really improve is just awareness around genomic healthcare and genomics in general. It’s a learning curve that’s going to happen within communities at different rates, and we need to be mindful of this because that rate will determine also health inequities that are experienced by those communities as well. So, we need to make sure that we are adequately approaching all communities to the best of our abilities. Having said that, target maybe more resourcing and educational opportunities for communities which have been underrepresented in health research and in genomic health research as well primarily, so we need to sort of prioritise certain communities in regards to our community outreach, because then we’ll dispel any myths that people might have and work towards chipping away at the mistrust that certain communities may feel towards just healthcare in general, but more particularly about genomic healthcare, ‘cos genomic healthcare brings up some unique challenges and some unique perspectives within communities.

So, there’s a number of fears about the future, but also misgivings about healthcare in the past as well that we need to acknowledge. So, by having community engagement initiatives, which are prioritised from the beginning and not just an afterthought, we can go a long way towards getting over some of the challenges of the past, but also not making new challenges for us in the future.

**Anna:** I think as a whole, the UK has got a long way to go with building trust with the GRT community. I think it’s going to take some time. They still are one of the most marginalised communities. For example, in the area that I live, there was a GRT funeral going on a few weeks ago, and all the pub shut because they didn’t want GRT communities in their establishments, and there is no other community or minority that that would happen with now. So, I think there is still quite a long way to go to gain the trust of the GRT community. And in terms of healthcare, I think we need to go right back to the start and learn about these communities, and understand their cultures and their practices, and how they work without that judgement. Living a nomadic lifestyle is still criminalised. There needs to be a decriminalisation around these communities before we can even start to begin to work out how to go there and allow them to access healthcare and knowledge and information around genetic conditions, and around health and mental health.

It’s going to be a very long road from here, but I think what we can start doing is to start that destigmatisation. If you are a doctor and somebody turns up in your surgery identifying as someone from the GRT community, understanding the background they come from, and not having all those prejudices, you know, which is very difficult to do, to get rid of those thoughts that you already have about someone. I think we need to make a real effort to start, and I think there needs to be changes within the NHS in order for people to access healthcare better. I think the resources that are given and the information that goes out needs to be more specifically tailored to these communities if that’s who you’re trying to engage with, because there’s so much that goes on in the community that’s not known outside of the community, and it’s not spoken about, and within different GRT communities as well. You know, there are different GRT communities all around the UK, and what goes on in them is not known to other GRT communities either.

So, it’s about being specific with the information that you’re getting out, with who you’re actually targeting. And I think a bit like we were saying earlier, it’s the women, you know. The women have childcare responsibilities almost all of the time, and they are the ones who bring up the children, but they’re not necessarily the ones that make the decisions about the children or the child healthcare. You know, women are expected to do jobs in the morning. Women are not available before 11 o’clock in the morning. So, think about when you’re making appointments for. Think about when you’re going. I think it is going to be a long, long road before we get there, you know, with building trust and getting the information out there, but I think we can make a start.

**Naimah: Yeah, it does seem like there is lots of ways we can start tackling it slowly. Moestak, I wonder if you had anything you wanted to add.**

**Moestak:** As a public health specialist, you know, we’ve not been taught genomic medicine or genomic health at all in terms of how that can benefit and radically change the NHS and improve determinants of health, so that’s a massive gap of knowledge within the healthcare sector and professionals. But I think in terms of addressing the historic mistrust, I think there needs to be an acknowledgement and a real openness around the historic, you know, abuse and unethical practices that have existed within health. There are other countries that are much more advanced in that and really embedding that within communities through pledges. That long-term kind of piece of work for me is missing. You know, it’s that wider education piece that’s missing that needs to be really embedded in the culture.

But I think also investing in the infrastructure in the community. Like far too often, if the long-term vision is not there, communities are reluctant to get involved and have trust within that, so I think that’s an important part as well. And I think it’s also about demonstrating the benefits of genomic medicine. I think that needs to be done in a community level way, through storytelling. I know that there’s now a lot of development around cancer treatments around genomics, but I think it’s about having those people who have those lived experiences from different communities to be able to share the benefits and demonstrate that through their way, and being appropriately reimbursed as well. I think that’s really important.

I think generally, I think there’s a long way we’ve got to go. I’ll never forget when I went to Vancouver on a conference around health, and there was a lot of reconciliation there, where there was really acknowledgement, and the indigenous communities there that have a lot of health disparities were able to kind of overcome some of that and start building as a community and addressing tackling health inequalities because that trust was built and that acknowledgement from high up, from government level, all the way trickled down to local. I think also patient centred approaches around – like we mentioned, we talked about linking the cultural norms and the values and the beliefs that people have, and the skills and the assets that they have to be able to lead on these solutions themselves, that really needs to be embedded to build trust.

Aman touched on the perception around what could be done with genomic data. I don’t know if Aman wants to elaborate a bit on that, but that’s really important. It’s a big barrier. It’s how do we create transparent ways of storing data, but also use various ways of communication. It doesn’t have to be traditional reports. It could be through podcasts. It could be like community messaging.

**Naimah: Yeah, I think that’s a really important point. Aman, did you want to come in on that?**

**Aman:** Yeah, I think sharing the stories of the past in an appropriate setting, in an appropriate manner as well – ‘cos it’s a bit of a double edged sword, ‘cos you don’t want to scare people who are unfamiliar with these stories, but at the same time there’s a moral responsibility for all of us involved in this space to speak about these issues, one from the perspective of acknowledging what’s happened in the past, so then people feel like, “Okay, you’re not trying to hide anything here,” but from the perspective of also that we need to make sure that we don’t repeat some of the mistakes in the future, and that as people involved in genomic healthcare and involved in this space, that we’re cognisant of these misgivings in the past, and we’re cognisant of our responsibility to safeguard communities in the future.

**Naimah: Okay, so we’re going to wrap up there. Thank you so much to our guests, Anna Smith, Aman Ali and Moestak Hussein for joining me today as we discussed the barriers to access to genomic medicine for diverse communities, and the impact it has on these communities. If you’d 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 and producer, Naimah Callachand, and this podcast was edited by Bill Griffin at Ventoux Digital.**