**Genomics 101 transcript: Why is diversity important in genomics research?**

**Marie Nugent**

**Naimah:** Why is diversity important in genomics? Today, I’m joined by Marie Nugent, who’s an engagement manager for the Diverse Data Initiative at Genomics England, and she’s going to explain more. So first of all, Marie, let’s start at the beginning. What is diversity?

**Marie:** I think it’s sort of a fiendishly seeming simple question, isn’t it, what is diversity, and I think you’ll get just as broad a range of answers as the people you might ask that question to. But for me, you know, it’s really got to be about how we do things. So to me, diversity is about recognising that there’s maybe a limited way in which certain things work, or the way in which we might go about doing certain things, and it’s also limited in terms of who’s involved in that and who might benefit from that. So, in the broadest sense, I think diversity means recognising the limitations of maybe what you currently do, and really looking for how can we open that up a lot more to provide the space and opportunity for a broader range of people and voices and experiences to really be brought into that and shape it.

**Naimah:** And can you tell me a bit more about what diversity means in the context of genomics?

**Marie**: I find this absolutely fascinating in the context of genomics, because genomics is really about how do we understand, you know, how our DNA, as an entire piece of information, is building us and shaping us as people, and having an impact on our lives, and, you know, for us predominantly our health. And the way in which we currently think about grouping people in genomics is unfortunately still very, very heavily influenced by social understandings of how people group together, not necessarily anything that’s really about your genetic ancestry, for example, which is very different. So at the moment, you know, it’s an interesting thing to play with and think about because in genomics it’s absolutely crucial that we understand the broadest sense of human diversity in terms of genetics and genomics, and only by doing that can we start to really fully understand what it means to be distinct, and therefore how small changes in DNA can have a massive impact on people’s health.

So, diversity in the context of genomics has to actually completely change the very fundamental ways in which we currently understand how people group together, so it’s really getting at the heart of that academic thinking about the topic. But it’s more than that, of course, as well, because as I’ve sort of already mentioned about what diversity means more broadly, it’s got to be about how we do things and who’s involved in that, and who benefits from it. So, in the context of genomics, it’s playing at the ideas of how we even understand how people relate to each other and how they’re different from each other, as well as how we do things. It’s a really complex but fascinating topic, to be honest, to be able to look at and study in some way.

**Naimah:** How does the inclusion of diverse populations contribute to improving genomic research?

**Marie**: Yeah, so following on from what I’ve just said, we fundamentally need to include everyone, you know. In order for us to really understand what genetic ancestry means and what difference looks like across different groups, and how that impacts health, we have to be able to capture, as best as we possibly can, you know, what true genetic diversity looks like in people. So, including as many people as possible who are different from what we currently understand is absolutely crucial. It’s the only way in which we can progress this area. And as I say, that’s in terms of how we think about it maybe academically and what we can do in terms of research, and what we understand, but it’s got to also be about the practice and how we do things. So, there’s involving people and having good representation of people in, say, data, but we have to think about how we’re involving people in how we do things and how we understand things, and how we make decisions about these things too.

**Naimah:** So, for these large groups of people, what are the challenges and barriers for including everyone?

**Marie**: So, I think there are a lot of challenges and barriers that hinder the inclusion of a broader range of groups of people in studies. I suppose the main one that I’m going to focus on is it’s actually the way in which we do research. It’s actually our culture, if you like, of work in this area. That’s one of the biggest barriers, and that’s because, you know, research is a very fast paced, very competitive environment and area of work to be in. Quite often, you know, things need to be done at pace, and things need results, and things need to be published and all that sort of thing, and I think there is sometimes this perception of not having enough time to slow down a little bit, think a bit more carefully and outside the box about how we might approach a piece of work, for example.

So for me, I think the biggest barriers actually exist within the existing organisations and people who do this work currently. We’re quite sort of blinkered, I think, still in terms of how we can even approach this work. And finding ways of approaching doing research in a way that’s kind of outside the traditional sort of ways of thinking is for me personally, in my experience of working in this area, one of the biggest challenges still.

**Naimah:** And finally Marie, how can we address these challenges?

**Marie**: I think it’s not easy for sure, because this isn’t a new thing that people have been trying to do, you know. There’s a big body of work, you know, in the context of the UK that’s been going on for a number of years, that’s been about sort of trying to open up and challenge, you know, existing research culture and things like that. But I think it has to be about our approach. So, for example, we have the power at Genomics England to think about how we approach the new initiatives, the new pieces of work that we would like to initiate. We talk about trust a lot in this space, but for me, it has to link back to how do we therefore change the way in which we do things so that it opens up a little bit more, people can see for themselves that we’re trustworthy and they can trust in this, rather than just saying, “Obviously, you can trust us because we’re doing research,” or, “We’re doing something that’s going to be brought into the NHS.” Unfortunately, that just doesn’t quite cut it for a lot of people for various fairly understandable reasons.

And I think, you know, we can make decisions about how we go about doing that work, and I think it’s about your priorities and things like that. So for me, the most effective way of actually addressing some of these existing challenges and barriers is to almost be brave enough to do it differently, and take that sort of perceived risk of maybe not doing things as expected and slowing it down, and allowing that extra time and space for people to come in and shape it, and not actually feel like we have to know everything and we have to make all the decisions. Sometimes I think it’s about, we hold the space, we have the resources and we have the access to the expertise, but how can we create the space where actually other people shape it and we just simply facilitate it. That’s the kind of thing I’d like to see organisations like ours and other research institutions and things like that start moving towards as facilitators of shaping work that will bring some sort of public benefit.

**Naimah:** That was Marie Nugent explaining diversity in genomics. I’ve been your host, Naimah Callachand, and if you want to hear more Explainer episodes like this, you can find them on our website at [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk). Thank you for listening.