**Genomics 101 transcript: What is ethics?**

**Will Navaie**

**Naimah**: What is ethics? Today I’m joined by Will Navaie, who’s Head of Ethics Operations at Genomics England, to find out more.

**Will**: Ethics is part of philosophy, and it’s part of philosophy that talks through a set of moral principles that govern our behaviour and our conduct. So, it might be thinking about whether something is good or bad. It might be thinking about whether something is good or better, or whether something is bad and worse. So, it’s about values and how we demonstrate those values kind of in a moral framework. So, I like to think of ethics as, just because you can do something, it doesn’t mean that you should do something. So, the law dictates to us what we can do, but ethics then talks about actually you need to look at the context around a law and to see whether something is reasonable, and so ethics to me is the should. So, should we do something? Just because we can do something, it doesn’t mean that we necessarily should do that thing.

So, in medical ethics, we have four pillars or four areas that we concentrate on. One is justice, and that’s making sure that something is fair and equitable and inclusive. And equity being the key here, so equity recognises that individuals have different circumstances, and equity allocates opportunities based on the needs of the individual. So, it’s not about giving everybody the same, but it’s recognising that to get an equal outcome for something, that some people will require more of something because of their set of circumstances. We also have autonomy, and autonomy in medical ethics is a bit of a focus sometimes, and what that is, is giving choices and respecting people’s decisions around that choice. Consent, we talk about a lot in medical ethics, but it is not the be all and end all. It’s really important, but actually it’s one principle among many that kind of make up ethics.

Another one of those four is beneficence, and that’s talking about everything we do must create benefit for people, and that benefit might be at an individual level, it might be at a societal level, so there’s lots of different ways of realising benefit. And the other, which is the flipside of that, is non-maleficence, and that’s making sure that everything we do doesn’t cause any harm to people.

**Naimah**: Okay, and then so if we’re thinking about ethics in the context of genomics, what does that mean?

**Will**: So, those four principles that we just talked about are applied to genomics as much as anything else, so there’s no exceptionalism to those, so we live by those four pillars, if you like. But what does make things complicated in genomics is that genomic data is not just about you. It’s not just about an individual. It’s about your family, it’s about your future family, and what that means is that we need to take those four pillars, those four areas, and look at them through a lens of a group rather than an individual. Where it becomes more complicated is the kind of interface between the law and ethics, and the way that the laws are written in this country and in healthcare are very much around individual rights, and that becomes really tricky when the decision making of an individual can affect other people in their family. And so, what we try to do is to think about how we can influence behaviour that we want to see. So, the law says an individual has to give their consent for a thing to happen. What we do is we take a step back and we say, “okay, but because there’s other people involved, we need to respect that.”

And so, we’re constantly thinking about how can we influence the behaviour that we want to see. So, we might say, “when you are thinking about whether you want to take part in medical research, or genomic medical research, you might want to speak to your family about this. You might want to speak to your children about this, because it does have implications on them.” And so again we’re using the sort of vehicle of consent to try and nudge those behaviours that we want to see. So again, it’s this kind of ethics complementing the law. So, the law’s not really working – it’s working to protect an individual, but it’s not necessarily respecting everybody, and so we just try to kind of affect those behaviours as much as we can.

**Naimah**: Okay, and then what’s the best way to demonstrate ethics?

**Will**: I think that’s a really interesting question, and I think it’s really important because ethics being part of philosophy means that very clever people have lots of opinions, and write lots of things, and there’s lots of words around ethics, but actually the really important thing is demonstrating that. So, in order to kind of build trust in something, you need to be able to demonstrate your trustworthiness, and i think the best way to do that is really through public engagement. If you don’t understand what people expect of you, it is not your role to tell people what to expect. It’s your role to listen and see what people expect of you, and once you understand what people expect of you, you then know how to act, how to behave in line with what people want from you, rather than telling people what to expect. So, in medical ethics, we talk about – or in healthcare in general, we talk about doing things with people, not to people, and i think the best way to demonstrate that is to listen. It’s to engage. It’s to act upon what the public are telling you, and sometimes those aren’t the things that you want to hear. But that’s how we make improvements. That’s how we build trust.

I think a really good example of this from Genomics England is the newborns programme. In ethics, we talk about the needs of science should never outweigh the needs of society, and scientists have said, “we think genomics can help with newborn screening and diagnosis of rare diseases.” So, what we’ve done is said, “okay, science has said this, we think that we can make improvements, but actually we now need to go and see what society thinks about this. Is it acceptable? If it is acceptable, what are people’s thresholds for what we can do? And so the whole programme and the generation study has all been driven by user involvement, public involvement, and we have learnt so much, and we’ve adapted our approach so much to that. And i think that it’s a really good way of us demonstrating that we have listened and that we have acted upon what we’ve heard. I’m really proud of the way that ethics has been actually genuinely embedded in the decision making around that.

**Naimah**: That was Will Navaie, explaining what we mean by ethics. 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. Thank you for listening.