

First Nations Genomics with Professor Emma Johnston Azure Hermes and and Professor Marcel Dinger

EMMA JOHNSTON:

Good morning, everyone, and welcome. I very much hope you enjoy your time with us today. I'm Professor Emma Johnston. I'm the proud Dean of Science here at the University of New South Wales. And I'm delighted to be hosting today's event. Our conversation on First Nations Genomics. Before I begin, I join you from Gadigal country and you'll be joining us from a range of Indigenous land and sea countries from across the continent, perhaps. So I'd like to pay our respects to the people who are the traditional custodians of the lands and the seas and to recognise their continuing connection to country. I'd like to pay my respects to Elders past and present and to extend that respect to other Aboriginal and Torres Strait Islanders who are joining us today. Today's session will be recorded. So if you miss any of it or you wanna watch it again, you can at your convenience and a link will be sent out in the chat section. A recording will also be emailed out to everyone who is registered for the event. We are encouraging live participation in this event. And so at any point in time, you can post a question in the Q&A chat function and through, the discussion with our panellists, I will try to integrate as many of those questions as possible into the conversation. Today's topic will be addressing the importance of inclusive science. Acknowledging that things have not always been done well in the past, and how both non-Indigenous and Indigenous scientists are putting reconciliation into action. We are working closely with communities with the aim of improving the science that we do, but also the outcomes for everyone, whether that be ecological, economic or social or health outcomes. So joining us today is Azure Hermes, who is the Indigenous Community Engagement Coordinator at the National Centre for Indigenous Genomics, which is at the John Curtin School of Medical Research at ANU. The centre focuses on using genomics to improve the health and wellbeing of Australia's first peoples and is forging a new approach to ethically and culturally challenging topic of Indigenous genomic research. Also joining us is our own Professor Marcel Dinger, who heads our School of Biotechnology and Biomolecular Sciences. He has more than 20 years of experience in genomics as both an academic and an entrepreneur. And Marcel is also a director of the governance board of the National Centre for Indigenous Genomics. Thank you very much for joining us today, both Azure and Marcel. OK, let's kick it off. So first, I'd like us to chat about what genomics is. And we've got a really diverse audience here. Some of practicing scientists, some others may be students or staff in different disciplines. So if I might begin with you Marcel, can we just have a brief explanation of what are genomes and how they might be important in Western medicine?

MARCEL DINGER:

Sure, Emma. I just also just start by acknowledging the traditional custodians of the land where I'm presenting from today, the Cammeraygal people of the Eora nation. So genomes, I think to explain that I think most simply, I always think about it where genome comes from and the genome comes from our mum and our dad. So we each inherit 23 chromosomes from our mother and 23 chromosomes from our father. And together those 46 chromosomes make the human genome. So those 46 chromosomes across them is distributed by DNA, which is essentially a really long string of characters of information, 6 billion characters, long. Hope may have heard of As, Cs, Ts, and Gs, and it's that code of 6 billion characters that really comprises what the human genome is. That information, just to put that in context, is the information really that programs a single cell when we're at the point of conception from an embryo all the way through to the development of a person. So it has all of the information in it that describes the development and the function of all of

our tissues and organs in our bodies, the brain, skeleton, the heart the eye, pretty much everything. So that's really everything that's there in the genome.

EMMA JOHNSTON:

OK, and what about the importance to Western medicine? How much do we need to understand about genomes in order to apply medications, for example, these days?

MARCEL DINGER:

Yeah, so I guess in medicine, one of the reasons that genetics and in the genome has become so important is that ultimately, virtually all disease is either originates from a defect or a variant in the genome, or the way that we treat an individual responds to information that's in our genome. So each have an individual response to different sorts of medications and treatments. And we've also got different predispositions to various kinds of disease. And virtually all diseases, even things like cancer, are ultimately stem from variants and changes that that occur within our genome.

EMMA JOHNSTON:

Fascinating. So, that sounds incredibly complex, of course, to someone who doesn't study genomes. But there's also a complexity and a sophistication and a depth to the way that Aboriginal and Torres Strait Islanders share a connection to their ancestors and their family lines. Azure, can I ask, do these deep connections align with any of the concepts of the hereditary based on genomes?

AZURE HERMES:

Thanks, Emma. So like Marcel, I just want to do a quick, brief introduction. I'm a Gimuy Walubara Yidinji woman from Cairns, far north Queensland. And I am coming to you from Ngunnawal, Ngambri country here in Canberra. And I'd like to also pay my respects to Elders past, present and future. Thanks for having me today. In answer to your question. And I think when Aboriginal people think about genomes, we think about our family and marriage and kinship systems. And although we don't use the word, we've never used the word genome in our dialect. Our genome is a direct link, a link that connects us here today with our ancestors. It's the link to basically our whole identity.

EMMA JOHNSTON:

Wow, that's pretty powerful. So they're telling us a lot about ourselves because they're also telling us about our ancestry, given that alignment with our ancestry. It must be incredibly important to, I guess, considering protect not only the privacy, but the ownership of that genetic information.

AZURE HERMES:

Yeah, definitely. The example I often uses is genomics is a bit like Pandora's Box. You can't open it a smidge and take out all the good things you want once you open. I guess the can of worms, it's open. And once someone starts looking at an Aboriginal genome, people are gonna wanna start looking at, say, population studies and how did Aboriginal people get here? And the road that we took to get here. And for non-Indigenous people, that might seem like not a big deal. It's almost necessary to have that information even. But in a world that's filled with people like Andrew Bolt and Pauline Hanson, it's actually really quite scary for Indigenous people because it actually gives them power to start defining, what our Aboriginality and what our identity is. And that gives them the evidence to start determining who can be Indigenous and who can't be. And the fallout from that is absolutely devastating if it's not protected. So I'm a really firm believer that if we're going to go down this road

of genomics, it's extremely important that you have to do it with Aboriginal people as partners and doing it together.

EMMA JOHNSTON:

Well, that's a great way to an introduction to the National Centre for Indigenous Genomics. Can you tell us a little bit about the centre and what its core mission is?

AZURE HERMES:

Yeah, sure. So the centre was founded in 2012. We have a historical collection of blood samples. We have around 7,000 from that were collected from thirty different 35 different communities across Australia between the 1960s in the 1990s. Not a lot is known about the consent process of those samples. However, given that majority of those samples are collected between the 60s and 70s, you could safely assume that proper consent wasn't obtained at the time. And that's for a number of reasons, mostly around ethics. So the samples were collected by someone called Bob Kirk, Professor Bob Kirk, who was doing a population study at the time. And so the 7,000 samples that we have of Aboriginal people are actually a part of a 200,000 collection worldwide collection that he has. When he passed away those samples then fell to Simon Easteal, Professor Simon Easteal who has been looking after them now for quite some time. So in 2012, the university decided that we should probably start making some decisions around these samples, whether it was OK for us to keep these samples, whether we should destroy the samples, what to do next basically. They got a consultative committee together, which was predominantly made up of Indigenous people. So people like Mick Gooda, Mick Dodson, Kerry Arabena, Marcia Langton, Glenn Pearson, and these really good prominent Indigenous people to look at our collection and to give us some advice about what to do. So they gave us eight recommendations, which the university accepted all of. And the three most important ones were that we had to form a national centre to house the samples. We had to have an Indigenous majority governance board to be custodians of those samples. And we had to actively go back and seek out all 7000 people and their families if they had passed away, and to not even talk about consent, but to ask that question about what to do. So essentially, my job at NCIG is to find 7,000 people across 35 communities and have that discussion.

EMMA JOHNSTON:

That's incredible. And what happens if a person has passed away?

AZURE HERMES:

Yes, well, it's really it's up to the community to decide for the families to make that decision. So there are a few options. One is that a family group could decide to keep the sample in the collection and we would do a consent form for that. The family could ask for that sample to be disposed off and we could dispose off that sample here in Canberra, or the family might ask for that sample to be disposed off and return to country for reburial, which we can also organise.

EMMA JOHNSTON:

OK, so we'll get onto that practice in the minute, just flipping a little bit to the modern age. So now in 2020 Marcel, what kind of consent process do you need to go through if you're using genomes in any of your medical research or the clinical trials?

MARCEL DINGER:

So conventional, I guess the sort of medical research that we do today in genomics. It would be typical for an individual to go through an informed consent process. And that would be a process that's been approved by an ethics framework, that's set by a national standard, and that's what individuals go through in order to be approved for or to be participate in genetic-based research.

EMMA JOHNSTON:

And do you happen to know if the person's passed away? Would it be a consultation with family similar in terms of if you wanted to keep genetic information from someone had already passed away?

MARCEL DINGER:

So at the moment, I don't think that's actually particularly well handled by a lot of the normal processes that we would undergo in typical medical research. And I think this is precisely where NCIG has developed its own protocols and methodologies to do this in a far more considered way. So that's actually leading the way for more than just Indigenous communities, potentially rural communities across Australia. So in the past, there have been some poor research practices, particularly with Aboriginal and Torres Strait Islanders collection when Bob was collecting... Is it Bob that was collecting the samples? Would you have simply just I guess, would people have even known that their blood was being collected?

AZURE HERMES:

Yes and no. So there were a number of different ways that collections, of blood was taken. The first was he wrote to different people. So native affairs clinics, the churches, police, whoever was looking after communities at the time, and he would collect samples that way. The other way would be that if someone else was doing a particular research project, say, for instance, Galiwin'ku in the Northern Territory who had a typhoid outbreak, he would write to the Northern Territory Health Department and ask to use those samples once they had completed their studies around typhoid. So I think if people most likely didn't know that their samples were being collected, I mean, they were obviously just told to provide a sample. And even if they did consent, whether or not they knew that their sample would then be given to somebody else to do a different research project is highly unlikely.

EMMA JOHNSTON:

Absolutely. So I'm gonna jump back to the problems that a lack of consultation and a lack of appropriate governments had caused in the past. I'll get back to that in a minute. But for the moment, first of all, I remind people that if they have any questions, please post them on the live Q&A, and then I'll go back to you, Azure because you've been putting reconciliation into action in more than just getting those concepts sorted, but actually in repatriation of samples. Can you tell us what you've done with the Aboriginal community in Galiwin'ku itself, which I understand is Elcho Island in the top end?

AZURE HERMES:

That's correct, yeah.

EMMA JOHNSTON:

What was the project there?

AZURE HERMES:

So Galiwin'ku is the fourth community that I've worked with here at NCIG. It's about, I don't know, it's about 3000 people just off and a little island off the coast of Australia. You can get there only by flight. It's a community that we had one of the largest collections from... So about twelve hundred samples all up collected in the 1960... 1968. As I mentioned earlier, there was a typhoid outbreak on the island, so the whole island had to have the sample collected for testing and their sample was then given to Bob Kirk to be added to his collection. I made the decision to go to Elcho Island, to Galiwin'ku for a number of reasons, but mostly because it was the largest collection we had. It took me a good 12 months to actually start taking consent from that community. And the reason being is that it's a very traditional community. English as a second, third, maybe fourth language that's spoken up there. And it's a very cultural community that they practice their traditions on a daily basis. And so we really wanted to make sure from the get-go that we were actually doing culturally the right thing for this community. So in the front end of my consultation, I spent a lot of time working with community organisations, making sure that people knew about NCIG, so that if family groups needed advice, and they went to these organisations, they knew who we were and what we were doing there. I spent a lot of time working with community leaders and Elders, working through participation lists because in 1968 we had a lot of people who had passed away. A lot of people had moved to different communities. We wanted to know, we make sure that we had the correct next of kin details the people who had passed away, and I also really wanted to work with my organisation partner that I'd been that I was working with Yalu Aboriginal Corporation, and I wanted to spend some time going through the language that we would be using because it all needed to be translated into language so that people could understand what we were asking. So I spent a lot of time working with my research partners, getting them comfortable with the language we were using, making sure that things could be translated. The process of actually taking consent was, was difficult, interesting, difficult, complex. And the reason being was because as soon as we started talking about people who had passed away, it created a lot of fear within the community. And the reason was because it was such a traditional community. The automatic response was, well, what does this mean? What does this actually mean for the people who've passed away? You're thinking you only have three mls of blood sitting in Canberra, but in actual fact, is that enough to prevent someone from moving on to the next world? Is their spirit still here? Is this why we're having so much bad luck? Because we're being punished that these samples still exist? So my original thoughts going into this community was that we were going to dispose of all of the samples, which I was comfortable with. It didn't worry me to do that. But as time went on and as we started having more conversations and the family group decision making started to come into play, people started to think, well, actually this would be really great to be a part of, but how can we do it without you having any blood samples in Canberra? So it was put back to me to come up with a way of how Galiwin'ku could be in this collection, but with us having no samples of theirs at all. And what the community actually let us do was to extract DNA and collect the data from the blood sample. But any blood product that was leftover and any leftover DNA had to be shipped back to the community for ceremonial reburial. So to get from meeting with them at the end of 2017 to taking my first consent in November 2018, it was a huge, huge process. I went back to the community every month for two weeks at a time just to make sure that we were talking and getting that message out there and letting people have time to process what it was that they wanted to do. And then in 2019, it took me another 12 months to actually do the repatriation process. So work with the community about what the most culturally appropriate way to return these samples would be and what that would mean. Is it just simply handing the samples back to the

family or should we have a huge community celebration or ceremony around it? So ultimately, in the end, we decided on a community ceremony and we created a memorial actually in the community. So we created a huge garden with some ceremonial burial poles which were commissioned by local artists. We brought the samples back, along with 30 representatives from different universities to be a part of the ceremony. And then there was a huge it's called a bungle, which is a dance or a huge bungle where the families came and collected their individual samples to take back to country for reburial.

EMMA JOHNSTON:

Well, what an incredible process. And to develop that trust in the end that the community were OK about having their samples sequenced, essentially, and that genetic information kept while the rest was repatriated. That's an incredible story. Marcel you were part of the final ceremony, has being involved with NCIG kind of changed the way you look at the research you're doing or even that you practice the research? Yeah, absolutely. So, I mean, the experience of going to Galiwin'ku and sort of I guess being an observer to this process was a huge privilege. I think foremost, it gave me an insight into an understanding of both the sensitivity of these sorts of samples and what this means and what this type of research means to the community and the interest, actually, that the community also have in the research that we are undertaking. And I think that was a that was really eye opening to me. I think as a scientist, we often become very disconnected or I guess abstracted from the research where samples come from, especially when we're doing human research. We often don't think about the individuals that these samples might originally arise from. We treat them as effectively as numbers on a database or something like that and I think to see the connectivity to that back into community was incredibly powerful and valuable and absolutely transforms the way that I think about doing human-oriented research of any sort. It's equally relevant, I think similarly relevant to studying for example, patients that are affected by a rare disease, for instance, and considering in the same way that these samples are connected to people, into communities, into a whole ecosystem, really, and understanding that and respecting that. And also, I think, really reflecting on what is the purpose of the research that I'm doing. How does it benefit the people that are actually given these samples and participated in this work in the first place? That must actually be a huge motivating force as much as anything in that you're now much more connected to the research question, as something that affects people's well-being directly and every day. Yeah, so it also is interesting because it means that the consultation process doesn't stop at the point at which you get consent. It has to continue all the way through to the whole journey and providing feedback. And what are we doing with this information? Yeah, look, we are getting some questions in from the audience, so I might just throw to you a couple of them. They're really interesting, tricky ones, actually. So the first one I'm gonna ask is around anonymization of data, which is really difficult to do in genomics if you're taking from a relatively small population pool. So the question is, have the discussion started on what anonymization will look like when publishing data or results of analysis once you've got the consent? So Azure, I'll throw to you first have they got to that point yet where the sequencing, for example, of the Galiwin'ku people's DNA has actually been used and whether it's... So the information is stored in a private data, archived. But when it's used, I presume there's a whole another layer of consent that's required around publication.

AZURE HERMES:

Yeah, so it's a couple of step process, for NCIG. So it's not a matter of we don't actually do research

ourselves. We do some internal research for our own sort of ongoing stuff, but we don't actually do the research as for ourselves. So there's a number of steps before people are even allowed to get to the point of looking at our data. The first is that I need to apply to our board, which has an access committee. And so what that basically does is it allows our board to make a decision about whether or not this is a piece of research that we think should happen. It goes to an access committee which is made up of representatives from the community. And then the next layer on top of that is to then go back to the community to decide whether or not they wanna be a part of a particular research. So if somebody after a period of time... If somebody it all comes back to say, yes, this is going to go ahead, it is all anonymous. People don't get to know who these samples belong to. They will get to know the community, the areas that the samples come from And that's just part of research. People need to know that But it's a matter of trying to protect that information as we possibly can, but also allowing Aboriginal people to make decisions about whether or not they wanna be a part of a particular piece of research. Yeah, but a complex process. Marcel can I talk to you about anonymization? Not necessarily in Indigenous context, but in the rare disease space. It must also be an issue.

MARCEL DINGER:

Yes, absolutely. So anonymization of genomic information is inherently problematic. It is essentially a fingerprint of an individual. So all of the information mentioned to truly anonymize an individual's genomic data set is really all but impossible. So when genomic information is generally published and made available for researchers, it's often done in an aggregate context. So you might, for example, take hundreds or thousands of genome samples and then put them together. And then that information can be just as valuable or extremely valuable to researchers for example, inferring new associations of genetics or genome to a particular disease. So that's often how it's done. There are some individual cases where individuals have given consent to make their genomes freely available and open and just recognise the fact that even if you don't connect to a name to it, there has to be an understanding that you or a relative could ultimately be connected back to that genome through just using computational methods, you can work it out and kind of work backwards again from the genome to come quite close to identifying an individual again.

EMMA JOHNSTON:

And this is happening with millions of people who are submitting their samples to private companies who are sequencing, such as Ancestry.com, and they've been used in ways that we might not have foreseen.

MARCEL DINGER:

Yeah. So, I mean, there was an interesting example of this in recently, a few years ago in the US where there was actually an unsolved case of a serial killer, where the information from a relative of that serial killer was called the Golden State Killer. That had been puzzling detectives for decades. And the information was ultimately from a relative of the perpetrator, had put their data into one of these ancestry.com or 23.com databases. And it had been searched and the DNA was connected back to that person. And that ultimately led to the arrest and conviction of the Golden State Killer. So it kind of shows I think that illustrates sometimes just how connected genomic and genetic information really is and how it can be used in quite unpredictable ways too.

EMMA JOHNSTON:

And how powerful it is. It also begs the question around profits. So in the medical space in particular, there's potential to make quite substantial profits from pharmaceuticals and precision medicine later down the track. The question we get from the audience here is do or should companies be paying Indigenous people for any profits made using the plasma or DNA and are there any arrangements for that?

AZURE HERMES:

Yeah, it's, it's actually a really great question because it's one that everybody thinks about all the time to actually get to the point where you're making money is a long and arduous process. Not to say that you shouldn't be paying people for that at NCIG we're trying to work out what that benefit-sharing would look like and how it would actually happen, whether or not, whether or not you get the companies to pay people directly, whether or not it goes into a community fund. It's a really difficult question to ask, but it's something that we've been trying to work through for quite some time because it is absolutely a possibility that, through this research, we could find something that's quite beneficial for not only Aboriginal people, but the whole population itself. So, yeah, we're thinking about it. I don't have the answer for you. I really would love to but would welcome any suggestions that people have.

EMMA JOHNSTON:

Thanks, Azure. And Marcel, so you've been in the entrepreneurial side of genomics as well. Have you seen any situations where money has returned to individuals who've provided genetic information?

MARCEL DINGER:

Yeah, interesting. So there are a number of companies around the world that have started to base their business models around that kind of concept where an individual invests not just their genomic, but their health information into a database. And then as that information is used or monetized or in whatever form that money can actually or some sort of dividend can return back to that individual in return for that. I can't comment on how successful these types of projects are they inherently require people to divulge an awful lot of private and often personal information to a third party in order to do that. But the concept is certainly there, I believe, to do it.

EMMA JOHNSTON:

It's obviously only going to increase these sorts of issues as genetic information is used more and more. I'm thinking in particular at the moment during the COVID crisis, everyone's having their spit analysed pretty... I know I've done a couple of times just to do the COVID test. Is there any chance that information could go astray or has Australia got its, I guess, governance sorted to protect those sorts of biological samples during a crisis? Has anyone heard? Marcel have you... Yeah, so, so all of the COVID testing that I'm aware of that occurs in Australia goes through the medical system. So they're done in pathology labs. So all of that work would be under the same constraints and regulations that any other form of medical testing would have. So it would be inherently kept completely private. So I don't think there's any risk in those scenarios. I think where the risk arises is when private companies start to offer direct to consumer type tests. So that's what we've seen in genetics with things like 23andMe and others, that provide the sort of testing and you might actually end up consenting to the use of your information in ways that you really, really didn't actually conceive when you signed up. You might be thinking that you were just signing up to find out some

interesting bit of ancestry information about yourself, but in fact, you've divulged information that could be used for all sorts of other purposes as well. For example, you know, targeted marketing or who knows? Or putting your serial killer sibling in jail. But who would have thought? So, getting back to some of the, I guess, broader pictures for Aboriginal and Torres Strait Islanders around how this information, might be used in negative ways, the negative stereotyping. Have we got examples in the past of where, I guess, biological information has been used to characterise Indigenous people in negative ways, Azure, are you familiar with that history?

AZURE HERMES:

There was the Vampire Project, which happened in the 90s, which really did put genomics for Aboriginal people back at least 20 years. It was a project that may have started with good intentions, but really didn't look at the community consultation aspect of working with Indigenous people. It really did think that it was a matter of coming in and just taking samples and then disappearing. And there were a lot of people at the time, my aunty, for instance, who were very opposed to this project and really lobbied hard for it to not happen in Australia, which they were very successful in doing. But it definitely left a very sour taste in people's mouths. And it took a really long time for, I think, scientists to recover from that.

EMMA JOHNSTON:

It's got an evil name. Why was it called the Vampire Project?

AZURE HERMES:

I think it was just the coming in and bleeding people, taking people's blood.

EMMA JOHNSTON:

Alright. That was the nickname. AZURE HERMES: Yeah. That wasn't the formal name. And what about the characterisation in New Zealand? Marcel, can you tell us a little bit about what happened there?

MARCEL DINGER:

Yeah, so it was about 14 or 15 or so years ago in New Zealand, where it started out as a study into migration of Maori and Pacific Islanders where genetics DNA was taken from, I think, hundreds or even thousands of Maori and other Pacific Islanders. And it was used under the notion of tracking migratory routes from Pacific Islands to New Zealand as they help the people from Melanesia and Polynesia came New Zealand in the first place. So that information and the genetics that was then captured in that process, some of that was used by other scientists to look at characteristics that were generalised across Maori. So there was a particular gene known as I think monoamine oxidase, which was involved in a few briefly, (UNKNOWN), it's a neurotransmitter that's involved in producing documented serotonin, which are kind of important brain hormones (UNKNOWN). And so this particular gene or defect in this gene cause or variants in this gene can cause different levels of these characteristics to appear. And some of these characteristics are associated with so very high or low levels of serotonin and dopamine can be associated with violent behaviour. So by characterising this particular gene with aggression and violence, they associate that that is a broad characteristic across Maori, was incredibly damaging to that community. And it was actually you know, there were newspaper articles, reports and all sorts that used this as a mechanism to almost explain the behaviour patterns of, of, of Maori in New Zealand. So this was totally, you know, as you can

imagine, for Maori people who had provided their information for this and then to see this information used in such a negative way against them without any consent whatsoever, not to mention the fact that the science was largely baseless in any case, was really very, very damaging and caused an immense amount of damage and a lack of trust between Maori and scientists in New Zealand for I think that damage is still ongoing today.

EMMA JOHNSTON:

Look, that actually speaks to an issue where I've got in the question and I apologise. I haven't noticed. There are a few more questions I'll run through a few now, but it really speaks to the idea that Western philosophy of science has been relatively reductionist and hierarchical. So, they're breaking that down to the single gene, which does X. That's a pretty I mean, classic example of how strict Western scientific philosophy in its very hierarchical nature explains the world. Is this at odds as do you think with Indigenous and First Nations world views? This is a question from the audience that might not be so hierarchical. And if so, and they're asking, can that hierarchical ladder model be flattened into a different story? So in other words, can we stop trying to pinpoint particular behavioural very complex things to particular genes by using Indigenous storytelling?

AZURE HERMES:

Yeah, definitely. I think Aboriginal people have a lot to offer in this space when it comes to genome science. So we don't... When we think of like I said earlier, when we think about genome science, we think about our kinship system and how our marriage system works, who you can marry from what tribe or what family group and who you can have children with because you don't want that line to be too close. So you're having children related to each other so close together kind of thing. What I really like about Aboriginal communities is and working with Aboriginal people in communities is that people aren't afraid of genome science. And I know that it is a sensitive subject and we have to tread carefully when you're having these discussions with people. But what I find is that people are actually very interested in being a part of this science and their part of being wanting to be a part of research. I think what Aboriginal people want nowadays and in communities is to be a part of that decision-making process. And I think for too long we've had lots of researchers going into communities and, taking stuff. They're always wanting something. They're wanting blood samples and they're wanting our stories and they're wanting our family histories and initially and essentially taking our intellectual properties and writing their papers and writing their grant applications and essentially becoming the subject matter expert on us. And so I think what communities are doing now is saying, enough, we don't want you to do that. What we want you to do is to include us in the decision-making process of this research project. So if you want to look at our genomes and you want our family history, then include us in that, include us in your research, include us in writing your papers, acknowledge us for the work and what we're contributing to you, and not just in a footnote at the end of your paper as an author. And so I think that we don't have to be so one-dimensional about things. We don't have to just go into communities for two weeks and pay someone a twenty-dollar voucher and leave with a blood sample. I think that you can actually create a really good narrative around people's stories and what they're telling you versus what you're seeing I guess in your outcomes.

EMMA JOHNSTON:

That's a really positive thing and it extends way beyond medical research. In fact, I'm just pouring my

way through this fantastic document, which is our knowledge, our way. So this is about Indigenous knowledge of land and sea, country and caring for land and sea country. Same deal too long. We've just been using the information, not consulting, not having participatory co-development of management and problem solving, and acknowledgment of authorship. So I think it's a phenomenon that's happening way across many, many scientific disciplines. I've gonna pivot now to another question, which is actually kind of turning it on its edge, on its side. Modern medicine is kind of famous for focusing on areas in which there are big client groups that there's profit to be made. So the question from an audience member is, are we in danger of not having enough information about Aboriginal and Torres Strait Islander populations because they're a smaller group and potentially not as important to the big pharma companies in terms of developing things such as personalised or precision medicine? I'll throw it to Marcel first.

MARCEL DINGER:

Yeah, absolutely. And that's a really valid point. So it's well recognised that the vast majority of the research that's been done to date and genomics has come from people of and populations of European ancestry, essentially white people, Caucasians from essentially English and into European descent. So other ethnicities and that includes, of course, Aboriginal, but as well as other, I guess, non-Caucasian ethnicities, whether it's Vietnamese, Thai and Maori, and so on, are all very, very poorly represented in these genomic databases. And it does have an enormous effect on how that information can actually be used for developing diagnostic tests. For understanding the relationships and of different sorts of diseases so we understand a lot about and it becomes sort of self-fulfilling in the sense that the more information we have about the certain group of people, i.e. people of European descent, the more we learn, the more treatments that we develop that work best in those communities. And so for those populations and you end up kind of continually creating a larger and larger gap between the health care that works very effectively and is effectively optimised for people of European descent and is suboptimal for everybody else. And I think that the case with Aboriginal genomics is, is really because the population, again, is relatively small. And I guess the motivation for a company to develop specific tests, for example, that target those populations aren't incentivized. And I think that's why it's so important to actually almost specifically address those disparities. And I think that part of what we're starting to see.

AZURE HERMES:

I also think just to continue on with that, we are a very small population, but we're also very diverse within our own population. So what I can say is, is at NCIG, when I was talking about we're doing our own sort of internal research, is a reference genome around Aboriginal people. And I can tell you that just some little snippets of what we found is that the diversity between someone who lives in Tiwi Island, versus somebody who lives in the desert and Titjikala is so different that it's like comparing someone from Bangladesh to the UK. And so when we talk about are we missing things? Well, yeah, we are. Because if you start just thinking that by sampling West Coast Indigenous people is gonna be enough to cover everybody, you're actually doing yourself a disservice because we are diverse in our own little groups. We don't just evolve from one group of people.

EMMA JOHNSTON:

That's fascinating. Look, Western medicine is so famous for focusing on men as well as white people. So we often have a disparate amount of information about how women are responding to particular

diseases. For example, it's not always the case, but has been commonly in history. And we have a question from the audience about how does men's and women's business in Indigenous communities relate, if at all, to genomic research? Azure?

AZURE HERMES:

So in terms of the participants that we have, I think we've got a really good balance of men and women as well as young and older generations. So I feel like it doesn't play too much of a role in only men providing samples. What I would say is that when we do consultation, though, we tend to move away from we tend to have separate discussions. So we'll have discussions with men around what they wanna do and then we'll have discussions with women around what they want to do just to try and follow those cultural protocols. But there's definitely nothing that I've come across at the minute where, yeah, it's just men that are giving samples.

EMMA JOHNSTON:

Is it's a phenomenon for genomics research Marcel or is that for other areas of research that there has been a predominance of looking at male health issues over females?

MARCEL DINGER:

Yeah, it's not something that I've been aware of in my experience and in genomic research to date. It's not something I'm not familiar with or I haven't seen that there's been any bias there.

EMMA JOHNSTON:

So a related question to this, women in men's business and having those separate conversations, we've got a question from the audience member, which is a little bit more general, but we can relate it to that question, which is if you're with communities who have samples in your centre in the NCIG and some community members wanna be involved. So that could be a women's group. And some don't want to be involved in a project, in a research project. How do you manage that difference?

AZURE HERMES:

Yeah, so we definitely work on individuals and what it is that they wanna do rather than a community consent kind of process. And I think this is what you mean. What happens one part of the community wants to and the other part doesn't? Do you need a community consent? I think that's maybe where you're going with that. So I think we definitely don't look at that. We look at more of an individual consent process. What we are trying to develop is an app which allows people to log on and look at particular pieces of research and to make a decision about whether they want to be a part or whether they don't want to be a part of it. So you'll always be opted into a piece of research unless you opt-out of it and we give people a big chunk of time to be able to make that decision about what it is that they want to do.

EMMA JOHNSTON:

OK, so they've already been... The project has already been approved by the Central Advisory Committee, and hence everyone's opted in unless they opt out.

AZURE HERMES:

Yeah, yes.

EMMA JOHNSTON:

That's a tricky approach. So we also have some questions here. And this is a particularly important one for universities is what about pathways for involvement? This comes from Brendon Burns. Thanks Brendon. Pathways for development of Indigenous researchers, PhD students or staff in analysis of Indigenous genomes? Are we making in it a sufficient effort here to get people trained up and involved?

AZURE HERMES:

Honestly, no, I don't think so. I think that the fact that we have very few Indigenous students that are coming into this space is evident that we're not doing enough. So I think that there is real scope for universities to start really trying to encourage Indigenous students to move into this space. I can speak in terms of NCIG and the work that we're doing at the moment, which is we're in the process of starting a summer intensive, which it's a course that we wanna run over the summer. It's completely interactive. It's allowing students to work in all the different spaces that genomics offers and trying to really focus on that second third-year students so that when they start making decisions about going on for honours and PhD, that this is a space that they would like to look at. And obviously, NCIG would love to take on more Indigenous students as PhD students if anyone's ever interested in doing that. But I think there's still more effort that can be made. I think there's a summer internship for Indigenous genomics testing program for people who might wanna just you know, it's one week. If you wanna do something a little less time consuming. And that is also something that could potentially be a benefit to some people, but definitely not enough being done in the space.

EMMA JOHNSTON:

So Marcel have we in one sense fail to make the value argument for why a degree or a job in genomics is not attractive to Indigenous people with them all we can do then?

MARCEL DINGER:

Yeah, I think there is. I mean, there has to be. I think that we clearly aren't doing nearly enough in this space. And then in an ideal world, we speak about inclusivity and participation of Indigenous people in the work that we're doing, but without the qualified expertise there to do it. We're still we're really hamstrung there and it would be wonderful to do so much more. To actually have truly inclusive science that actually had Indigenous people as actually part of the whole endeavour. I mean, in our school, I can speak to that we have an Indigenous honours scholarship that's available now for Indigenous students that have gone through a Bachelor of Science degree and can go into an honours degree in our school, which covers things like genomics and bioinformatics and these sorts of things. It'd be wonderful to see more of those opportunities available.

EMMA JOHNSTON:

Yeah.

AZURE HERMES:

I also think that what people forget is that we have a lot of really good non-Indigenous people that are leading the way for working in the Aboriginal genome space. And that's fantastic. But without these students coming through, it means that we also have non-Indigenous people becoming the subject matter expert to our genome, which is not ideal. And so I really think that universities really

need to take the lead in trying to encourage these students to come through, whether it is and on a scholarship or whatever. But there definitely needs to be more done in this space in order for Aboriginal people to take control and ownership back for ourselves.

EMMA JOHNSTON:

And given that really strong alignment between the whole history of genomic research, what it means, and people's understanding of connection to family, to family lines, to ancestry, you could make a much clearer argument, I think. But there's also a negative history that needs to be kind of discussed and I'm moved on from in order to make sure that Indigenous people aren't scared of genomics because it's been misused. Yeah, it's really interesting conversation. I'm just gonna pop in a little advert for you in a study here at the moment, because we're also trying to increase our Aboriginal and Torres Strait Islander scientists and just open right at the moment. If you're interested in the science and engineering preparatory program, we're open for applications. And that program is designed to support Indigenous students. Before they get to university, so to transition to university and apply for an undergraduate degree and further information on how to apply for that group, we will post that in the chat. So we've got some staff in the background here. He can post that link. So final couple of questions, because we're running out of time, but we've got lots of fascinating questions. I don't know which one to choose, but they're all really interesting. Do you think it would be useful for genetic counsellors to have specific training in engaging with Indigenous communities? How about that?

AZURE HERMES:

Yeah. So recently I've been doing for the last two years, I've been running a... I've been invited to participate in a genetics counsellor course with UTS, which has always been fantastic with genetic counsellors or aspiring genetic counsellors. And it's just a full hour of just talking about community engagement and the things that I've experienced while I'm there. But I definitely think that it's worthwhile if there's a chance for genetic counsellors to actually go out to community just to experience what it's like being in a community and to get an understanding what people are going through is fantastic. I think there's definitely benefit in that.

EMMA JOHNSTON:

Marcel in your school is no such thing as kind of training and genetic counselling that would be more in the medical school, is that right?

MARCEL DINGER:

Yeah, that's right. The counselling, well, that genetic counselling isn't taught UNSW, in Sydney yes taught at UTS. But I absolutely agree that that embedding more of that training in Indigenous communities would be incredibly valuable.

EMMA JOHNSTON:

And obviously there are so many aspects to genomics, including a whole lot of mathematics. Got a really pertinent comment from Lachlan. Let's take it even a step here is the same for computer science. There's a lot of computational bioscience and very few Indigenous people in data management or high performance computing. And that's certainly the way forward for a lot of biological sciences, whether it be human genomes or biological genomes that we're dealing with. Well, it's been a wonderful conversation. I haven't got to all of the questions. I apologise to the

audience members who we haven't got to, but you can always damp them Spam Marcel and Azure directly with your questions. So I'm sure they'd be happy to answer some of them. They're fascinating. But in the meantime, we will end this conversation with just one last question for Azure and Marcel, just if you could pick one thing from NCIG that's a new process or a new procedure that could be applied in other places around the world or around Australia, what would it be?

AZURE HERMES:

(CROSSTALK) I'll probably have two points, I think working and NCIG is a working example, I suppose, of a new era of science where people are directly involved, where real blood and real DNA equals real life and real-life stories. And so that's a really intimate relationship and not something that we are comfortable with in the science world I think up until now. And NCIG is trying to develop ways to manage that new personalised science, I suppose. And I also think that what we can learn from NCIG is that actually letting people have their way actually delivers more engagement. So, for example, more samples means more help doing the work than conducting things in a very bossy and hands-off way. And I think scientists are always used to thinking objectively. But what we're trying to do is show that if you just loosen up a bit on the very clinical data-driven approach and deal with real humans in front of you, I think scientists can get sort of what they want and need. And, of course, the community get what they want and need. And therefore, everyone's a winner really

EMMA JOHNSTON:

A great ending. And Marcel.

MARCEL DINGER:

Yeah, I would just certainly echo everything that, Azure just said as well as I think my own postmodern learning was really around shared governance models where the participants in research are more than just have tokenistic role, which I think is what's been traditionally the case in both Indigenous research, but also in a lot of the rare disease research that I've been involved in and other health-oriented work and really having it as being truly participatory and having it completely involve co-designed even ideally, I think that when you're talking about the sort of research having a true understanding of the communities, individuals and people that are contributing information and as a society before really intellectual property. that having a genuine engagement with that group is immensely beneficial not only because it's the right thing to do. But I think more importantly is perhaps is that it provides a lot of insight into and genuinely valuable information into the actual discourse of that science in the first place. So I think across from both directions, it's a real Win-Win situation to do that.

EMMA JOHNSTON:

So genuine consultation all the way through. But also co-involvement in the research projects seems to be the take-home message. And one thing it brings up is probably the need to have a good look at the way that we fund research programs so that we can build in the time and the money and the support for that true engagement to take place. So I thank you so much for that to Marcel and to Azure for that conversation today, that collaborative conversation. Just a reminder to everyone watching this has been recorded and a link will be sent to you if you missed any of it or you'd like to share it. And we also if you have a spare moment, we have a brief survey in the Q&A session so you can fill in that survey. And finally, happy National Science Week, everybody. This is the first in the series of events that we'll be running over the next little while about inclusive science and the next

one coming up on neurodiversity. And a link to that information will be posted in the chat as well. But this week, we also have an any number of fantastic events online and free from you UNSW in celebration of National Science Week. So I hope you can join us for more of these events over the next few days. Thank you, everyone, and have a great afternoon.