
Global Aboriginal DNA research casts light on human genome

Reporter: Kim Landers
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ELEANOR HALL: It's a collaboration between the world's oldest living culture and its newest science and its scientific director says it has profoundly changed the way he approaches his work.

Professor Simon Easteal is the director of the National Centre for Indigenous Genomics at the Australian National University.

He has been working closely with Indigenous Australians, including the Human Rights Commissioner, Mick Gooda, to bring Aboriginal DNA into the global science on the human genome.

Professor Easteal is in Sydney today to give a talk at the Human Rights Commission about his work and he joined me in the studio earlier:

SIMON EASTEAL: Well, around the world there are large projects going on in developing the underpinnings for what's now being referred to genomic medicine.

These are large data sets of genomes that have been collected and what we're aiming to do is ensure that in this process which is largely currently built around people of European ancestry and Europe and North America is extend it to include Indigenous Australians.

ELEANOR HALL: Is Indigenous DNA so different though from European DNA?

SIMON EASTEAL: There are subtle differences all around the world so this is particularly the case with rare genetic variation that is associated with rare diseases.

It's also relevant in cancer where you have mutations that are associated with disease. These vary from place to place.

We know that that's the case and we know that we can't develop a knowledge base that's useful to everybody that's simply based on people from Europe.

ELEANOR HALL: So as the director of this centre you are asking Indigenous Australians to give their permission for you to use their DNA and that of their ancestors for research.

Now this is, of course, a highly sensitive issue given the history of white scientists taking artefacts and even the remains of Aboriginal Australians out of the country without permission, how wary are Indigenous Australians about this when you first approached them?

SIMON EASTEAL: Well, they're justifiably extremely wary and it goes beyond that because of course the genetic theories have been used in the past to justify racial discrimination.

We're not just asking for permission here, we're working with Aboriginal people and Torres Strait Islander people to develop a framework where they're in control, they're

in charge and we're embedding the expertise, the genomics bioinformatics and other biomedical expertise that is required to this in a framework that has Indigenous governance.

ELEANOR HALL: When you say they're in charge, how does that work in something so extremely specialised in science?

SIMON EASTEAL: Well, the key to this is the Indigenous Governance Board that Mick Gooda chairs so that all the decisions, all the policy framework, all the ethics is all controlled by the Indigenous Governance Board and beneath that we have a research advisory committee.

We have an access committee of Indigenous people that make decisions on the use of the data that we will be generating. We also work closely with our local health organisations, cultural organisations and with the communities, the elders and the families and the communities.

ELEANOR HALL: The ANU already has an extraordinary collection of Indigenous DNA that was built in the second half of the last century. Tell us about that.

SIMON EASTEAL: That's really where we got started, and in amongst that there are approximately 7,000 samples that were collected at 43 locations beginning in the 1960s and going through to the 1990s and we were really faced with the dilemma what to do with this.

It was appropriate to stop working on it in the 1990s and wait until we'd had an appropriate dialogue with Indigenous people about what to do with it.

So we set up an external committee of Indigenous people and put ourselves in their hands and said what should we do?

They were very enthusiastic that this was an extremely important resource, not just scientifically but also historically and culturally and that it should be managed appropriately.

ELEANOR HALL: And all these samples that were collected in the second half of last century, you don't know whether or not consent was given so I guess you have to presume it wasn't. How would you have felt as a scientist if the decision had been, okay, we destroy it all?

SIMON EASTEAL: I would have been disappointed but I would have accepted that that was the case.

All the indications from the field notes and the correspondences is that this was done in a respectful way, it was not a cohesive process but we really don't know.

We do start from that position and we go back to people, we explain both at the community level, the family level and the individual level and working through organisations as I said that what has happened, and that we don't really know what happened back then so we're here now to ask for your permission either directly if people are still living or if people have passed away, on behalf of their family members.

ELEANOR HALL: And what are the tangible benefits that the science of genomics can offer Indigenous Australians?

SIMON EASTEAL: Our focus has been on medical and health benefits. Most particularly at the moment that's relevant in, as I said before, rare diseases.

There's an example last year of a family in the Western Desert for example where this was relevant.

ELEANOR HALL: Tell us about that family.

SIMON EASTEAL: Well, the clinical geneticist involved there were trying to understand what gene and what particular variant of the gene was associated with this inherited disorder in the family.

And they thought they had the answer but because there's no reference material for that area, for the people from that area, they didn't know whether it was simply something that was common there, although it was rare elsewhere and we know that happens around the world.

But if it was causal then it had profound implications in terms of the treatment and management of the condition, and indeed when they were finally able to confirm that, they then were able to treat the members of that family who were affected appropriately.

Now if the kind of resource that we're trying to create were available, that would have happened a year earlier with better outcomes.

ELEANOR HALL: And you centre's website says that this connection between the world's oldest living cultures and its newest science is transforming all of those people involved. How has it changed you?

SIMON EASTEAL: We talk about the DNA having stories about people's health and about their past and giving, in a sense, respect to that fact that we tend in the lab, and I have to say through my career, I've tended to see these as little tubes in the freezer that you take out periodically and do things to and get data and then write it up and so on.

But there is in the minds of some people we've spoken to, a really profound and almost spiritual connection to that material in the sense that that is indeed part, either an extension of someone or part of someone and that it needs to be respected and treated in that way.

ELEANOR HALL: And I understand that the samples are used obviously for scientific and medical purposes but there are also potential cultural benefits of exploring this DNA. What are they?

SIMON EASTEAL: At a more practical level, there's a potential here to reconnect with family where that may have been lost and there's been a lot of interest in that.

ELEANOR HALL: I guess the Stolen Generation has...

SIMON EASTEAL: Exactly, exactly and then going further than that, the potential to identify the source of remains that were removed and taken to museums and hospitals and so on that are now being repatriated.

ELEANOR HALL: Professor, thanks so much for joining us.

SIMON EASTEAL: Thank you.

ELEANOR HALL: That's Professor Simon Easteal, he is the director of the National Centre for Indigenous Genomics and you can hear a longer version of that interview on our website later this afternoon.