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Hidden family secrets
revealed by genetic
testing
Genetics Unzipped

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Kat: Hello, and welcome to Genetics Unzipped - the Genetics Society podcast with me, Dr Kat Arney. It's become cheaper and easier than ever to access genetic testing, and more and more people are having their genomes 'done' for reasons of personal interest, health or ancestry.

But what happens when an innocent genetic investigation reveals dark family secrets? And how do we properly engage and inform people about genetic testing and research, so that they really know what they're getting into?



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Who's the Daddy?

It's been impossible to ignore the rise in direct-to-consumer and medical genetic testing over the past few years. And as the cost of whole genome sequencing falls - and the potential personal, health and financial value of genomic data rises - this trend is only likely to continue.

But do people really realise what they're signing up for when they spit into a tube or squirt out a blood sample?

As we head into the next decade, ethical issues like informed consent and privacy for genomic testing and research are e to ignore - especially as your genetic just belong to you but is also shared with



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THE GENETICS SOCIETY PODCAST

When Jack Nunn started doing a PhD at La Trobe University (<https://scholars.latrobe.edu.au/display/j2nunn>) in Melbourne, Australia, looking at how to involve people in genomics research, the most obvious place to start was with his own family. But he could never have predicted the secret that would be revealed once they started looking into their genes.

Jack: So I'm a big believer in get your own house in order, sort out your own backyard first and talk from personal experience. So I started doing a PhD about genomics. The working title was Genomics Identity and Community, which was far too big and vague.

However, I did think, well, I'll get my mum a DNA test, because she wanted to find out who her grandfather was etcetera. And she did find that out. She got some other, unexpected results though which were quite interesting.

I encouraged her to share her raw data from the DNA test on GEDmatch, which is a free, open source way of sharing your raw data from different services. Someone got in touch with my mum on this service and said, "I think we're related.", and I said to my mum, "Be careful, this could be a scam."

And then other people started popping up. We started to triangulate the data and it turned out that this person thought my mum was their half-aunt. So, this asked a few questions.

My mum actually discovered that she had a half-sister through this service. Then other half-brothers and half-sisters started popping up online.

This was quite unexpected. So, after being in touch with a few of them it actually became apparent that my mum was conceived with a sperm donor. This would have been about 1948, 1949. This was, in fact, the first place in the world that sperm donation was done, artificial insemination.

It so happened that one of the people who was conceived by a sperm donor had made a couple of films about this, one called Offspring, one called Biodad - a guy called Barry Stephens in Canada.

So suddenly we realised this wasn't kind of a scam on the internet. My mum was actually one of perhaps somewhere between 600 and 1,000 people conceived by this one man, Bertold Wiesner.

Kat: Woah, back up. So there's a guy, he's working in a fertility clinic, he's donating his own sperm and he's made a thousand babies?

Jack: Potentially. The records were purposefully destroyed. This is at a time when the legal area was very -- the House of Lords were saying artificial insemination was the work of Beelzebub.

The clinic was run by a woman called Mary Barton. She'd actually been to India and seen a lot of families that had trouble conceiving. Of course, in those days they just blamed the woman. And anyone who knows anything about anything knows, of course, it can be either. So, coming back to England she worked to help families conceive who were having difficulties.

Bertold Wiesner was an Austrian scientist who in the 1930s saw the way things were going. He didn't identify as Jewish, but the Nazis labelled him as that. He went to Edinburgh University and did a lot of the science around, you know, if you wee on a stick you can tell if you're pregnant.

That was his work. They wrote a British Medical Journal article about their work and they had a clinic that people could come to.

My grandma, for example, she went to this clinic. She used to work for the Air Ministry. When she got married she was made to quit and she was given something that was given a dowry payment. This is, of course, in the 1940s. That was about a

year's salary. Basically, it was somewhere around that amount that was given to the clinic. I believe that they did run a free clinic once a week for people too.

The journal article said that they selected donors from intelligent stock, so we're talking about eugenics here, too. They, as far as we can tell, had three main donors, one of whom was Bertold Wiesner, another was a man called Derek Richter.

The details are not clear, so I won't speculate but what we do know is that there are at least 20 half-siblings in touch now. Therefore, I've got potentially thousands of half-cousins.

So from starting a PhD with a working title of Genomics Identity and Community, I suddenly find myself part of potentially the largest single ancestor cohort on planet earth. Which is quite strange

Kat: So this is putting Bertold Wiesner up there with Genghis Khan?

Jack: He's in third place.

Kat: How did it feel for your mum, for your family? Have you talked to any of the people who turn out now to be your clan?

Jack: Yeah. By a strange coincidence I was the first person to talk to my mum after she discovered it. I live in Australia; she is in the UK. She said, "I'm in a bit of shock." And my mum doesn't say that lightly. My first thought was that my mum and dad were going to be brother and sister.

Kat: ...?

Jack: That's where my mind went with this. Then when that wasn't true, for me, everything else was a relief and kind of interesting. My mum handled it very well. Not to speak for her but we've got new family now, we've got new relations.

Of course, it's different for every person and it does ask that question, how important is your DNA? I think it's as important as you want it to be, which can be not at all or completely. And that's a personal decision.

We have been lucky enough to meet up a few times. We had an event in London last year where I met a lot of them for the first time. In fact, just last weekend we had another meet up.

Kat: When you all got together and met up, were there actually physical characteristics? Could you go, "Ah, that's Bertold's nose, you can see it in everyone!"?

Jack: Actually, the one thing that's happened to me is that I met one of my mum's half-sisters who happened to live near me. I actually got a bit spooked when I saw her because not only did she look a little bit like my mum but her mannerisms were very similar. And I hadn't seen my mum for about a year and it was a nice feeling but it was a weird one.

It's that - are we just code walking around? And yes, we are, is the short answer. So, what is it to be human? What is it to be family? These words are being challenged by these new realities.

I think that's what I love about genomics is that it's opening up a new frontier on understanding ourselves. And suddenly I find myself part of the group that might be best placed to help start to answer some of those questions.

I used to think nature, nurture was a wide-open debate and that it was fairly wide. You know, you're not going to turn into a banana but -- after meeting my genetic relatives, we had things like a similar sense of humour, mannerisms are very similar. And yes, I have personal feelings about the nature, nurture debate now -- I'm a lot more hard code than I like to think I am.

Of course, it will be a wide open debate forever, but the really interesting thing now, the question on my mind is well, suddenly this cohort of people who are descendants of Bertold Wiesner will of course be of interest to medical research and could potentially save lives.

So my PhD supervisor said, "Well, it's kind of beyond coincidence that you're looking at this subject and then discovered yourself to be a part of this. To not incorporate it into your PhD would be a huge missed opportunity." To say, very briefly it was of course ethically complicated.

Kat: I'll bet.

Jack: And we worked very closely with the LaTrobe University Ethics Department, who were incredibly helpful. We got it going and effectively, we invited some of the siblings or half-siblings to be part of an online discussion. We used that method for a group of people affected by a rare disease as well.

Basically, it's asking the question - if we were going to do research with this group, how would you like to talk about how you'd like to talk about how you might do the research.

Kat: Careful!

Jack: And of course, this is the first preliminary stage. What's interesting is - and not to speak for anyone in the group but there's a genuine belief from a lot of the people that this is a good opportunity to perhaps help answer this nature/nurture discussion.

The next question is - how do we go about doing that? And certainly with Science for All, the organisation that I've started, we're looking at evidence informed ways of involving people who have shared ancestry. Which could be indigenous peoples, it could be these kinds of groups.

Of course, there's another group from Derek Richter as well, in parallel. I daresay, probably, we are the first of many who will make such discoveries. Whether it will be as large a cohort I don't know. Who can say? I hope not, but you just don't know.

It might be happening right now. People who thought they'd perhaps get away with this in the past, or never considered this would be a thing - it's coming and it's coming for everybody.

So for me, the question isn't how interesting this is or how this feels. It's that we need to very urgently come up with ways of answering the question of how do we share power in these decision-making ways? How do we make it that - yes, we are all unique and precious snowflakes but we are also 99 percent similar to everyone else and have a fairly uniform crystal structure.

So if somebody says, "I don't want to be part of this", but actually you discover certain things about someone else - the obvious example would be identical twins or something - does that identical twin get to veto their twin having their genetic test results?

Kat: Yeah. I think I did see a story about two twins. I think it was testing for Huntington's disease and one wanted it and one didn't. I think in the end, one of the relatives accidentally blabbed the answer to the twin that didn't want to know.

So I can see that if you've got lots of people out there who don't realise they're related but actually are, this is a whole modern can of worms that humanity has never really had to deal with.

Jack: Of course, and it's coming. And with the accessibility, the drop in cost, it's coming soon. This is why I wanted to do my PhD in this area because I didn't really see anyone talking about

this or thinking about it. We need to be ready and we need to be ready now.

Bringing into the mix legislation around insurance, employment, let's say even rising nationalism - bringing that into the mix - we have a potential nightmare scenario on our hands if we don't work out our preferred realities.

There are lots of possible realities. We need to collectively decide what our preferred ones are and how we share power in making those decisions so that it isn't just what certain people want.

Kat: We'll be coming back to Jack later on, but in case you'd like to know more about the incredible story behind Bertold Wiesner and his fertility clinic, we'll put some links on the page for this show on the website, GeneticsUnzipped.com

- [Bertold Wiesner - Wikipedia](https://en.wikipedia.org/wiki/Bertold_Wiesner)
(https://en.wikipedia.org/wiki/Bertold_Wiesner)
- [British scientist fathered 600 children - Daily Mail](https://www.dailymail.co.uk/health/article-2126761/Bertold-Wiesner-British-scientist-fathered-600-children-donating-sperm-fertility-clinic.html)
(<https://www.dailymail.co.uk/health/article-2126761/Bertold-Wiesner-British-scientist-fathered-600-children-donating-sperm-fertility-clinic.html>)
- [Watch Offspring on Vimeo](https://vimeo.com/128603400)
(<https://vimeo.com/128603400>)

The Only Way is Ethics

Jack's family never expected to discover such a dark truth about their origins from a simple test, yet thousands of people all over the world are merrily taking genetic tests and putting their data online. But have they really thought through the implications?

To find out more about the ethical issues around the fast-changing field of consumer and medical genomics, I caught up with [Anna Middleton, Head of Society and Ethics Research](https://www.sanger.ac.uk/people/directory/middleton-anna) (<https://www.sanger.ac.uk/people/directory/middleton-anna>) at the Wellcome Genome Campus in Cambridge.

Anna: The landscape has just changed enormously. Genomics has exploded into a mainstream arena. Whether that's via healthcare and the new genomic medicine services that are occurring in the NHS, or whether it's via direct-to-consumer testing online - so you just do a Google search of genomic test or genetic test and loads of companies will come up. It's everywhere now.

Kat: Given the ubiquity now, of the idea of genes and genetic testing, how is the public perception of this kind of technology?

Anna: Well, it really varies. You can walk into Boots now and see the double helix spinning on a beauty counter. It gives an air of science and credibility and --

Kat: Here comes the science bit!

Anna: Yes, this is complicated stuff that you should understand. But also, it can create a distance because it make you think, "Well, it's science-y so therefore I won't understand it. So there's an element of what do I trust and what do I not trust with this?"

The way that genetic testing - particularly the direct-to-consumer tests - is marketed, is often about; discover something about yourself, discover what you should be eating or what your exercise routine should be. Or, use this in your healthcare.

Actually, a lot of those claims are really overstated. Read the small print because often what you'll find is, they can't really offer you very much.

Kat: There are lots of different kinds of test you can do, from the clinical genetic test looking for specific diseases, to what skin care should I have. How have these different kinds of tests caught the public imagination?

Anna: Well, from our research we're finding that people aren't distinguishing between the different types of test. So a genetic test is just a genetic test whether it's for something really serious and life-threatening or whether it's for something really benign or recreational. People aren't really distinguishing between the different types of test.

That's actually a very important thing to go into because if you're wanting to explore whether you have a predisposition to inheriting breast cancer or not, that's a really serious issue that you can talk to a GP about, speak to a health professional about. Buying an over the counter direct-to-consumer test to answer that question is not the right way to go.

Whereas, if you're interested in ancestry or - I don't know, fitness and nutrition, then that's a completely different kettle of fish. I would just say, "buyer beware", and take those tests with a pinch of salt, really. They are just a bit of fun.

Kat: And one of the other things in the small print, obviously, is that it's not just your genome. Your genome is similar to many people that you're related to. If you're an identical twin it's

identical to that.

Now we're starting to see more and more stories of - now more people are getting their genomes "done", for want of a better word - unusual stories starting to emerge; family secrets, misattributed parentage, I believe is the correct phrase and for example, stories where people have gone to sperm donors or fertility clinics and have not turned out to have the baby with the parentage that they expected.

Can we expect to see more of these kinds of stories and what does that really mean, for people who just buy a test of the shelf and think, "This is fine, this will just tell me something fun"?

Anna: Yes, absolutely. Even if you've never personally had a genetic test or bought a test, if you're biologically related to somebody who has then their data will be online somewhere. It will sit in a database that is probably being sold to industry and is probably being shared around the world at the moment.

So even if you're not currently having any sort of interaction about your genome, if your biological relatives are then it can link back to you. Particularly with the ancestry sites where people upload their own family trees and they label relatives on there, that they haven't asked for their consent to do that.

So you can extend the kind of information that's out there about relatives and so that is how you can track people down.

Kat: There's kind of two things here. There's one thing about maybe discovering - let's call them breaks in the family tree that you weren't expecting. For example when your dad or someone's dad is not their real dad. Then also, the police force is now starting to use this information to triangulate towards people's identity.

Do you think this kind of information and this message is really well enough understood by the people who do choose to take genetic tests or direct-to-consumer tests?

Anna: No. There's not enough information about the way data sharing happens and also the fact that many companies, their business model is to sell your data on. So, there's much more needed in terms of transparency about the way that the data is used.

But in terms of access to data sets, well, for example, Golden State Killer, which I guess you might have heard about, which is where quite an insecure database was accessed, full of genomic

data from ancestry sites and things, uploaded by people themselves trying to track down relatives.

This was used as the way to track down killers by the FBI in the USA. Those killers themselves hadn't uploaded their data and they hadn't had genetic testing themselves, but it was their relatives that had. So it is possible to track people quite easily.

Actually, what we say now in terms of research and then taking consent for research is we say to people; we can't fully guarantee that your data won't be accessed by somebody in the future, even if it is de-identified. If your data is online then there's always a possibility that you can be identified.

People can either choose to take part in research or not on the basis of that but I think the key thing is to be transparent. One of the things that we're looking at in our research is whether people actually care. Do they mind being identified, de-identified?

What we're finding is that if people feel strongly about the purpose of the research and they see the value of genetics in helping to understand human health and disease and the links between genes and disease, then actually they don't really mind so much about the risks of identification. Because the value of doing the research outweighs their own personal privacy. Which I think is really interesting.

Kat: I guess it's fine if you know that your dad is definitely your dad and that there are definitely no murderers in your family, I suppose?

Anna: Well, [Laughter] there's always the risk that unexpected things will pop up. If you talk to the ancestry companies they will often say that's a positive thing. People often enjoy --

Kat: That is going to ruin Christmas! We did an ancestry test and then it turned out you're not my dad. That is not a positive thing.

Anna: I totally agree. The way that the companies spin it is that this is exciting and this is all new information. There needs to be much more information about the possibility of these things before you actually have testing.

Also, the other thing is, there needs to be forewarning about a possible emotional reaction, even just to getting information about yourself. Because often, you don't anticipate that you're

going to be quite shocked or overwhelmed or struggling with something, until you actually have the tests and the results are there in black and white.

Often with these companies, there's nobody there to pick up the pieces. So there needs to be much clearer information about what the potential outcomes are.

There's new regulation coming into the UK, *in vitro* diagnostics regulation, that does actually mention the need for genetic counselling to accompany some of these really serious tests that are looking at really serious, life-threatening conditions.

Kat: So, let's unpick what we mean by genetic counselling because I can appreciate that if you have a life-threatening hereditary condition in your family, yes, you're going to want to talk through that.

The implications of that, what can this test tell us, how on a shade of black to white, to grey, how much can it tell us about risk?

But what about genetic counselling more broadly, and particularly, going into some of the more recreational, direct-to-consumer areas? What do genetic counsellors need to be doing and coming into

Anna: I think genetic counsellors should not be gatekeeping access to all genetic tests but they do have a part to play, when we're testing for really serious life-threatening conditions that are strongly inherited, you might call it fully penetrant. So if you have the gene variant then you are very likely to get the disease. Those conditions which are quite unusual and quite rare.

Kat: So this would be something like Huntington's disease?

Anna: Yeah, or the inherited young onset bowel cancers, for example or cystic fibrosis or Duchenne muscular dystrophy - these conditions where you have the genetic variant and you are likely to get the disease.

Because there, prior to having the test there might be lots of things to think through about; how you're going to communicate the results to relatives, the timing of testing, what you're going to do with the results, what screening you're going to have, whether you're going to have risk reducing surgery. All those sorts of things need to be thought about before you go for testing.

So that's within the realms of medicine. Separate from that, the more recreational genetic testing, yes, it can throw up all sorts of surprising things but a genetic counsellor doesn't necessarily need to have an hour's consultation before you have the test.

I do think the companies should provide access to genetic counselling to people who are post-test who are actually quite anxious about what the results have revealed.

Kat: And in the case where tests do throw up surprises, for example in the case of the fertility clinic where suddenly you discover that there's many, many people who are your relatives you never realised. Or unexpected family relationships. What sort of access to support can people find there?

Anna: Well, there's very limited access to support. Genealogists particularly are often not trained in any counselling or psychotherapeutic interventions. So there's a real gap in the market in terms of the right professionals to be picking up the pieces when it's needed.

Often you hear of companies that do nutritional and sporting kinds of genetic testing. They will talk about dieticians or naturopaths or sports scientists picking up the pieces. When you're talking about ancestry testing it might be genealogists or ancestry specialists who pick up the pieces. But not specifically trained in that emotional dynamic.

So who would do that? Well, it could be genetic counsellors or it could be other people that just trained in how to have a very sensitive conversation about the potential impact and the emotional kind of turmoil that people are going through.

Kat: I remember at university, people just started to go into bioinformatics and this was the hot thing. We've seen over the past twenty years all these companies springing up, offering genomic analysis, genetic testing, direct-to-consumer testing.

Are there enough genetic counsellors to be picking up the pieces here? It just strikes me that everyone wants to do the genomic analysis and the sequencing and all that cool stuff and no one wants to sit down and work out how you communicate the results and what this means.

Anna: So I'm the departing Chair of the Association of Genetic Nurses and Counsellors at the moment. We know that there's about 300 genetic counsellors in the UK.

Kat: That's not a lot.

Anna: No, it's not many and there's 7,000 worldwide. They are very highly trained and competent to practise in genomic medicine. The worry is, they take their six years of training and they just get sucked out of the NHS. Particularly in industry, earning three times the salary and they're not there to do their core job that they've been trained for.

So yes, there's a real need to upskill health professionals generally in how to have a conversation about genomics. Actually, there's a big push from the government to help nurses.

If we think about the 60 million nurses worldwide, how do we get genomics into their curricula and their practise and their registration processes so they can have conversations about genomics?

Kat: What about something like chatbots? Could, one day, your genomic test come along with a genomic chatbot that will chat to you and talk you through everything?

Anna: Yes, absolutely. Chatbots are definitely the future. They're not, definitely not going to replace genetic counselling, which is --

Kat: Good for you!

Anna: -- which is a very patient-centred, dynamic dialogue. At the heart of that is a thing called the Therapeutic Alliance, which is evidence-based. But the actual information giving about what genetics is, yes, a chatbot could do that.

Actually, that would be really great, to get more mainstream conversations happening. You know, what is a gene? What does this test mean for me? What are the consent issues I need to think about? What are the screening options available?

None of those need counselling, as such but information, yes, a chatbot could do that and that's one of the things we're going to be working on in the future.

Kat: Anna Middleton, from the Wellcome Sanger Institute, who's not likely to be replaced by a chatbot any time soon.

You can find out more about her work looking at the ethical, legal and social implications of genomics online at genomethics.org (<http://genomethics.org/>), and Anna also tweets at [@genomethics](https://twitter.com/genomethics) (<https://twitter.com/genomethics>)

Nothing About Me Without Me

Kat: As Anna points out, it's vital that people have access to information about the implications of genetic testing and research - as well as access to counselling if necessary. It's also really important to find the right ways to help the public engage with issues around genomics, especially as it's only going to become more prominent in the coming years.

Given that it's the topic of his PhD, I asked Jack Nunn for his thoughts about how best to go about this tricky task - and the risks of getting it wrong.

Jack: My worst fear is that we'll lose public trust in the research. I think involving people is going to be central to public trust and participation in future genomics. If we don't get that right, it won't happen.

For example, if there's a breach or people don't feel that their needs or priorities are being reflected. For example, we know that people of European or Asian ancestry are hugely over-represented in terms of the number of genomes that have been sampled.

So the question is, how can we actually ensure that people feel that genomics research is for them? That phrase, "Nothing about us without us."

My nightmare scenario is that there will be a breach of or public trust will be broken. People will clam up and go, well, I'm not going to choose to give my data to research. Then the long echoes of that could be felt for generations. That's a huge risk for me.

My question is, how can we do it well? How can we do it right and can we bring some evidence-informed methodology into that?

Kat: I think this is so important because we have the idea of the human genome and we have the idea of our own personal genome and this matters, this really matters to us.

So what is the best way of finding out from people what they think is acceptable? Can you just do an online survey, a Twitter poll? What is the best way of engaging people with this kind of work?

Jack: Yes, I think that's a great question. Certainly the first step we took was conducting a systematic scoping review of about 100 genomics projects around the world, linked with the Global Alliance for Genomics and Health. Actually looking at that question.

Part of it was the language. So for example, if you're in Canada maybe you use the word "engagement" and if you're in England, you use the word "involvement". In England you're a patient, in Australia you are what they call a "consumer", you consume medicine or what have you.

So the linguistic analysis alone was - are we talking about the same thing here? And then I was looking at what methods did they use to involve people? Was it a survey, public dialogue, face to face events? Then what tasks were people involved in? Were they identifying topics, were they involved in ethical oversight?

So we had the results from that and about 30 percent of global genomics projects were involving people in some way. Some of them involved people in every stage.

Examples of excellent or best practise would probably be the UK Biobank. Certainly Genomics England as well and what the Precision Medicine Initiative has called "All Of Us". They showed or demonstrated involvement at a lot of stages.

What I also knew to be true is that there are a lot of projects that were doing it that weren't reporting it. Reporting is inconsistent and not systematic. So you can't then create an evidence-informed way of involving people.

The problem with that, of course, is if you go to Wellcome Trust or whoever is funding research and say, "You should be involving people", and they go, "Okay, how much is it going to cost and what's the best way to do it?", and no one can answer that question at the moment.

I think that's quite important. So what I've created as part of my PhD is something called Standardised Data on Initiatives (STARDIT), which is a standardised way of reporting the who, what and how. So, who was involved, what tasks they do, how did they do it, how you're sharing your data.

That's really getting into the power sharing as well. For example, one of the projects I'm working on is the Aboriginal Precision Medicine project with Aboriginal communities in New South Wales, Australia. Really, that's where you're going into communities and you're saying, "We would like to do research with you ..."

Kat: "...not on you."

Jack: Exactly. And that's a huge shift. It should go without saying there's an enormous legacy of problematic or perhaps one might even say bad research, in Australia in particular. Coming from perspectives more anthropological and all of the history that implies. So really, to come in with an evidence-informed method to go; this is how we are planning to share power.

I suppose the main learning from my PhD is you've got to involve people in designing how they are involved. So if that sounds like I'm disappearing up a rabbit hole, I'm very willing to admit that. That's why I'm trying to bring a bit of evidence to it.

I think this also widens out to -- we need to think about genomics not as just a human thing and not as just a medical thing. I think it's very important to remember that we automatically medicalise genomics very often when we talk about humans. It can also mean things like ancestry or what have you.

Of course, a good example is British Columbia in Canada. They talk about genomics as agriculture, forestry, farming and then humans as a sub-category of that. And involving indigenous peoples in that is also - in the management of agriculture, forestry and also ethical involvement in genomics research.

So, indigenous peoples around the world, those cultures - guess what? They've already got there and realised that this holistic thinking; we are of the earth and will return to it and are absolutely dependent on it. And actually making the space to incorporate those views, those values into research, whether it's health or environment, is essential.

I think taking that more holistic systems thinking approach to involvement is important to. So that's where STARDIT, as I'm calling it, the Standardised Data on Initiatives - what we're doing is attempting to come up with a systematic way of planning involvement and reporting it.

And reporting the impacts of it so we can start to create living systematic reviews that can give data on what is perhaps the most effective way of involving people for the cheapest amount. Or, what is the best way to involve a lot of people or do you want a citizens jury to reach a decision on a complex thing?

So, as someone planning research you can start to plan how you will involve people at different stages. Of course, what's interesting is if you're truly doing what's called participatory action research or co-design and sharing power, you have to listen to what the needs of the local people are.

You've talked about words like health and certainly health and wellbeing - wellbeing comes up more in the language of Aboriginal health services in Australia. They come back and say, well, what about other animals? What about the systems and the rivers and their genomes and this data?

That's certainly true and parallel in Canada, with the indigenous peoples there. For example, we're working with Aboriginal people to look for critically endangered species using environmental DNA as well.

So there's lots of different ways of involving people in research and it doesn't just stop at humans. It's about that transparency, that openness, that involvement at every stage.

From what should we do and how should we do it, through to the data disseminating and getting around the campfire at the end of the evening to share knowledge in a way that our ancestors have been doing for thousands of years. We call that Campfires and Science.

Kat: Jack Nunn, director of Science for All. You can follow Jack on Twitter, he's [@jacknunn](https://twitter.com/jacknunn) (<https://twitter.com/jacknunn>), and find out more about Science for All, Campfires and Science and the STARDIT initiative online at [ScienceForAll.World](https://scienceforall.world/) (<https://scienceforall.world/>)

That's all for now. Next time we'll be swimming off in search of our inner fish.

You can find us on Twitter [@geneticsunzip](https://twitter.com/geneticsunzip) (<https://twitter.com/geneticsunzip>) and please do take a moment to rate and review us on Apple podcasts (<https://podcasts.apple.com/gb/podcast/genetics-unzipped/id1446661695>) - it really makes a difference and helps more people discover the show.


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You can find out more and apply to join at genetics.org.uk
[\(http://genetics.org.uk/\)](http://genetics.org.uk/) Our theme music was composed by
 Dan Pollard, and the logo was designed by James Mayall,
 transcription is by Viv Andrews and production was by Hannah
 Varrall. Thanks for listening, and until next time, goodbye.

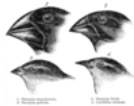
Kat Arney (*/?author=5ac259a7cd99af7a1206af24*)

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Jan 2 S3.01 - Investigating the icons of evolution, from Darwin's Finches to the March of Progress

[\(/blog/2020/1/2/investigating-the-icons-of-evolution-darwin-finches-march-progress\)](/blog/2020/1/2/investigating-the-icons-of-evolution-darwin-finches-march-progress)

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