

Anna Middleton - Talking about genes

Anna Middleton, Wellcome Trust Sanger Institute

AudioPlayer [Listen Now](#) Download as mp3 from the show [What's in your genes?](#)

Kat - As Misha mentioned, before she took her gene test, she wanted to discuss it with her family. But how do you go about starting conversations like this, especially if all this talk of genes, DNA and genomes is a bit confusing? To get the conversation flowing, genetic counsellor Anna Middleton, based at the Wellcome Trust Sanger Institute in Cambridge, has teamed up with advertising exec Julian Borra to make a series of short films about different genetic concepts.

Anna - I've been looking at how to start a conversation about genomics with people who know nothing about genomics. The reason being that genetic technology is being mainstreamed across healthcare services now. So, it's in paediatrics, ENT, dermatology, obstetrics, and it's moved out of the specialist clinical services, clinical genetic services across the NHS. So, more people than ever before are having to engage with the technology. You might say, "Well, it's not really very relevant to me because I'm not currently using health services" but maybe your relatives are and that's the key thing about genetics is that everybody that we're biologically related to contains information that might be relevant to us too. It's about really reaching the general public and their relatives with very generic messages about genetics really. So, I've been looking at how to do that and employing the skills of the advertising industry who are very well-versed at reaching mass populations, turning complex ideas into simple messages.

Kat - How do you go about starting a conversation about genetics? How have you been trying to get advertisers to help us with this?

Anna - We're doing something I guess quite innovative, in that we're combining methods from social science and methods used in market research and advertising. So, I've done a series of focus groups resembled as a public that are completely detached from genomics currently. So, I've met with a choir, I've met with a council residents association group, I've met with the women's guild group. I even went down and joined a Men's Curry Club. I've met some parents at the school gates and I've listened to how they naturally talk about issues to do with genetics. So, I prompted them for words like DNA, gene, genetics, genomics, and asked them what those terms mean to them and then listen to the natural conversation. I then analysed those in a qualitative sense and taken those themes to Julian Borra who is my partner from the advertising world. He's ex-Saatchi & Saatchi Creative Director. Julian and I then bounced around the

themes. So see how natural conversation is happening and then to overlay a narrative on top of that.

So we wanted to see what metaphors, memes, ideas, people are currently using and then we've given a bit of a creative makeover and turned those into series of animations. The animations, we just use them with these metaphors to try and start a conversation. We don't actually know if they work or not. This is a research project but what we're doing is we're showing animations and asking people to let us know what they think of them. If there's anything that resonates, if there's anything in there that sparks the conversation or makes people go, "Oh! That's kind of interesting. I guess I'd like to share that in some way by talking to other people about it or sharing it via social media."

Kat - Was there anything that surprised you when you started talking to people and you've got something back say, "I had no idea that people didn't understand the meaning of this word or thought about things in this way."

Anna - What was fascinating was that when you say the word 'DNA', the natural response from most of the groups was, "That's something to do with identifying bodies. Is that to do with crime scenes?" When you said that words 'gene and genetics', people said, "Is that to do with families and things that were in families and that's obviously true?" When I said the word 'genomics', there was often this sort of long pause, the silence, and most people said, "I have no clue, I haven't heard of it." And then they would start to break down the word literally. "So genomics – is it to do with gnomes by any chance?" Really taking the word literally. It's very alien concept, alien term so we really like that and we decided to capture the idea of the gnome and see if we could use that as a metaphor for the sequencing. So, the little bearded gnome with the fishing rod, sequencing, looking for information, fishing through all your DNA and seeing is there's anything useful and interesting in there. so that formed one of the animations. Of other things that popped up, I didn't actually ask about fears or harms or anything like that, but independently, people mentioned insurance in relation to genetics. So they felt that they could be discriminated against. They'd heard about insurance companies potentially using genetic data to formulate changes to policies. Most people don't actually know that they can't be discriminated against from the basis of a genetic test for insurance companies – they're not allowed to ask if you had a genetic result. But nevertheless, there's this misconception that there will be mass exploitation. So, we made that the heart of one of the animations as well.

Kat - What can people do if they want to see the animation and take part in it? What do ask the people to do?

Anna - What we'd really like them to do is to go to genetube.org. that's our little research website and you click in there, you can see the animations. You get asked a few questions, you can bounce around between the animations, just let

us know what you think. You might love them, you might hate them, either way, it's very useful to know. You might think, "No idea what this is all about. What's the point?" So you might think, "Actually yes, that would help me start a conversation." This is just trying to do evidence-based science communication and trying to work out how to do it better. I mean, this is really just a starter, just to get some ideas. The next level would be actually to turn these into proper films and to build on the ideas, and to try and get a bit more evidence about what works and what doesn't.

Kat - It is going to be more and more important that the general public understands more about genetics. Where do you think are the key gaps? Is it at schools? Is it more widely in the media? Or is it just everywhere?

Anna - I think there is a lot of information out there about the science of genetics. You just have to go on to YouTube and you'll see thousands of films that will give you the science. What we were trying to do is just something a little bit different, a little bit more creative, trying to deliver the messages in a slightly different way. And to work out whether they work or not and if they do, then we could build that into something that is useful for schools and is useful for patients and is more widely available. So, it would take genetics out of the more niche market into the mainstream market. So, it should be really stages of trying to work out how to do that. So, if it can go mainstream then fantastic. I think we got a long way to go before we reach that point though.

Kat - You wonder if as many people would talk about genetics as talk about the football.

Anna - The wonderful thing about genetics is that it just connects us all. It's what ties us to our relatives and ties us to humanity. It's all about us. It's all about our identity. To me, that's far more exciting than the football.

Kat - Anna Middleton, and you can watch the films and contribute to her research project at genetube.org