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Melting Pot Lunch Blogs

Who decides what's right in genomics? Why the public matters.

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Anna Middleton

Topic for Melting Pot Lunch 20 September 2017

'Geno-what'? A new technology is sweeping across the NHS, but what can it offer and what does it mean?

Genomics - the ability to test for 20,000 genes in one go - is now available in many clinical services. Whilst you may not have personally accessed such testing, someone you are biologically related to may be offered it. And the

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questions that they have answered may be of interest to you too.

Genomics really is a social concept, a family affair. Our academic work at Connecting Science, part of the Wellcome Genome Campus, aims to explore what people know, understand and want from genomic technology. It also aims to find out the evidence base to help conversations around genomics so that we can all join in, as and when we need to.

Why does this matter? The amount of public debate surrounding genomic technology – including ethical and societal implications – suggests that this is a topic unlikely to disappear.

In the media, public concerns regarding privacy, perceived harms and expectations of control over data have been well-voiced. As one news reporter so memorably phrased it – could advances in genomics result in a whole new class system, where “insurance or mortgages are out of reach for a new genetic underclass (https://www.youtube.com/watch?time_continue=1&v=nU2lqML6jRE)”?

Genomics is influencing all areas of biological research (<https://connectingscience.wellcomegenomecampus.org/wp-content/uploads/2016/10/CS-ANNUALREVIEW-WEB-LOWRES-compressed.pdf>), impacting medical decisions, and starting to change how we see ourselves as humans and individuals. It's therefore essential that those outside the scientific community have a chance to understand what's happening, voice their concerns and ultimately influence policies.

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This isn't easy when non-scientists think they've misheard the pronunciation of genome and think we are talking about gnomes (we jest not, this misunderstanding has come up in three independent focus groups we've done with members of the public!).

Nevertheless, it's essential that we continue to explore ways to start the conversation - enabling everyone to explore genomic science and its impact on research, health and society.

Anna Middleton is head of Society and Ethics Research at the Wellcome Genome Campus.

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