

Your DNA your say

Dr Anna Middleton

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Genetic research has the potential to unlock many answers in medical diagnoses and treatment. Whole genome and exome sequencing are available now in the NHS in England and other health care systems around the world. This fast paced new age has given rise to interesting ethical and moral questions that **my group explores**.

However, research – particularly that in the field of genomics - can only be successful if DNA and medical data is **donated by thousands** (or ideally, millions) of people, and then stored in online databases where it can be accessed by scientists and researchers from all over the world. But how do people feel about their genomic data (their entire blueprint, more personal than a fingerprint or an iris scan) being incorporated into Big Data?

I'm leading an international research project, called **Your DNA Your Say** for **Global Alliance for Genomics and Health**. This takes the form of a 'film-survey' experience. First, a series of short films introduces participants to the practical and ethical issues of DNA and medical data sharing; then, a survey follows in which participants are asked for their views on data donation and whether they perceive any harms associated with this. A selection of the films has found an audience as a standalone piece, and to date it has been selected for three film festivals. In 2016 it screened at the Raw Science Film Festival in Los Angeles and Viten Film Festival in Bergen, Norway and it has just been selected to screen in the New Filmmakers New York 2017 winter showcase.

With much of the personalised healthcare agenda resting on genetic and genomic data, it is likely that we will each need to make decisions about how our genetic data is used, when it comes to improving diagnosis, treatment and care.

The survey is open to all, whether they are currently using health services or not and presents an opportunity to find out more about the ethical issues DNA and Big Data raise and to have a voice in future policy that will affect us all. The film-survey is available at www.yourdnayoursay.org.



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Dr Anna Middleton leads the Society and Ethics Research group part of Connecting Science at the Wellcome Genome Campus in Cambridge.

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