

🕒 31 JAN 2012 ☰ Health, Science

## What your genes could mean

Dr Anna Middleton, genetics researcher at the Wellcome Trust Sanger Institute, on why we need to talk about what your genes mean and how much people want to know.



Public engagement about [genomics](#) is de rigueur at the moment. The anticipation is that genomics will soon become integrated into our lives in ways we have never experienced before; we therefore need to know what is possible and what we have to gain.

A whole genome test on a single saliva sample can tell a person about their genetic risks for hundreds of conditions all in one go, ranging from whether they are predisposed to developing Alzheimer's disease or diabetes through to whether they are sensitive to certain antibiotics or whether their children might be at risk from inheriting something specific.

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Read more: [Do you want to know what diseases lie in store?](#)

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The [Human Genomics Strategy Group](#) have reported recently on the [steps the NHS needs to take to embrace genomic technologies](#). In

parallel with this, genomic researchers, who traditionally would conduct their research on anonymous samples, are facing increasing pressure to share genomic findings with the volunteers who provided the samples.

With the enthusiasm for the NHS to start implementing genomic testing and the shift in thinking about genomic testing in a research setting there is now an urgent need to understand what the public and professionals want in terms of feedback of genome data. With this in mind we at the [Wellcome Trust Sanger Institute](#) have designed an international social sciences study that explores some of the ethical implications of whole genome evaluation and asks people: what would you want to know?

**The anticipation being that genomics will soon become integrated into our lives in ways we have never experienced before.**

We use an online questionnaire containing 10 short films, which describe the ethical issues surrounding feedback of genomic information.

Participants then tick boxes in a series of brief questions. Anyone can participate (e.g. lay members of the public, research participants in whole genome studies, genomic researchers and health professionals etc) and it takes about 20 mins to complete the survey.

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[Take the questionnaire - click here](#)

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Participants need have no prior knowledge about genomics and we are hoping that this international survey will be the largest of its kind. The aim is to provide robust empirical data to support policy making about the sharing of data from genomic studies and this should be useful, not only in a research setting but also in a clinical setting.

Any interested readers are very welcome to participate and details of the study and questionnaire can be found via: [www.genomethics.org](http://www.genomethics.org).

*This blog was originally written for the Wellcome Trust.*



*Photo courtesy of Genome Research Ltd.*

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