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Do you want to know what diseases lie in store?



Tom Clarke
Science Editor

Scientists are trying to gauge attitudes to genome testing with the biggest ever ethics survey. But would you want to know your risk of getting certain conditions? Channel 4 News looks at the issues.





Genetic analysis of your saliva or blood can now reveal more about you than ever before – including your past, present and future health.

But it is a sensitive issue. Would you really want to know if a killer disease lurks, unavoidably, in your future? Or is it better to be prepared?

Now researchers are launching what they hope will be the [biggest ever survey of public attitudes towards the issue](#), to find out what people think.

[Take the questionnaire - click here](#)

At the moment, when people take part in a “whole genome study”, all of their genes are examined by researchers – 20,000 plus – even if the scientists are only looking for the genetic root of one disease, such as breast cancer.

However, because they examine all of the genes, they may also

uncover increased risks of other conditions, from Alzheimer's to diabetes. It has not been standard practice to share this information with the study participant – but should it be?

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different interesting things in
their genome.**

DR ANNA MIDDLETON, WELLCOME TRUST
SANGER INSTITUTE

That's what an ethics team from the Wellcome Trust Sanger Institute wants to find out using a [new online questionnaire](#). They hope it will be the biggest survey of its kind to date. Anyone can take it, and no prior knowledge of genetics is needed – it is purely designed to gauge opinion.



The Wellcome Trust Sanger Institute's ethics researcher Dr Anna Middleton said: "We need to understand what people want from whole genome testing.

"Policy is being written worldwide on what researchers should share from genome studies and yet much of this is based on anecdote and intuition. We aim to address this by conducting an international study that asks members of the public, health professionals and researchers for their views."

Katrina Mcardle has a child with developmental delay who is taking part in a whole genome study. She has taken part in the questionnaire because she wanted her views on the topic to be heard.

"I am very keen to get a diagnosis for my son and the genome

research may offer this, but I'm not sure I want to know lots of additional information about his future health that is unrelated to his diagnosis. Everyone should think about these issues and fill in this questionnaire."

As the technology advances, the question becomes more urgent, scientists said.

Professor Anneke Lucassen, consultant in clinical genetics at the University of Southampton, said: "It is soon going to be cheaper and easier to look at all of a person's 20,000 genes in one go rather than searching for an individual gene, as currently happens.

"That raises all sorts of ethical issues about what genetic results you share with people. Very soon this technology will be used in the NHS and we urgently need research that tells us what people want to know."

Dr Middleton told Channel 4 News there are ethical questions across the board – for participants, the researchers themselves, and the NHS.

"It's not just research – as the NHS embraces some of this technology, it will become a clinical issue which could affect all of us," she said.

Read more: [What your genes could mean](#)

For ordinary people, the key question is whether you want to know. The data itself spans from life-threatening conditions to whether you are predisposed to curly hair, for example – and elements of it are uncertain.

For researchers, there is a concern that gathering all of this data could, as Dr Middleton put it, “compromise or even cripple” the aims of their original research into a particular condition.

And for the NHS the implications could be huge.

“If lots of this data comes out then the NHS will need to get involved. The average person will have about 100 different interesting things in their genome – we’ve calculated that’s about 5 hours of clinical time per person,” Dr Middleton explained. This figure – already difficult to achieve for the stretched health service – not even take into account longer-term counselling needs which could be necessary.

However one frightening scenario – of insurers taking into account genomic information – is not on the cards.

“There is a moratorium from the government – insurers are not

allowed to discriminate on the basis of genetic data,” Dr Middleton said.

What do you think?

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Valerie Callen: “I would not want to know. Why would I want to spend my whole life worrying about dying, which is inevitable anyway! I say, live and happy living!”

James Snowdon: “There’s something a little bit ‘playing god’ about any kind of genetic profiling. How long until parents can decide to abort children because of a high diabetes risk? Frankly I’m all for this though – let’s go the whole way and bring on designer babies and mechanical organs. Yay modern medicine.”

John Hickman: “I’d love to know, so I can do all I can to avoid nasty conditions but I think there also needs to be very capable information available on the implications of findings when discovered, almost a counselling service.”

Colin Robinson: “In my opinion this will no doubt come down to monetary terms in the long run...Insurance companies and care providers will use this information...I have no problem with people knowing what the risks for themselves are. They can use it to make informed decisions on lifestyle and parenting and so on. The real problem for me is whether we will be disadvantaged/prejudiced against because of the same information.”

Article topics [dementia](#), [NHS](#)