



# VIEWS AND REVIEWS

## PRIMARY COLOUR

# Helen Salisbury: Should patients pay for genetic tests?

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Our technophile health secretary recently announced that patients will be able to pay the NHS to have their genome analysed as long as they consent to their data, appropriately anonymised, being available for research.<sup>1</sup> Is this a good idea?

The NHS currently works on the basis of need: if you need a test or treatment it's free at the point of use. If you want it but don't need it, or if it's not likely to be cost effective (often quite contentious decisions), you'll have to buy it outside the NHS. This proposal introduces something akin to co-payment, a system prevalent in insurance based systems where the patient has to contribute directly to healthcare costs.

Funding issues aside, this genetic testing has no obvious benefit to the patient. In my generalist, GP understanding, genetic testing is useful in characterising tumours, so that treatment can be tailored to the patient, or in identifying which patients with an adverse family history may be at risk of inherited diseases.

Even in the latter case, this isn't always information that the patient wants if no preventive action is available. Predicting the risk of Alzheimer's is often mentioned in reporting on this topic, but I'm not sure I'd want to know that I have an above average risk of developing dementia if there's nothing I can do about it.

Patients who receive the results of genetic tests will need help in understanding them

Of course, people can do things to modify their risks, such as stopping smoking, eating well, moving more, drinking less alcohol, and taking part in evidence based programmes for early detection of treatable conditions. The results of genome testing are unlikely to change that advice, but might knowing your genetic risk affect how eagerly you embrace it? It may make you all the more keen to put on your running shoes to stave off

a heart attack. Alternatively, it may make you feel out of control and fatalistic about your health: why not have another cigarette if your genes already predict an early death?

Luckily, we don't have to speculate, as a helpful meta-analysis<sup>2</sup> shows that information about genetic risk had no effect at all on the behaviour of participants in 18 relevant studies. The research wasn't all of the highest quality, but the results were consistent.

One fairly certain prediction is that patients who receive the results of genetic tests will need help in understanding them. Just 230 consultant clinical geneticists were working in the UK in 2017,<sup>3</sup> and I doubt that they'll have the capacity to take on this task. It's therefore very likely to fall to GPs, who will have a lot of work to do to develop the relevant expertise.

Mr Hancock, what would you like me to stop doing to make time for this extra work?

Competing interests: I am a GP partner, I teach medical students at Oxford University and St Anne's College, Oxford, and I answer readers' medical problems for *Take A Break* magazine. I am also a member of the National Health Action Party and serve on its national executive committee.

Provenance and peer review: Commissioned; not externally peer reviewed.

- 1 NHS to offer paid-for DNA tests if patients share data. *BBC News* 26 Jan 2019. <https://www.bbc.co.uk/news/uk-47013914>.
- 2 Hollands GJ, French DP, Griffin SJ, et al. The impact of communicating genetic risks of disease on risk-reducing health behaviour: systematic review with meta-analysis. *BMJ* 2016;352:i1102. doi:10.1136/bmj.i1102 26979548
- 3 Royal College of Physicians. Clinical genetics: workforce and job planning. 30 Jun 2017. <https://www.rcpmedicalcare.org.uk/developing-physicians/specialties/clinical-genetics/workforce>.

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