How useful is personal genetic health information?

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Genetics and genomics are increasingly in the news. People can buy genetic tests on the internet, without providing a medical reason or involving a health professional. But how useful is personal genetic health

information, and are there any downsides to buying tests?

I am a researcher in the Radcliffe Department of Medicine at the University of Oxford, and a genetic counselor working with patients with inherited cardiac disease and their families. I see at first hand the benefits of genetic testing in the NHS, but also the variety of questions people want to discuss before going ahead with a test.

Buying a 'direct to consumer'; (DTC) genetic test is different from an NHS genetic test in many ways, so when the UK Parliament announced an inquiry into Commercial genomics in 2019, I submitted written evidence along with many health professionals and academics, commercial providers and other interested parties.

The Research & Public Policy Partnership scheme opened in late 2019 and seemed a good opportunity to start to build a program of research that would have policy input from the start, ensuring its relevance for policy. The University Policy Engagement Team suggested approaching Dr. Peter Border at the Parliamentary Office of Science and Technology (POST). Together with a General Practice and ethicist colleague, Dr. Andrew Papanikitas, we put together a proposal outlining how we would work together and what we wanted to achieve.

We had planned an event bringing together a range of stakeholders in April 2020 in Oxford, but due to the COVID 19 pandemic it was quickly clear that could not happen. Pivoting quickly, one of our first spends was a subscription to an online meetings platform, and in fact the team has never met in person. We spent some time thinking about how we could adapt, and arrived at a plan to hold a series of online meetings with the people whose views we were interested in hearing.

We wanted to consider a range of perspectives about three sources of personal genetic health information: the NHS, which offers genetic

testing to people with a rare disease or cancer and at risk relatives, commercial genetic testing which can be bought by anyone who has the financial means, and research testing.

We reached out to commercial providers, NHS professionals, genomic scientists, patient representatives, legal experts, charities funding medical research, and ethicists and other scholars with expert knowledge. Fortunately most people contacted agreed to take part; perhaps an advantage of the adapted setup meant that people could more easily commit to a shorter (90 minutes) meeting from home.

All meetings were recorded and professionally transcribed. After each meeting the team analyzed the transcript, met to discuss in depth and agree areas of further interest. This process allowed us to direct the next discussion, by posing key questions to one or two 'witnesses," and encouraging other witnesses to offer perspectives. The meetings felt quite intense because we covered a lot of ground, but our mild worries that witnesses might clash were not realized—everyone was good-natured.

Our learnings fed into a summary document for POST which contributed to the parliamentary inquiry.

We have successfully bid for more funding with an additional policy partner, Health Education England Genomics Education Program to develop inclusion of ethical considerations, including those identified in our partnership, into health professional education.

Looking to the future, we will use what we've learned to articulate areas requiring further policy-directed research.

This has been a new way of working for Andrew, Peter and me. The practical issues raised by needing to work collaboratively yet remotely

seemed very challenging at the start, but have perhaps been balanced by the advantages offered by setting up a structure for accessible meetings.

The three of us have very different professional backgrounds, and that has sometimes meant listening and adapting to unfamiliar ideas and ways of thinking. The content of the outputs we've generated is very different from those I had expected, and have highlighted new areas of interest for me. The new project is testament to the value we've derived from the partnership.

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