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SPECIAL ISSUE

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Live up to the Hype?**

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The Ethics of Online Genomics Tests

JACQUELINE SAVARD

There is a significant difference between the expectation and reality of direct-to-consumer personal genome testing, creating a gap where interesting tensions and ethical dilemmas sit.

“**T**hey can test for that?” This is often the response when I explain that I study the ethics of genomic tests that consumers can buy online.

For the past 7 years I have been studying the field of direct-to-consumer personal genome testing in Australia. This includes following the regulatory changes that have occurred and how they have impacted upon certain companies and the field as a whole. This has been amusing to a degree, as some companies would disappear from the internet only to re-appear with new branding and names a few months later.

There has also been a shifting tide of reactions to the field from the media, researchers, clinicians and the academic world. This ranged from scepticism and distrust that this new approach to genomic testing could offer anything of value, and has evolved

to the stage where teams of researchers, companies and disease-specific research institutes are now partnering with testing companies to carry out research projects.

My work has examined what Australians know, think or expect from this technology. To do this I talked with consumers of the technology and found out what it was like for them to become “genetically aware”.

Before I get too far, let’s go back to the original question I first started with: are these tests even possible? The answer is: yes, they are. This is a rapidly expanding market. Genetic tests are now available for numerous things, from ancestry and health broadly to more specific things such as genetic testing to determine what diet you should be following, genetic testing for cosmetics to see if you have the right genes to look younger for

longer, and genetic fidelity testing where you can submit items of clothing to find out if your partner is faithful or not.

While some people like to buy books or clothing online, others are keen to purchase an “at-home” genetic test or direct-to-consumer personal genome test. The type and availability of each of these tests has changed in response to different market demands, regulatory restrictions and overall consumer interest.

After ordering the test, a collection kit is posted from the testing company to the consumer. In this kit are instructions for collecting a DNA sample. This can be a test tube the consumer has to spit into, a cheek swab of cells scraped from the inside of the consumer’s mouth, or it can be an order form for a pathology laboratory that will collect a blood sample for submission to the testing company.

Once a sample has been collected, it is sent back to the company for testing. After 6–8 weeks the test results are made available to the consumer. How this happens will depend on the testing company and sometimes the type of test sought.

The results of the test are not a long listing of the A, T, C and G nucleotides that create the consumer’s genetic code (although some companies do offer this). Instead, reports are provided by the testing company that interpret and explain what the consumer’s genetics mean for the type of test the consumer bought. For example, if the consumer was testing for ancestry purposes, the results might include a map of the world with certain regions highlighted, suggesting that the consumer’s ancient ancestors originated from that region.

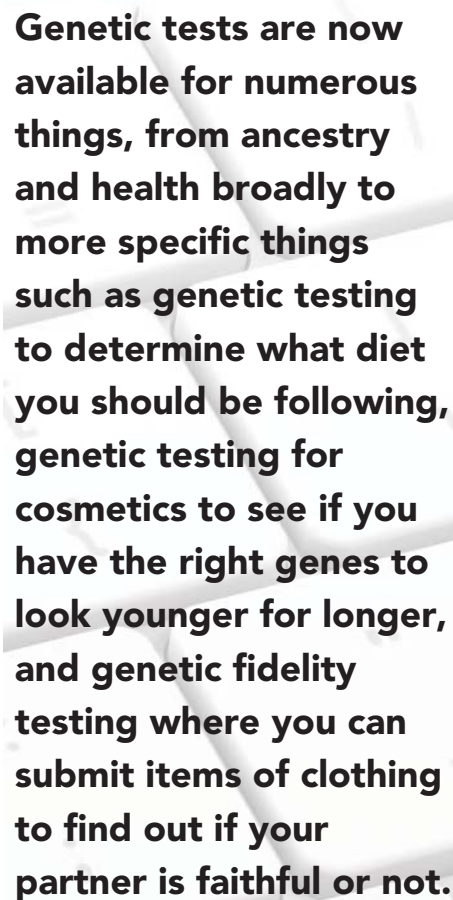
What the results mean, however, will depend on a number of factors – the most important being the consumers themselves.

Imagine an envelope on the table in front of you – in it is a report that contains information about various predispositions to health conditions, like diabetes, heart disease and certain types of cancer. You can also find out what your fitness is like: are you likely to be better at endurance sports or sprinting sports?

You can also find out about your family – not your immediate family (although we will come back to this) but your ancestors from tens of generations back. Would you like to know which region of the world they migrated from? Or are you mainly interested in what colour your eyes are, if you have a low tolerance to alcohol or if you can taste bitter foods (which might explain why coriander is not your favourite spice)?

All of these facts and figures are now available to you, and they are based on your genetics. Would you open the envelope to have a look?

Before you get to the envelope, what did you think about when each of the different types of tests and their results were mentioned? Were you thinking about a family member with one of the conditions? Or were you thinking about that third cousin



Genetic tests are now available for numerous things, from ancestry and health broadly to more specific things such as genetic testing to determine what diet you should be following, genetic testing for cosmetics to see if you have the right genes to look younger for longer, and genetic fidelity testing where you can submit items of clothing to find out if your partner is faithful or not.

from the family reunion you just know is not related to you?

What the test results say is, of course, important. But in some instances what’s more important are the motivations driving consumers to seek this information and what they do with it once they have it.

These two perspectives represent the expectations and the reality of direct-to-consumer personal genome testing. From the stories I heard in my research from participants who had undergone testing, and from other reports by researchers in other countries, there is a significant difference between the expectation and reality of direct-to-consumer personal genome testing – creating a gap where interesting tensions and ethical dilemmas sit.

This gap is an interesting space because it is not immediately talked about when consumers talk about their experience of testing. Instead, this space can be defined by the sense of disappointment some consumers of this test talk about and feel when they reflect on their testing experience.

Part of this disappointment is a reflection of hype and over-promise that exists around these tests. Within this hype and over-promise, however, lies a kernel of truth: that there is quite



Maksim Kabakov/adobe

a lot about human genomics that we don't know.

To put the field in perspective, it was less than half a century ago that scientists designed a way to sequence the human genome. Today we suddenly expect scientists to be able to tell us what it all means. This is not to say that one day we will be able to do this – just maybe not now.

Another part of this disappointment is closely linked with what we hope this information can tell us. Importantly, we want to know what our genetics can reveal about our lives and whether knowing this information now could help us change our current life, future health or even re-interpret our past.

The difficulty with placing such importance on our genetics is that, with such an emphasis on genetics, is there something else being lost or overlooked? For example, when we place a higher value on genetics and new technologies, what do we then judge to be of lesser value? And if we start to value genetics as a stronger explanation for health, illness and disease or where our ancestors come from, how does this affect how we see not only ourselves but the world around us as well?

In this complex and difficult space, we begin to ask questions around whether or not testing is something we should

be doing. Each question can often reveal another layer of consideration that inevitably makes the decision more complex. An example of this is the initial decision to pursue testing.

The decision to undergo testing is not an easy one. Some people will order a test, receive it in the post and, instead of submitting their sample, leave the testing kit in their desk drawer, waiting to be opened or purposely left unopened. Alternatively, the test can sit there as a quiet reminder, prompting consumers to ask the hard questions. Is there more you could know? Is there more you should know? And at the centre of this tension is the main question: do you want to know?

One of the many ethical challenges that arises when genetic testing is considered is the idea of wanting “to know”. This concept has created both good and bad consequences for both for those who decide to pursue testing and those who decide against it. Often this idea is viewed as the end of an argument, but I propose it is actually the starting point for a conversation.

For example, if you do want to know – why do you want to know? What do you think this test could tell you that would be worth knowing? Alternatively, if you do not want to know – are you concerned about what the test might reveal, or are you comfortable with what you currently know and do not have a desire to find out more?

Considering these questions and the potential impacts that the information has is part of the decision-making process people go through when considering whether or not to be tested. This process becomes more complicated when we are reminded that genetic information will not only reveal information about ourselves but also information about our genetically related family.

When exploring the ethical issues that direct-to-consumer personal genome testing raises, it's important to acknowledge the fact that seeking and receiving genetic information does not happen in isolation. Genetics connects the individual to their family; the testing process connects the individual to the testing company, and the presence of these tests in the marketplace and society enables genetics to be part of daily life – from something as routine as a visit to the gym, to deciding who to have children with, and to how we see and understand ourselves.

With such a wide and varied reach for these tests it seems ethically responsible that consumers should be provided with access to appropriate support to help them seek clarification about why they seek this information and what it could mean once they do have it. With some tests this is currently done but, like most online purchases, do we really read the fine print on the returns and exchanges policy? This is especially important, because we cannot change nor exchange our genetics.

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