Protect consumers from gene tests

Dr Ainsley Newson (2009)

"Without a doubt, this is the most important, most wondrous map ever produced by human kind," said President Bill Clinton in 2000 when the first human genome sequence was published. Less than a decade later, we may soon be able to obtain our own genome sequence. For around $400 (£247), several online companies will already sell you a "snapshot" of your genome. This estimates your risk of developing certain diseases and will even predict whether you are likely to enjoy the bitterness of broccoli.

But just around the corner is whole genome sequencing: your entire DNA sequence on a memory stick. Far from the $3 billion (£1.8 billion) spent on that first genome sequence, unlocking our DNA is now faster, more accurate and cheaper. The cost has reduced to less than $50,000 (£30,878). Soon it will be less than $1,000 (£647).

Disclaimers

Whole genome sequencing is alluring. It could offer useful predictions of our future health and susceptibility to disease, helping us better control our health. It could also predict how we will respond to a particular prescription drug.

It is, however, still limited. We don’t know what all human genes do and how they interact with our environment. Most genes will only give a probabilistic, not certain, indicator of whether we will develop a particular disease. This vast amount of information will have little meaning without professional interpretation.

The companies providing whole genome sequencing recognise this and have long disclaimers stating that clinical inferences are unproven, the test is for informational use only and should not be taken as medical advice.

There are also ethical issues. Should third parties ever have access to these data? Should we test babies or children? Is it acceptable for the companies providing these tests to use your data for research? How can we best ensure people understand this test?

Doctor knows best?

One significant issue is whether testing should be offered via doctors or direct to consumers. One company is only offering whole genome sequencing via doctors, a move criticised by those who think these tests are no different to buying over-the-counter medications in a pharmacy.
If consumers are well-informed and are simply finding out recreational information that has little health value, what is the problem? What could a clinician add when this information is so uncertain?

This may risk a paternalistic 'doctor knows best' attitude, denying people the right to their own genetic information.

I support people's rights to their own genetic information, should they want it. But to label this information as "recreational" is misleading, particularly given that one US study has already shown that consumers don't see it this way.

**Irresponsible**

It won't be long until the knowledge of gene-disease associations improves. It is irresponsible to offer testing without legitimate access to pre-test counselling and clinical support. This could also provide a drain on NHS resources as people consult GPs, who may lack the required knowledge, for support and interpretation.

Of course it is important for people to have access to good information to influence their health care. But we can do this while minimising the risk of harm, not least by ensuring the limitations of the test are not buried in a legalistic consent form.

Without sound clinical oversight most people will be left in charge of a significant amount of information of uncertain significance and little direction as to where to go for reliable interpretation.

Personal genomics may turn out to be an expensive way to be told to eat more greens and do more exercise but once that information becomes complex, professional clinical interpretation should be provided with the test. This is not paternalism but responsible consumer protection.