



Association of Genetic Nurses and Counsellors

A constituent group of the British Society for Genetic Medicine

Direct To Consumer (DTC) genetic testing: top tips for patients

There is a multitude of Direct to Consumer genetic tests online. It is impractical for the BSGM and its constituent groups to endorse or support a particular product, but here are a few top tips to help patients with DTC testing:

What are you interested in?

Are you wanting to use the DTC test for recreational curiosity or are you concerned about a particular genetic condition that may be running through your family? The Genetic Alliance has some great information on the sorts of things a DTC can and cannot tell you:

<http://www.geneticalliance.org.uk/docs/direct-to-consumer-genetic-testing.pdf>

You want a diagnosis?

If you want a genetic test for a specific condition that is running through your family, you might be able to get this via NHS genetic testing services. Talk to your GP and ask for a referral to Clinical Genetics. A DTC test may be able to offer you information about one specific condition that you are interested in, but it also may offer lots of other information at the same time. You need to think through whether you want all this additional data, remember it is not just relevant to you but also to your relatives.

Choose a company that has real people you can talk to!

It is definitely worth picking a company that will offer you the option to speak to someone about the results. If there is a genetic counsellor on board, even better. Whilst it isn't necessary to have full 'counselling' as a mandatory part of the process, you might feel that after you've got the results, it would be good to talk them through with the people who found them for you.

Negative results may not be negative

If you are found by a DTC company to have a negative result, i.e. you don't have the altered gene that has been tested for, it doesn't necessarily mean that you are not at risk from the condition. It may just be that they haven't tested the full set of genes that can be tested.

Read the small print

Does the DTC company claim to be offering testing 'to improve your health?' This implies that you can use the information to make clinical decisions. However, this should really only be done if the testing has been repeated in a clinically accredited lab (as found in the NHS) and thus you know the

result is a real one and backed by robust data. So check the small print – is the company ‘clinically accredited’ or are they actually doing ‘research’? If they are not clinically accredited, then you’ll need to get any results confirmed first before you should use them to change your healthcare.

You might not be able to bring your DTC report into the NHS

It’s complicated. In a publically funded health service such as the NHS, there are guidelines for Clinical Genetics services accepting a referral for genetic testing. For example, if you have a carrier result for a really rare recessive condition, where it is very unlikely that your partner is also a carrier, then it is unlikely that a Clinical Genetics service would need to see you (because the risk of you having a child with the rare condition is very small). However, if you were found to be a carrier of a *common* recessive condition, then you and your partner could be seen to discuss the risks of the condition appearing in your children. If a DTC test reveals you are a carrier for a very rare genetic condition, then why not ask them to test your partner to see if they are also a carrier? If the results from this second test reveal your partner is also a carrier, then that is the point when you could receive a referral into the NHS Clinical Genetics services.

Things the NHS wouldn’t do

If your raw genomic sequence data is given to you by a DTC company, the NHS does not have the resources or time to interpret this for you. However, there are other commercial companies online that will interpret raw data; a simple Google search will reveal these.

What will the DTC company do with your data?

It is distinctly possible that your personal genomic data will be shared with other people, i.e. sold to other companies or to researchers. The aim of this is usually to help support drug discovery or conduct further research. Many people don’t have a problem with this, but it might just be worth knowing so you can make a decision as to whether you are happy with this. Nothing personally identifiable such as your name or date of birth would usually be shared with the genomic data, but still, it’s worth checking first.

If you are panic buying on Christmas eve, pick the jumper instead!

The DTC companies offer such a wide range of testing, from ancestry data through to Neanderthal genes, through to breast cancer risk. The fun stuff should be seen as just that – fun, interesting, curious. But what might also be tucked amongst the funnies are serious pieces of health information, e.g. risks for diabetes, Alzheimers and Parkinson’s. Whilst these might feel very disconnected to you, they may inspire terror in others, so it might be better to avoid the DTC test as a present.