



Over-the-counter Genetic Susceptibility Tests

*Information for individuals, families and
non-specialist health professionals*

Over-the-counter Genetic Susceptibility Tests

In recent years, there has been an increase in the number of genetic tests that are available to buy over the counter or on the internet. Many of these tests attempt to give you information about your risk of developing health-related conditions in the future.

This leaflet will give you some information about these tests, which are known as “**genetic susceptibility tests**”.

What are genetic susceptibility tests?



They aim to estimate your risk of developing certain common conditions in the future. They cannot diagnose you as having a condition.

The tests involve taking a DNA sample (usually saliva, or scraping a few cells from inside your cheek) and mailing it to a laboratory which conducts the test.

DNA is the chemical in our cells that gives our bodies instructions about how to grow, develop and function. It's a string of coded messages organised into specific instructions called genes. We all have tiny variations in our genes, called SNPs (pronounced “snips”). Some SNPs may have no effect on us, while others may, for example, influence our appearance. Genetic susceptibility tests look for SNPs that have been linked to an increase or decrease in risk of developing certain conditions.

What can be tested for?

If you decide to take a genetic susceptibility test, it's important to be clear about what exactly you will be tested for.

Most over-the-counter genetic susceptibility tests aim to estimate your risk of developing certain “common complex conditions”. Common complex conditions



include many types of heart disease and most forms of diabetes. They are called “common” because they are a common cause of serious ill health or death, and “complex” because whether a person develops the condition depends on many of their genes as well as environmental and lifestyle factors. For example, making lifestyle changes such as eating healthy food and exercising can make a real difference to your risk of developing many common complex conditions.

There are some conditions that are caused by a fault in just one gene. Most “single-gene conditions” are rare, but others, such as cystic fibrosis, are more common. Tests for single-gene conditions can be done on the NHS and are not available as over-the-counter tests. For

information on these tests, please look at our leaflet called ‘What is a Genetic Test?’.

(http://www.gig.org.uk/gig/docs/eurogentest_WhatisaGeneticTest.pdf).

What can the test results tell me? And what can't they tell me?

The results **can** provide an estimated indication of your risk of developing certain conditions in the future, and how this compares to the average risk.

The results **can't**:

- ◆ diagnose you as having a condition.
- ◆ tell you whether or not you will definitely develop a condition in the future, when you might develop it, or how severe it might be.
- ◆ take into account alterations in your genes that might develop during the course of your life.
- ◆ tell you how your lifestyle might influence your risk.

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Test results can be difficult to interpret. Reputable companies should be able to provide support after you have taken the test, to help you understand the information you have been given and what implications it might have for you.

How useful are the tests?

Genetic susceptibility tests can only provide a partial picture of your risk of developing a condition.

The tests typically only look for a fraction of the total number of SNPs (“snips”), or genetic variations, that we know about. What’s more, these variations normally only have a very small influence on your risk of developing a condition, and sometimes the link with a condition may be weak. The company providing the test should be able to demonstrate to you how strong the link between the condition and the test results is.

It’s also important to remember that for the vast majority of conditions, your genes only partly influence your future health risks. Other factors, such as your medical history, your lifestyle and your environment also play a role. So having a higher genetic risk does not mean that you will definitely develop a condition, and having a lower genetic risk doesn’t mean that you definitely won’t. For example, a test result might show that you have a lower than average genetic risk of developing diabetes, but if you are overweight and have an unhealthy diet, this might mean that you still have a high risk.

Any estimate of your risk of developing a condition also needs to be put in context. For example, the results might tell you that you are twice as likely as the average person to develop a particular condition. However, if the average risk is 1% (1 in a 100) that means that you still only have a 2% (2 in a 100) risk of developing it – and a 98% (98 in a 100) chance of not developing it.

Will the information the test provides make a difference?

It could be helpful to ask yourself what you hope to be able to do after getting the test result that you can’t do now. You might also wish to think about whether there are any steps you could take if the test results indicated that you had an increased risk of developing a condition. For example whether there are any:

- ◆ lifestyle changes you could make to reduce your risk, such as eating a healthier diet, exercising or stopping smoking?
- ◆ preventative measures, such as screening programmes?
- ◆ treatments for the condition?

How might the test affect me emotionally?

Before deciding to take a test, you might also like to think about the potential emotional impact and ask yourself questions such as:

- ◆ Why am I considering taking this test? Why now?
- ◆ What do I hope the test will tell me?
- ◆ Will the test be able to answer my questions?
- ◆ What if I get a result that I am not expecting?

Test results that indicate an increased risk for a condition could cause unnecessary anxiety or stress. On the other hand, results that indicate a low risk could lead to a false sense of security (which might mean symptoms are ignored) or complacency about the effects of an unhealthy lifestyle.

If you wish to talk through the potential implications before taking a test, you could ask the company offering the tests if they can provide any support such as counselling and advice. But if you have any doubts, speak to your doctor (GP).

Will the test results have any implications for my family?

The results will not have much of an implication for your family because they estimate your risk of developing “common complex conditions”. They are called “complex” because whether a person develops them depends on many of their genes as well as environmental and lifestyle factors. This means that they are far less likely to be inherited than conditions that are caused by a fault in one gene, such as cystic fibrosis. Tests for “single-gene conditions” like these are not currently available over



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the counter or on the internet. The British Society for Human Genetics advises that single gene tests should currently be provided in the context of a consultation with a trained doctor or a genetic counsellor.

Should genetic susceptibility tests be used on children?

The UK's Advisory Committee on Genetic Testing stated in 1997 that: "Genetic testing services supplied directly to the public should not be supplied to those under the age of 16." (The Committee advised the Government on developments in genetic testing, and its work is now part of the role of the Human Genetics Commission.)

What will happen to my personal information?

It is important that you know who will have access to your personal information and to your DNA sample. You should check the privacy policy of the company providing the test so you know how your information may be used and whether customer information is shared with any third parties, for example for marketing purposes. Some companies may post test results online for customers to log in and access. If this is the case, you should make sure that the website is secure.

Will the test results affect my insurance prospects now or in the future?

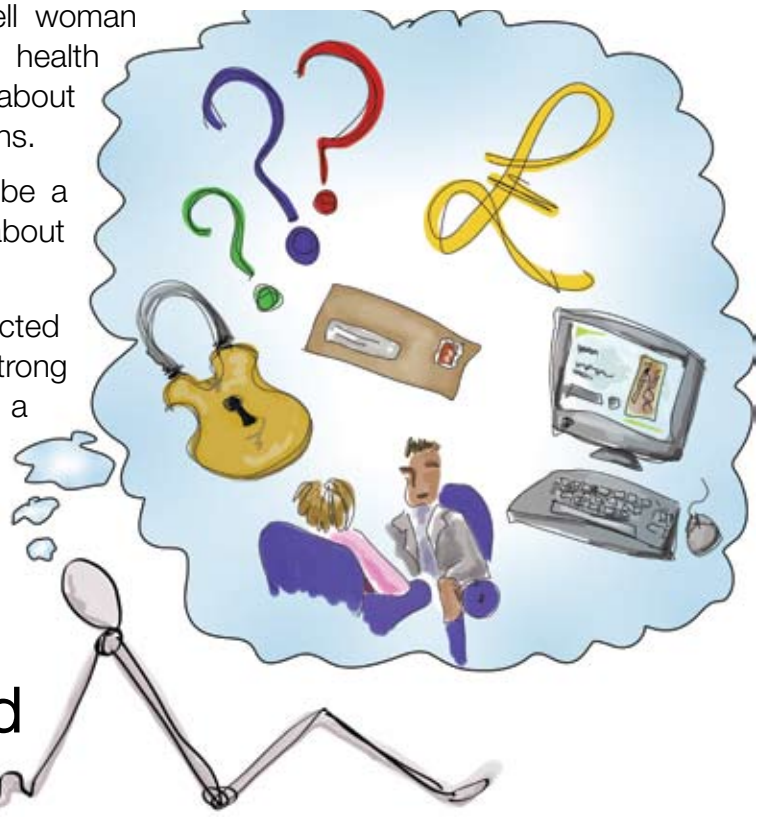
The Government and the insurance industry have ruled that until 2014, results from predictive genetic tests (tests that are done on the NHS for conditions caused by a fault in a single gene) can't be included in applications for life insurance policy with insurers who are members of the Association of British Insurers. However, because there is a lot of doubt about the usefulness of over-the-counter genetic susceptibility tests, they have not yet really been considered by the insurance industry. This could change in the future, though.

Are there any other ways I can find out the information I'm looking for?

There are some standard non-genetic clinical tests that can give you a good indication of your health risks, for example tests to measure cholesterol levels. Your doctor (GP) would be able to advise you about these. Many GP surgeries run well woman and well man clinics, which offer health check-ups and can offer advice about reducing your risk to future conditions.

Talking to your relatives can also be a good way of finding out more about your family's medical history.

A small number of families are affected by genetic variations that have a strong impact on risk of developing a condition. If you have a family history of a disease or condition and you are concerned about it, speak to your doctor (GP).



What support and information can I get if I decide to proceed with a test?

- ◆ The company selling the test may offer counselling services.
- ◆ There are a number of condition-specific organisations that offer online information on how you can reduce your risk of developing the condition, e.g. Cancer Research UK (<http://info.cancerresearchuk.org/healthyliving/>) and the British Heart Foundation (www.bhf.org.uk), which also has a Genetic Information Service (0300 456 8383 - lines open from 9am to 6pm Monday to Friday).
- ◆ The NHS Choices website (www.nhs.uk) has lots of expert information on conditions, treatments and healthy living.
- ◆ If you have questions or concerns about your health, speak to your doctor (GP).

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What questions should I ask the company providing the test?

We have listed some questions that you may wish to consider asking the company providing the test, or finding out from their website:

- ◆ Is there a proven link between the results of the test and the condition it is intended to detect? How strong is the link – is it definite, probable or possible? How big was the population studied in order to determine this link? Has the evidence for any link been published in a peer-reviewed academic journal?
- ◆ What counselling resources do you offer if I want to discuss the implications of taking the test(s)? Are your counsellors independent and fully qualified?
- ◆ How will my sample be taken?
- ◆ Is your laboratory accredited?
- ◆ How reliable are the results? Do you repeat the test to make sure the results are accurate?
- ◆ How will you send me the results?
- ◆ Will the results tell me anything that is clinically affecting me?
- ◆ Will the results be in non-technical language that explains what the result means for me?
- ◆ Is there someone I can ask if I don't understand what has been sent to me? What sort of expert is this? Is this included in the price I pay?
- ◆ What happens to the sample and my personal data when the test has been completed?
- ◆ How long will my sample be kept for?
- ◆ Will my sample be analysed for purposes other than the carrying out of the genetic test(s) that I am purchasing?
- ◆ How will the privacy of my sample and data be safeguarded?
- ◆ Do you share or sell any information to other organisations?
- ◆ Will you try to sell me anything else after I receive my results?
- ◆ Do you have a clear redress policy in case, for example, I feel I have been given an incorrect result?
- ◆ Do you have an ethical review committee?



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A charity registered in England and Wales (No. 1114195) and in Scotland (No. SC039299).
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Design and artwork by Needham Griffin Limited (www.needhamgriffin.co.uk)

This leaflet was made possible by an unrestricted educational grant from Roche