

Insurance and Genetics

Information for patients

For some types of insurance it is necessary to provide medical information, including genetic information, to the insurers in order for them to set up your policy and work out your premiums. This leaflet outlines answers to questions you may be asking about how genetic tests could affect your insurance.

Do I have to tell the insurance company about a hereditary (genetic) disease that runs in my family?

If it is requested on your insurance application form, then you must give the insurers any information about current or previous illness amongst family members. This includes their genetic test result if it is the cause of their illness as this is a diagnostic test.

Companies will use information about your family history to calculate your risk as they have always done.

Will the insurance company ask me to have a genetic test?

No. The Association of British Insurers (ABI) has a Code of Practice on Genetic Testing that states that people seeking insurance must not be asked to have a genetic test in order to get insurance.

I have already had a genetic test. Do I have to tell my Insurance Company the results of this test?

If you have not had the illness but have been offered a genetic test because there is a known gene change in the family or because no family members with the illness can be offered a genetic test, you are having a 'predictive' genetic test.

In 2018 the Association of British Insurers agreed to an open-ended moratorium which means that you will not have to disclose the results of your predictive genetic test to them when you are taking out insurance, this applies to certain types of insurance cover (critical illness, income protection or life insurance). This will be reviewed every 3 years.

This table shows what information you do/do not need to disclose for different types of insurance.

Test	Predictive Genetic Test	Diagnostic Genetic Test
Life insurance of less than £500,000	No	Yes
Life insurance of more than £500,000	No	Yes
Life insurance of more than £500,000 for Huntington's disease	Yes	Yes
Critical illness insurance	No	Yes
Income protection insurance £30,000 per person	No	Yes

Do I have to tell my insurers about any genetic tests taken after my policy has started?

No, you do not have to disclose the results of any genetic test taken after your insurance policy has started, for as long as the policy is in force and not altered.

Do I have to tell my insurers the genetic test results of family members?

Insurers cannot ask for the 'predictive' test results of family members. However, if a relative has been diagnosed with a genetic condition based on a diagnostic test then you will need to mention this when asked for your family's medical history.

What happens if I have a genetic test and the result is negative, which means I have not inherited a genetic disease that runs in my family?

You may want to tell your insurance company about negative diagnostic or predictive genetic test results. Many insurance companies will take this result into account, and it could counteract the effect of an unfavourable family medical history on your premium.

What will insurance companies do with my genetics result?

Your genetic information is private, and insurers are required to adhere to data protection legislation and ABI rules. Any genetic information about you is securely locked away and only brought out by the staff who need to use it in order to prepare your policy. Any genetic information that you provide is confidential and will not be shared with any other insurance company unless you agree to it. The genetic information is destroyed when it is no longer relevant, so you don't need to worry about it being passed onto other agencies.

Can insurance companies really interpret my genetic test results properly?

Insurance companies employ staff and medical experts who are trained in the interpretation of medical information and test results. If you believe that your results have been interpreted incorrectly, you should contact the insurance company to ask for a reassessment. You also have right to appeal and have any complaint heard fairly.

I have been asked to take part in a genetics research project. Could this affect my current or future insurance?

No. The moratorium states that customers will not be asked to disclose any predictive or diagnostic research genetic test results.

The important things to remember are:

- No research will affect any policy you have already taken out.
- Only tests where you know the results could, even in principle, affect any future insurance. With many research projects, participants are not told their test results.
- Even if you know the results, insurers will only consider results of tests done as part of a clinical diagnosis.

Overall taking part in research is not something that affects insurance. Feel free to discuss this issue with your doctor, nurse or genetic counsellor before taking part in a research study.

Where can I find more information?

The ABI:

www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/

www.abi.org.uk/globalassets/files/publications/public/genetics/code-on-genetic-testing-and-insurance_embargoed.pdf

Genetic Alliance

<https://geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/>

Contact information

Your local genetics service:

South East of Scotland Clinical Genetic Services
Molecular Medicine Centre (MMC)
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

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