

Genetic testing for faulty breast cancer genes, confidentiality and insurance

What information can your insurance company request?

Quick facts

- **Results of tests for faulty breast cancer genes are kept confidential, other than in exceptional circumstances.**
- **Your insurance company can only ask the results of your genetic test if you have already had cancer and you took that test to find out whether a faulty gene is responsible for your diagnosis.**
- **Your insurance company cannot ask for the results of a genetic test if you have not had breast or ovarian cancer and you took the test to tell you about the likelihood of you developing one of these cancers in the future.**
- **Your insurance company can ask for information from your GP about your medical history and your family's medical history, which could alter your insurance premiums.**

What is genetic testing for faulty breast cancer genes?

Most people in the UK do not have a significant family history of breast cancer, and even fewer carry known faults in their genes that increase their risk of developing breast cancer. People who have at least a one in 10 (10%) chance of having faulty breast cancer genes are able to have genetic tests on the NHS, to discover whether or not they have inherited these faults.

The test uses a blood sample to check for known gene faults, e.g. faults in the BRCA1, BRCA2 and TP53 genes.

If you have genetic testing, there are UK guidelines to protect the confidentiality of your results. There are also rules, agreed between insurers and the UK Government, about whether or not your insurance company can ask about your results.

Are the results of my tests confidential?

Your genetic test results will be kept confidential and your doctor is not allowed to tell anyone that you have taken a genetic test or to reveal the results without your permission.

There are exceptions to this rule:

- Under certain circumstances a healthcare professional may inform members of your family of the results from your genetic test. This might occur in cases where it will help those relatives understand their own genetic risk, allowing them to make decisions about their own healthcare. Before speaking to any relatives, your doctor should talk about this with you and discuss any concerns you might have.
- In extremely rare circumstances the courts could also authorise police or lawyers to use the information contained in medical databases. It is highly unlikely that this will happen, and even less likely that the results of genetic tests for breast cancer would be useful in a criminal investigation.

Can I choose whether to share my results?

When you give a blood sample for a genetic test, it is quite common for you to be asked to consider:

- Whether the results of any genetic test can be shared with your relatives. As your relatives might also have an increased risk of breast cancer, your results may be of interest to them. Getting your permission to share information could be very helpful to your family in the future.
- Whether the blood sample can be used for research into familial breast cancer. You will not get any results back yourself from this research. If you agree then your sample will be anonymised and will help scientists understand more about breast cancer genetics. You do not have to agree to this if you do not wish to.

Can my insurance company ask about my test results?

In theory, the results of genetic tests could be of interest to a range of insurance companies. However, insurers agreed with the Government a set of rules to govern what information insurance companies are allowed to request.

Whether or not your insurance company can ask for your test results depends on the type of test you have had.

You may take a genetic test if you have not had breast or ovarian cancer, to tell you about the likelihood of you developing one of these cancers in future. Insurance companies cannot currently ask about the results of these genetic tests. They also cannot ask you to take this kind of genetic test or for the results of any such test taken by a relative, or use this information if it's accidentally given to them.

However, you may have had a breast or ovarian cancer diagnosis and have had genetic testing to find out whether a faulty gene is responsible for your cancer. Insurance companies can ask about the results of this kind of test (unless they were part of a research study). They can also ask about the results of any such test that a relative has had. These results could influence your premium.

In practice, this means your insurance company might be able to gain some information about the faulty breast cancer genes running in your family, even if they cannot ask for the results of all individuals. If you would like advice on whether or not your insurance company can request this information, you may wish to speak with an independent financial advisor.

What about genetic tests taken as part of a research study?

Any genetic test you have as part of a research study is not considered part of your medical care. Insurers agree that customers will not be required to disclose the results of any genetic tests they received as part of clinical research.

Can my insurance company ask about my family's medical history?

Insurance companies can ask you about your own medical history and your family medical history. With your consent, they are allowed to ask for medical reports from your GP. They can also ask about the results of tests family members who have had cancer have taken to find out whether a faulty gene is responsible for their cancer. This means insurers could gain information about your family's increased risk of breast cancer.

In some cases, insurance companies may ask you to undergo a medical examination, but this cannot include genetic testing.

Insurers will usually only ask your GP for information on the medical history of first degree relatives (your parents, siblings and children) on their report forms. In some cases, insurers can ask for information on family members less closely related to you.

Why can't insurance companies ask about some genetic test results?

Until at least 2017, there is an agreement between the UK Government and the insurance industry that bans insurance companies asking you for any results of genetic tests taken to predict the likelihood of your developing cancer in the future when you take out life insurance, critical illness insurance or income protection insurance.

Insurers will not use results from genetic tests taken to predict the risk of developing breast or ovarian cancer in future when setting premiums for private medical insurance, travel insurance or long-term care policies.

The agreement is reviewed every three years by the Department of Health and the Association of British Insurers to decide if the agreement should continue beyond 2017. The agreement was reviewed in 2014 and the decision has been made to extend it until 2019.

If I already have insurance, do I have to disclose new information?

You are only required to disclose health information at the time you take out an insurance policy up until the policy start date. After your policy starts, you have no obligation to disclose any additional information (including the results of genetic tests) to your insurer, unless you decide to change insurers or take out a new policy.

What can I do if my or my relative's test result increases my premium?

Every case is considered individually and the premium you pay will depend on the type of insurance policy you are buying, how long that policy will stay in force and the likelihood that the event you are insuring yourself against will happen. It is often useful to shop around. You can either make enquiries to various insurance companies yourself or you can use an Independent Financial Adviser (IFA). IFAs will make enquiries on your behalf and will offer you independent advice on which company offers the best policy for you.

If my test shows I don't have a faulty gene, could this help reduce my premium?

If you have not had breast or ovarian cancer and you have taken a test to help predict the risk of you developing cancer in the future, and the result shows you do not carry a faulty gene identified in your family, insurance companies are not obliged to take this into account. Each insurance company will decide how to deal with this situation on an individual basis.

However, if you choose to share the results of this kind of a genetic test, their genetics expert must look at your case. This expert (called the Nominated Genetic Underwriter) is fully trained in the rules and regulations on using this information and has access to trained medical clinicians, whom they can call on for additional expertise if needed.

If I have had risk-reducing surgery, could this help reduce my premium?

If you have a family history of breast cancer and have since had risk-reducing surgery, you can choose to tell your insurer about your situation. Some insurers may take this into account, but they are not obliged to.

Who can I complain to if needed?

You can contact the Genetic Tests Arbitration Scheme or the Financial Ombudsman Service to seek help in resolving problems with your insurers.

About Breast Cancer Now

We're Breast Cancer Now, the UK's largest breast cancer charity – and we're dedicated to funding research into this devastating disease. We believe that if we all act now, by 2050, everyone who develops breast cancer will live. Join us at breastcancernow.org

This leaflet is based on up-to-date research evidence and aims to give the best information available. All information was reviewed by appropriate experts and members of the public. We advise readers with concerns about breast cancer to discuss them with a health professional.

If you would like more information about the sources of evidence on which this publication is based, please contact info@breastcancernow.org or call 08080 100 200.

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Breast Cancer Now

Fifth Floor Ibex House 38 Thistle Street
42-47 Minories Edinburgh
London EC3N 1DY EH2 1EN

breastcancernow.org

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