



Genetic testing for hereditary cancers

Most cancers occur by chance but some are hereditary (run in the family). This leaflet explains what to expect as your clinician has recommended that you have genetic testing because they suspect your cancer could have been caused by a genetic mutation (harmful change) or that you may be at risk of developing a further cancer due to a genetic mutation.

What causes hereditary cancer?

Hereditary cancers are due to a mutation in a gene that normally works to protect against cancer. It is important to identify patients who have hereditary cancers. Knowing whether you carry a harmful change in a gene gives the team treating you more information about the type of cancer you have. This information can be used when making decisions about the recommended treatments, for example, which chemotherapy drugs or surgery would be most suitable. It will also give information about your and your family's risk of developing cancer in the future and how to best manage and potentially reduce these risks.

What is genetic testing?

The R207 test involves sending blood samples to a genetic testing laboratory. The laboratory will look for harmful changes in a range of genes that may cause an increased risk of developing breast, colon, endometrial and ovarian cancer. The genetics team will send you and your cancer team the results of the test by post. The results will be shared with you within twelve weeks.

What if no harmful changes are found?

This result would be reassuring as you are unlikely to be at increased risk of developing another, new cancer in the future. It also means family members are unlikely to be at increased risk of developing cancer. However, if you have a significant family history of cancer in addition to your own diagnosis, your cancer team can refer you to the genetics team for an assessment and will take this information into account when deciding on your management options.

What will happen if a harmful change is found?

Your cancer team will use the result to decide on the best treatment. The genetics team will see you to explain what the test result means for any risk of cancer, your options for cancer screening and measures to reduce these risks. They will evaluate your family history and can provide information for family members, so they can access genetic services at their local genetics centre.

What does this test mean for my family?

As most cancer happens by chance, **it is unlikely a harmful change will be found**. If no harmful changes are identified, it would indicate that your cancer was unlikely to be due to hereditary factors, which would be reassuring for you and your relatives.

If your test shows you have a harmful change, it is possible that some relatives may also have the same harmful change. Relatives who are found to carry the harmful change will be offered treatment to suit them.

Do I have to have the test?

No, having this test is optional. Your decision will not affect the standard of care you receive from the hospital or doctor. If you are unsure about taking the test, we recommend that you have further discussions with the cancer team and with your family.

Will my information be confidential?

If you consent to have the test, this will be documented in your medical notes. All data collected about you will be held under the provisions of the 1998 Data Protection Act and stored in secure files. The only people who will know your identity are staff at the hospital and a few trained staff reporting the results, who are bound by a professional duty to protect your privacy.

Insurance implications of genetic testing for individuals who have cancer

If you have been diagnosed with cancer and have been offered a genetic test because of your cancer diagnosis, you are having what is called a *diagnostic* genetic test. This includes cancer diagnoses that occurred in the past, even if treatment has been completed. The diagnostic genetic test may either be a full test of one or more genes associated with developing cancer such as BRCA1 and BRCA2, or a specific test for a genetic harmful change that has been identified in a relative.

For life, income protection and critical illness insurance policies, insurers can ask for information about your diagnostic genetic test to set the level of cover and cost of your premiums, in the same way as they ask about the rest of your medical history. For example, if you have been diagnosed with breast cancer that is due to a BRCA1 mutation, that genetic information is part of your personal medical history. However, insurers cannot ask you to take a genetic test and can only ask for the results of a genetic test you have already had.

If you are offered a diagnostic genetic test after your insurance policy is in place, then you do not have to disclose that you have had a genetic test or the results of the test.

If you are taking out a new insurance policy after you have had a genetic test, you will need to disclose that you have had the test and the results.

Genetic test results do not have to be disclosed for health or travel insurance policies, but associated medical conditions such as cancer diagnoses do need to be disclosed.

Insurance implications of genetic testing for individuals without cancer

If someone is being offered a genetic test because there is a known harmful change in the family, you are having what is called a *predictive* genetic test.

The Code on Genetic Testing and Insurance states that information about predictive genetic tests for possible cancer risks due to harmful genetic changes is not used by insurance

companies to determine if a policy is offered, or to determine the cost of the policy. The agreement relates specifically to life, income protection and critical illness insurance products only. Health insurance and travel insurance policies are not specifically covered by the agreement, but also do not require you to disclose this.

Good to know

- You are welcome to contact the gynaecological cancer clinical nurse specialists on 0118 322 8195 or email Gynaecancernurse@royalberkshire.nhs.uk if you have further questions
- The result of your genetic test may affect any new life insurance or critical illness policies that you take out.

Further information

<https://www.ovacome.org.uk/hereditary-ovarian-cancer-info>

<https://targetovariancancer.org.uk/about-ovarian-cancer/genetic-genomic-testing>

References

Genetics Unit, The Royal Marsden NHS Foundation Trust

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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Next review due: June 2028