

Northern Gynaecological Oncology Centre, Queen Elizabeth Hospital

BRCA1 and BRCA2 Gene testing

Information sheet for patients with ovarian cancer

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Why am I being offered this test?

You are being offered a test to look for BRCA1 and BRCA2 gene mutations because of your ovarian cancer diagnosis.

Background information to BRCA gene testing

Around 7000 women in the UK develop ovarian cancer every year. In the majority of these women the cancer has occurred by chance. However, in a small number of women the cancer develops because of an abnormality, known as a mutation, which occurs in a specific gene. A gene acts like a piece of coded message which tells our bodies how to function normally. We know that inherited mutations in the BRCA1 and BRCA2 genes can increase the risk of a person developing cancer including breast and ovarian cancers. These inherited mutations are more commonly found in patients who have a strong family history of ovarian and/or breast cancer but can also occur even if there isn't a family history.

What are the benefits of having the test?

Knowing whether or not your cancer has occurred because of a BRCA1 or BRCA2 gene mutation is important. It will provide you with information about your risk of developing other cancers in the future. Having this information will help the team who are looking after you make decisions about future treatments for your cancer, if needed.

Does the test result affect my family?

For most women, the test result will be normal (no BRCA mutation found) and your family will know that your cancer was unlikely to have been caused by inherited factors that might increase their risk of cancer. If your test shows you have a BRCA mutation then your relatives will also be able to meet with the genetics team to find out more information and decide if they want to have the test too. If you have children, then there is a 1 in 2 chance that you could have passed this on to them (both sons and daughters).

What will happen if a BRCA1 or BRCA2 mutation is NOT found?

This is the more likely result, as the majority of people will have a cancer that has happened by chance, rather than because of a BRCA1 or BRCA2 mutation. However, if the team looking after you think other genetic abnormalities might be involved in your cancer they can ask the genetics team to meet with you. In addition, if new cancer genes are discovered in the future then the sample you have already given may be tested, with your permission.

What will happen if a BRCA1 or BRCA2 mutation IS found?

The genetics team will send you an appointment so that you can discuss the results with them in more detail. They will talk to you about what the results mean, including the options available for screening to reduce your risk of developing a second cancer. They will also discuss your family history with you and provide information for family members who may wish to undergo testing.

What will happen if the test result is unclear?

In a small number of people tested a gene mutation is found that we might not have seen before or understand its significance. This is called a 'variant'. We may be unsure whether it is linked to your cancer and have to do more tests. In this case the genetics team will send you an appointment to discuss the results in more detail.

Do I have to have the test?

No, it is entirely your decision. If you decide not to have the test your care will continue as usual based on the information the team have about you and the cancer.

Do I have to make a decision today?

No, you can take as much time as you need. If you are still not sure we can make an appointment for you to meet with the specialist genetics team for further discussion.

If I want the test what happens next?

We will ask you to sign a consent form and a blood sample will be taken for the test.

When and how will I receive the results of the test?

The results will be sent to your cancer team and if appropriate you will receive an appointment to see the genetics team. You should know the results of the test within 12 weeks.

Who else will find out about my test result?

The test result is kept confidential under the 1998 Data Protection Act. The only people with access to your result are the health care professionals involved in your care and the trained members of staff who are involved in reporting the results of the test.

How does this affect my current or future insurance policies?

There is currently no law in the UK that prevents discrimination on the basis of genetic differences. However, there is a voluntary agreement (called the Concordat and Moratorium on Genetics and Insurance) between the Department of Health (DOH) and the Association of British Insurers (ABI). This agreement includes ten commitments from the insurers on the information they will and will not ask of their customers. For example you are not required to tell them if you have had a BRCA test or the result of the test; this applies to existing and future policies. The Moratorium is currently in place until 2019. More detailed information is available at the DOH and ABI websites listed below.

Who can I contact if I have any concerns or comments about my treatment?

We aim to provide the best possible service and staff will be happy to answer any questions that you may have. However, if your experience of our service does not meet your expectation and you would like to speak to someone other than the staff caring for you please contact the Patient Advice and Liaison Service at the Queen Elizabeth Hospital on 0800 9530667 or by emailing pals@ghnt.nhs.uk.

For further information or discussion please contact:

Macmillan Clinical Nurse Specialists in Gynae-Oncology on 0191 4452123

Dr Hughes, Consultant Medical Oncologist on 0191 4452124.

Useful websites for further information:

www.macmillan.org.uk

www.gov.uk/government/publications

www.abi.org.uk

Data Protection

Any personal information is kept confidential. There may be occasions where your information needs to be shared with other care professionals to ensure you receive the best care possible.

In order to assist us to improve the services available, your information may be used for clinical audit, research, teaching and anonymised for National NHS Reviews and Statistics.

Further information is available via Gateshead Health NHS Foundation Trust website or by contacting the Data Protection Officer by telephone on 0191 445 8418 or by email ghnt.ig.team@nhs.net.

This leaflet can be made available in other languages and formats upon request

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