BRCA Gene Testing

Gynaecology Oncology
Women & Children's Services

This leaflet has been designed to give you important information about your condition / procedure, and to answer some common queries you may have.

Introduction

This leaflet has been produced to give you general information about your blood test for BRCA (BReast CAncer). Most of your questions should be answered by this leaflet. It is not intended to replace the discussion between you and your doctor, but may act as a starting point for discussion. If after reading it you have any concerns or require further explanation, please discuss this with a member of the healthcare team caring for you.

What is a BRCA gene testing?

In most people cancer occurs by chance. In a minority of people with ovarian cancer (approximately 15%) or breast cancer (approximately 3%), cancer occurs because they have a mutation in the BRCA1 or BRCA2 gene.

BRCA1 and BRCA2 mutations result in increased risks of breast and ovarian cancer. They occur more frequently in women who have both breast and ovarian cancer, those with particular types of cancer, and if there is a strong family history of breast and / or ovarian cancer. It is important to identify if a cancer is due to a BRCA1 or BRCA2 mutation because it provides you and your doctors with information that can help treat your cancer and to reduce your risk of future cancer. It can also provide information for relatives about their risks of cancer.

Why am I being offered this test?

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

What are the benefits to me?

Knowing whether or not you carry a mutation in BRCA1 or BRCA2 gives the cancer team more information about your cancer. This can help when making decisions about the treatments recommended for you, for example which chemotherapy drugs or surgery would be most suitable. It will also give better information about your risk of developing cancer in the future.

Does having the test have implications for my family?

In most people the test will be normal and we will not find a gene mutation. This would be reassuring for relatives as it would indicate that your cancer was unlikely to be due to hereditary factors that would put them at very high risk of cancer. If your test shows you have a gene mutation, it is possible that some relatives also have the mutation. Relatives would be able to discuss this with a specialist geneticist and have a test if they chose to.

What will happen if no mutation in BRCA1 or BRCA2 is found?

This is the most likely outcome, as most women with cancer do not have a mutation in BRCA1 or BRCA2. This would be reassuring in suggesting you are unlikely to be at high risk of developing another new cancer in the future. The cancer team will be able to use this information in their management decisions. Very occasionally mutations in other genes can be involved in causing breast or ovarian cancer. New discoveries are being made all the time. If a new gene test becomes available in the future the genetics team may be able to do the test using the sample you have already provided. If your doctors think other genetic factors might be involved in your cancer they may refer you to the Genetics Service for further advice.

What will happen if the test result is unclear?

Occasionally, we find a gene change, known as a 'variant of unknown significance VUS'. This means that it is not currently known whether or not this gene change causes any increased risk of cancer. Genetic testing will not usually be offered to other family members for this gene change. However, sometimes further testing may be considered, or research studies offered, to try to find out more about the significance of such variants in the future. You will be referred to the genetics team to discuss the variant and any additional options.

Having the Test

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, which will be based on the available information.

What if I am not sure if I want to have the test?

You can still consider this in the future. If you want further information and discussion about the genetic testing, you may be referred to the genetics team.

What will happen next if I say yes?

If you decide to have the test, you will be asked to sign a consent form. A blood sample will be taken for the test.

How will I receive the results of the test?

The oncology team will inform you of the results of the test by post, or other method if agreed. The results may take up to 8 weeks to come back from the laboratory.

Will my information be confidential?

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 the hospital staff and a few trained staff reporting the results and all staff are bound by a professional duty to protect your privacy.

Should you require further advice on the issues contained in this leaflet, please do not hesitate to contact the
GYNAE-ONCOLOGY CLINICAL NURSE
SEAMAR BHULLAR
Tel 03033 305904

Useful Information

Information on Gynaecology Services at Northern Lincolnshire and Goole NHS Foundation Trust can be found at: https://www.nlg.nhs.uk/services/gynaecology/gynaecology-cancer

Yorkshire Regional Genetics Service
http://www.pathology.leedsth.nhs.uk:pathology/Departments/Genetics.aspx

Department of Clinical Genetics,
Ward 10, 3rd Floor,
Chapel Allerton Hospital
Chapeltown Road,
LEEDS LS7 4SA
Tel: 0113 392 4432 Fax: 0113 392 4434

Information about You

We collect and use your information to provide you with care and treatment. As part of your care, your information will be shared between members of the healthcare team, some of whom you may not meet. Your information may also be used to help train staff, to check the quality of our care, to manage and plan the health service and to help with research. Wherever possible we use anonymous data.

We may pass on relevant information to other health organisations that provide you with care. All information is treated as strictly confidential and is not given to anyone who does not need it. If you have any concerns please ask your doctor, or the person caring for you.

Under the Data Protection Act (1998) we are responsible for maintaining the confidentiality of any information we hold about you. For further information visit:
https://www.nlg.nhs.uk/patients/privacy-dignity

Patient Advice and Liaison Service (PALS)

The Patient Advice and Liaison Service offers confidential advice, support and information on any health related matters.

If you have a comment, concern, complaint or compliment about the care or service you have received from the Trust you can contact the PALS team as follows:

Telephone: 03033 306518

Email: nlg-tr.PALS@nhs.net

There are also offices at both the Diana Princess of Wales Hospital (near the main entrance) and Scunthorpe General Hospital (on the C Floor, near the outpatient department), should you wish to visit.

Please note: PALS should not be contacted for clinical advice relating to the content of this leaflet. The service should be contacted directly in the first instance.

Northern Lincolnshire and Goole NHS Foundation Trust

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Woodland Avenue
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