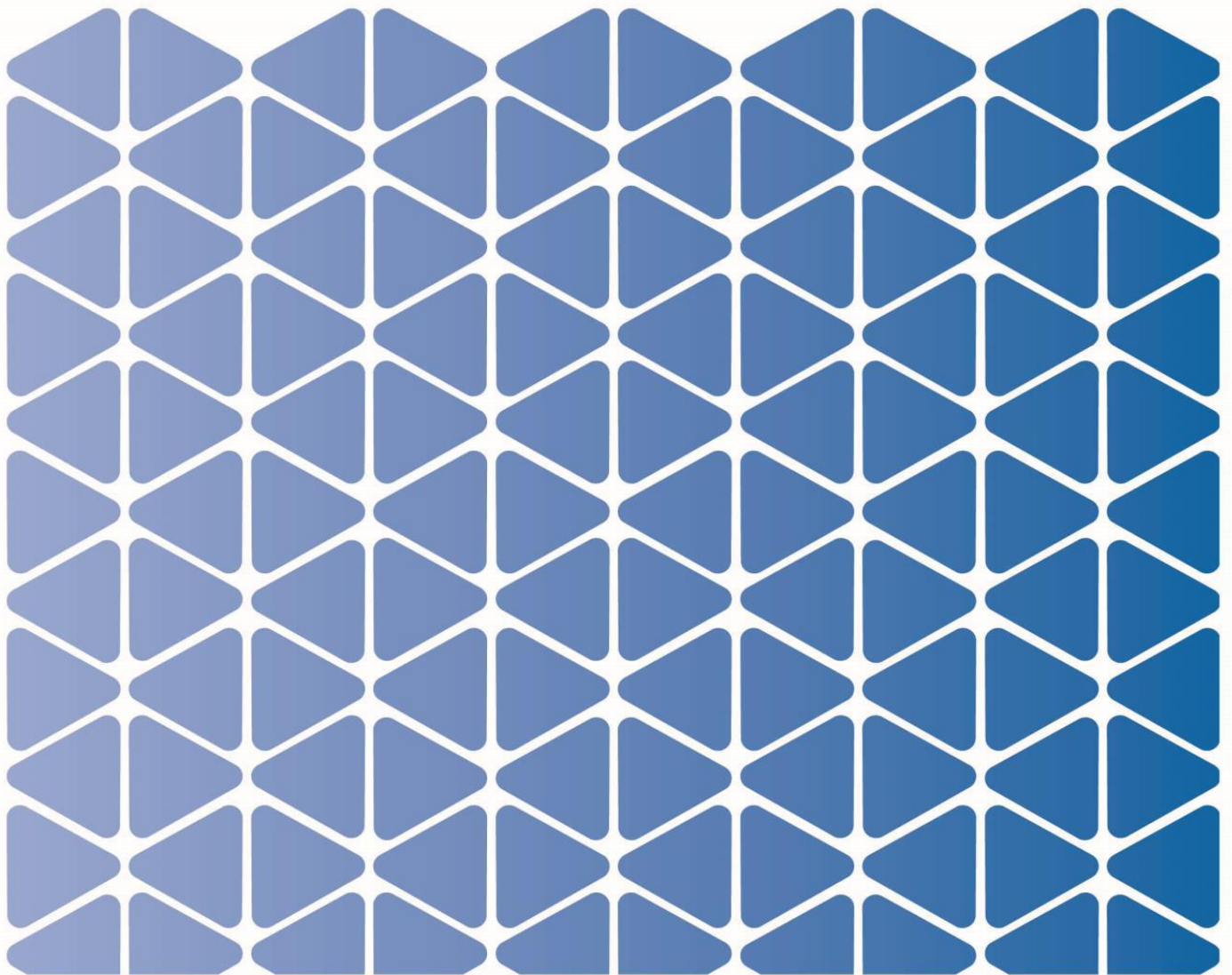


PATIENT INFORMATION

Gynaecology Oncology

**GENETIC TESTING FOR HEREDITARY
BREAST AND OVARIAN CANCER**



Gynaecology Oncology

Genetic Testing for Hereditary Breast and Ovarian Cancer

Information for people having genetic testing through Oncology or Surgical teams.

Why am I being offered genetic testing?

The type of cancer you have is sometimes associated with a genetic link to breast and/or ovarian cancer.

What does genetic testing involve?

A blood sample is needed to look for changes in the known breast and ovarian cancer genes. This now includes a 'panel' of genes linked to your type of cancer.

We all have two copies of each gene, one copy inherited from each parent. The genes usually help to protect against cancer, but if someone has certain changes in one of these genes, their risk of cancer may be increased.

Which genes would be tested?

Ovarian cancer patients: Nine genes in total are tested, including;

BRCA1, BRCA2, PALB2, RAD51C and RAD51D. Each of these genes are also linked to breast cancer risk in families.

MLH1, MHS2 and MSH6; problems with these genes can cause a condition called Lynch Syndrome, which also increases the risk of colorectal cancer, uterine cancer and sometimes other forms of cancer. Regular bowel screening is advised for those with Lynch Syndrome.

BRIP1; this gene is currently thought to be linked solely to increased ovarian cancer risk, mainly in post-menopausal women.

Breast cancer patients: Five genes in total are tested, including; BRCA1, BRCA2 and PALB2. These genes are linked to high risk of breast, ovarian and prostate cancer.

ATM and CHEK2 genes are associated with more modestly increased breast cancer risk. Risk management is reviewed on a case by case basis by clinical genetics

Should I have genetic testing?

Knowing that your cancer was caused by a gene alteration may change your cancer treatment. It could also tell you whether you have a higher risk of other cancers and this might help to decide about options to manage those risks. Knowing that there is an inherited link to increase cancer risk might also be useful for your relatives.

This information can be difficult to process during cancer treatment. If you feel that it would be difficult for you and your family to know that your cancer was due to a genetic problem you can decide not to have genetic testing now, but you could still choose to have this test later.

What would it mean for me if I carried a gene alteration?

Ovarian cancer patients: Some drug treatments work better for individuals with gene changes for example changes within BRCA1 & BRCA2. Most of these drugs are included in your standard treatment. Your oncologist may also be involved in research projects to trial new drugs that target gene changes.

Breast cancer patients: Carrying a gene alteration increases your risk of developing other breast cancers, some genes are also linked to ovarian cancer risk. This means that you will need screening for other cancers or you may be given options to reduce the cancer risks (such as extra surgery). Your surgeon will be able to discuss the options available to you.

What would it mean for my family if my test showed a gene alteration?

If a gene change is identified your relatives might also have inherited it. They could choose to have a test to see if they carry the same change. This could help them to make decisions about their own screening and possible measures to reduce their risk of cancer.

Sometimes, it can be difficult to deal with this information. It is important that any relatives considering genetic testing discuss this with a genetic counsellor or genetics Doctor first. Their GP can arrange for them to be referred.

What could the test results show?

1. The test might show an alteration in a gene which clearly stops that gene from working. This would explain the reason for your cancer.
2. The test might show no gene alterations making it less likely that your cancer was caused by an inherited gene problem.

3. Some alterations in genes are smaller and may not affect the way the gene works. Current genetic knowledge suggests these small changes are probably not related to your cancer.

What happens next?

If you decide to have genetic testing a blood sample will be taken and your DNA extracted and tested for gene alterations. Your oncologist or surgeon will let you know when these results are available.

Results are usually available in about 4-6 weeks.

If your result shows that you carry a gene alteration your oncologist or surgeon will refer you to the clinical genetics team to discuss what this means for you in more detail. All the teams involved in your care can help to support you and your relatives in dealing with this result.

If you are unsure whether to have the test it might be helpful to provide a blood sample before your treatment starts. Your DNA can be extracted and stored ready for testing, if and when you give consent.

Genetic testing and insurance

The current agreement with the Association of British Insurers is that the results of a genetic test on an individual with a cancer diagnosis CAN be taken into account when quoting for life insurance, critical illness or income protection policies. If a gene alteration is found through your testing and a 'predictive' test is then offered to your relatives. Insurers would NOT be allowed to ask about the results of these further tests on relatives.

More info on Genetics and Insurance:

<https://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/code-on-genetic-testing-and-insurance/>

Where do I go if I have more questions?

If you have any questions about genetic testing you can talk to your oncologist, surgeon or specialist nurse.

The Specialist Nurses can be contacted by phone or email Tel: 01905 733257

wah-tr.gynaecancercns@nhs.net

If you are still finding it difficult to decide about genetic testing one of the genetic counsellors at the West Midlands Clinical Genetics department can help by talking to

you about whether this is the right decision for you — call them directly on: 0121 335 8024

Where can I get further information?

There is a support group for hereditary breast and ovarian cancer.

breastcancerogenetics.co.uk

Hereditary Breast Cancer Helpline: 01629 813000

Some information about cancer can be found on the following websites:

<http://www.cancerresearchuk.org/>

<http://www.macmillan.org.uk>

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.