Genetic testing after a diagnosis of breast cancer

Patient information and consent form

You have been offered a genetic test to see if the breast cancer you have been diagnosed with has been caused by an alteration in one of your genes.

Background

Genes act as instructions that tell the body to make or do something. We inherit genes from our parents and sometimes they have an error (this is sometimes called a pathogenic variant, mutation, or alteration) that can be passed to us and increase our risk of diseases, such as cancer.

The test that you have been offered is a called panel test; it looks at a number of genes. The genes called BRCA1, BRCA2, PALB2, CHEK2, ATM, RAD51C and RAD51D are all included in this test. This list of genes may grow over time. We all carry these genes and they help to protect us from developing certain cancers. If there is an alteration in one or more of these genes some of that protection is lost and cancer risks may be higher than average. The exact risk depends on which gene is involved, as well as the age, gender and lifestyle of the person.

Why am I being offered a genetic test?

You are being offered genetic testing as you meet the eligibility criteria. This may be due to the details of your breast cancer such as your age or type of tumour, or may also be due to other cancer in your family.

Being eligible for this genetic test usually means there is at least a 1 in 10 (10%) chance that your cancer happened because of an inherited risk caused by an alteration in a cancer gene. Being eligible for the test does not mean you have an inherited risk of cancer. About 9 out of 10 people tested receive a normal result, meaning no gene alterations have been found.

What could the test results show?

Testing may find an alteration in a cancer gene. This may be a reason why you developed breast cancer. This result may alter your cancer treatment or surgical plans. This result may mean you have a higher chance of developing a new breast cancer in the future and/or other cancers for example ovarian cancer. The exact gene alteration will affect the future cancer risks.

You should be referred to the Genomic Medicine Service where you can discuss the result in more detail, including information about future cancer risks, screening or risk reduction options as well as discussing how you can share the results with family members to help them access the right care including the possibility of having genetic testing themselves.

Testing may not find an alteration in any of the tested genes. If testing does not find an alteration in any of the genes then no inherited explanation for your cancer has been found. There could still be an inherited cause for your cancer but it is now less likely. In rare situations a result like this is reclassified in the future, if new information causes the results to be reinterpreted. A new report would be issued to your doctor if this happens.

If you have a very strong family history of cancer or an unusual pattern of cancer diagnoses in the family then your breast team may still refer you to the Genomic Medicine Service for a review of whether other genetic tests are possible. Families with a close relative with young breast cancer may still require early breast screening. This can be reviewed in a breast cancer family history clinic.

What does the test involve?

If you decide to have the test, a blood sample will be taken from a vein in your arm or from your PICC line. Genetic testing will happen in the laboratory where your DNA will also be stored. The results will take about 6-8 weeks and the team who arranged the test will inform you once the results are available. Please get in touch with them if you are not informed about the results when expected.

What are the possible benefits of having the test?

If a genetic alteration is found:

- the result could alter your cancer treatment
- it may allow other relatives to access 'predictive' genetic testing to guide their cancer screening and risk management options
- it may help you understand why breast cancer occurred
- it may guide your future screening for new cancer risk

If no gene alterations are found:

- this can be a relief for some people as it reduces the chance that strong inherited risk was involved
- It can guide the risk assessment/screening recommendations for other relatives

What are the possible negatives of having the test?

If a gene alteration is found:

- it may cause worry or concern about your own future cancer risk
- it may cause worry or concern about family members
- it may affect any new life insurance or critical illness policies you take out in the future. See the Association of British Insurers (www.abi.org.uk) for more information

If no gene alterations are found:

- no genetic testing is likely to be possible for close relatives (unless they are also eligible based on a cancer diagnosis in them)
- you may feel worried about why cancer occurred in you

Do I have to have a genetic test for inherited breast cancer risks?

No. Some people decide that having information regarding a possible genetic cause for their breast cancer is not helpful at this point. You do not have to have genetic testing and can still receive treatment and care. Genetic testing is offered now as in some cases the results could alter cancer treatment. If you are unsure about testing you can decide to have your DNA stored for possible future use or may wish to consider the offer of genetic testing in the future.

Consent

- I agree to have a panel test looking for alterations in a number of genes linked to inherited breast cancer risk including BRCA1, BRCA2, PALB2, ATM, CHEK2, RAD51C and RAD51D.
- I understand that this test is not intended to diagnose whether I have or will get a cancer in the future. It is intended to tell me about my inherited genetic risk.
- I understand I will have the opportunity to discuss the test, its results and consequences in more detail.
- I understand my sample will be stored for possible future testing.
- I understand that my result and/or sample may be shared with health care professionals across the UK to help interpret genetic results and clarify the risks for others including other family members.

Optional signed consent:

Signed (patient) _____

Name (PRINT) _____

Date _____

Signed (clinician) _____

Name (PRINT) _____

Date _____

Alternatively verbal consent can be taken by the clinician and detailed in the records

Verbal consent taken by

Clinician (PRINT) _____

Date _____