The ROYAL MARSDEN
NHS Foundation Trust

Patient information

Genetic testing for hereditary ovarian cancer (R207)

Information sheet for patients with ovarian cancer

In most people, cancer occurs by chance. Approximately 10% of ovarian cancers are hereditary and due to a harmful change (mutation) in a gene that normally works to protect against cancer. It is important to identify patients who have hereditary ovarian cancer.

Why am I being offered this test?

You are being offered a test to look for harmful changes in *BRCA1*, *BRCA2, PALB2, MLH1, MSH2, MSH6, BRIP1, RAD51C, and RAD51D* because of your ovarian cancer diagnosis. Individuals with a harmful change in *BRCA1*, *BRCA2* or *PALB2* have an increased risk of developing breast and ovarian cancer, and slightly increased risk of other cancers, compared to the general population. Individuals with a harmful change in *MLH1, MSH2, and MSH6* have an increased risk of developing colon, endometrial and ovarian cancers cancer as well as a slightly increased risk of other cancers. Individuals with a harmful change in BRIP1, RAD51C and RAD51D are at moderately increased risk of ovarian cancer

What are the benefits?

Knowing whether you carry a harmful change in an ovarian cancer gene gives the cancer team more information about your cancer. This information can be used when making decisions about the treatments they recommend for you, for example, which chemotherapy drugs or surgery would be most suitable. It will also give information about your risk of developing cancer in the future and how to best manage and potentially reduce these risks.

What if no harmful changes are found?

This is the most likely outcome, as most women with ovarian cancer develop it by chance. This result would be reassuring as you are unlikely to be at increased risk of developing another, new cancer in the future. Your family members are unlikely be at increased risk of developing cancer. However, if you have a significant family history of cancer in addition to your own diagnosis the treating team can refer you to the genetics team for an assessment. Your treating team will consider this information in their management decisions.

What will happen if a harmful change is found?

Your cancer team will use the result to guide treatment decisions. The genetics team will see you to explain what the test result means for your future 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 the family members, so they can access genetic services either at The Royal Marsden or their local genetics centre.

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What implications does this test have for my family?

As most cancer happens by chance, it is unlikely a harmful change will be found. If no harmful change is found this would be reassuring for relatives, as it would indicate that your cancer was unlikely to be due to hereditary factors, which would put them at increased risk of cancer. If your test shows you have a harmful change, it is possible that some relatives will also have the same harmful change. Relatives who are found to carry the harmful change will be offered personalised risk management programme.

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 that I want to have the test?

We would recommend that you have further discussions with 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 record of discussion form. A blood sample will be taken for the test and sent to genetics laboratory for analysis.

How will I receive the results of the test?

The genetics team will send you and your cancer team the results of the test by post. The results are reported in six to eight weeks.

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 staff at The Royal Marsden and a few trained staff reporting the results, who are bound by a professional duty to protect your privacy.

Good to know

- You are welcome to contact the genetics team on 020 8661 3375 if you have further questions or can ask your treating team to refer you for an appointment.
- The result of your genetic test may affect any new life insurance or critical illness polices that you take out. For more information, please refer to the Association of British Insurers (www.abi.org.uk) or to our Insurance information leaflet in the Patient Information Library on the Royal Marsden website (www.royalmarsden.nhs.uk)