



Genetic testing after cancer diagnosis

Information for patients with cancer

Why am I being offered these tests?

You have been offered genetic testing because you have cancer. The aim of these tests is to give you information that will help you.

There are two main types of genetic testing being offered to you:

1. Testing your cancer cells. This is normally done on the sample we took during your diagnosis. This is called 'somatic testing' or 'tumour testing'.
2. Testing your blood or saliva to find out whether you were born with a higher chance of getting cancer than most other people. This is called 'germline testing'. This test may give information that could affect your family.

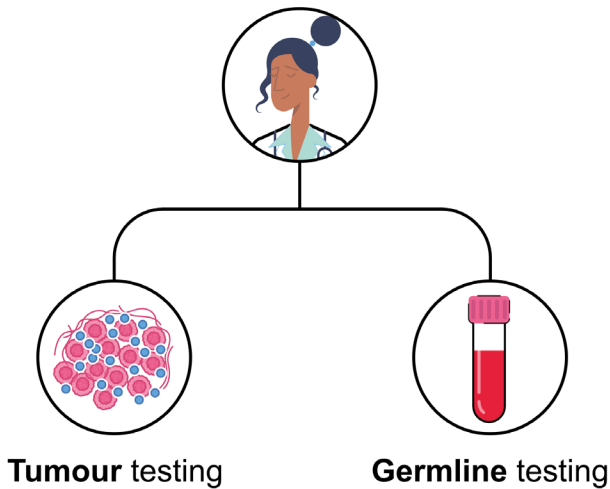


Figure 1: The two kinds of tests offered

How could these tests help me?

The first kind of genetic test (tumour testing) is done on your cancer cells. This test could help find out what treatments are likely to work well for you.

The second type of genetic test (germline testing) is done on normal cells from your blood or saliva. This test could help both you and your family:

- For you: It would tell you whether you are more likely to develop another cancer in the future. If so, your medical team can help you reduce the chance of getting cancer again. The test will also tell your doctor more about your cancer and what treatments they should give you.
- For your family: If the test shows you were born with a high chance of getting cancer, then some of your relatives might have the same high chance. They won't know if this is the case unless they get tested too. If they do have the same high chance of getting cancer, they can also be offered help and support.

Do I have to take the tests now?

No. You can choose if you want to be tested. You can decide later if you don't feel ready to make a decision right now.

What will happen next if I say yes?

For genetic testing of your cancer cells (the first kind of test), you only need to say that you agree to the test. We will then send your cancer sample for testing. We normally use the sample we took during your diagnosis. We are unlikely to need another sample. For genetic testing of your normal cells of your blood or saliva (the second kind of test), you will be asked to sign a consent form. A blood or saliva sample will be taken for the test.

How will I receive the results of the test(s)?

For genetic testing of your cancer cells, your doctor will tell you at your next appointment.

For genetic testing of your normal cells, in your blood or saliva, your cancer team will contact you about the results when they arrive, which may take up to six weeks.

What are the possible results?

Results from testing your cancer cells



The results from your cancer cells might show which treatments are best for you. This information might not be useful right now, but it could help in the future if you need extra treatment, or if your cancer comes back.

The results from genetic testing of your cancer cells might also give clues as to whether you were born with a higher chance of developing cancer than other people. But it is not possible to know this for sure just from testing your cancer cells. This is why you were also asked for a blood or saliva sample.

Results from testing your normal cells (blood or saliva sample)



"Negative test" or "Gene change not present"

This means the test did not show that you or your family were born with a higher chance of getting cancer than other people.

"Positive test" or "Gene change present"

This means that you were born with a higher chance of getting cancer. This might be one of the reasons why you have cancer now. It might also mean that some of your family were born with a higher chance of getting cancer.

You will be offered an appointment with an expert to talk about how this might affect you and your family.

Uncertain results or no result

Sometimes we are not sure what the test results mean. Occasionally, we don't get a result at all. If this happens, you may be offered repeat and/or further tests to find out more.

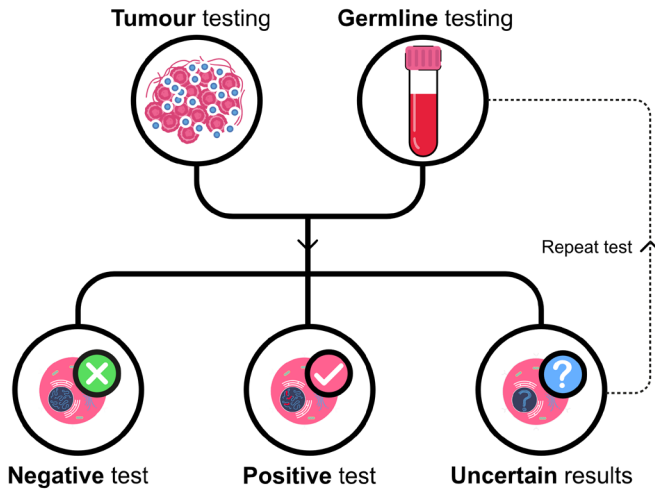


Figure 2: A summary of possible test results

What will happen if the result from my normal cells is negative?

A negative test will still help your medical team to decide on the best treatment for you. It also means that your risk of getting another cancer in the future is no higher than most other people.

If the test comes back negative, you might wonder why you have cancer now. The reason is usually that your cancer has been caused by natural wear and tear that has built up in your body as you have got older. This wear and tear happens in all of us, and it is why cancer is more common in older people.

What will happen if the result from my normal cells is positive?

If the results show you were born with a high chance of getting cancer, we will make sure you receive extra support and information. You will be seen by an expert to provide you with information and guidance about how to reduce the chance of getting cancer again in the future. You may be offered check-ups to spot any further cancer early. We will also explain what the results mean for your family and what can be done for them too.

Does having the test(s) have implications for my family?

Genetic testing can make people worried about what it will find, and they are scared that it will affect their family.

However, most test results come back negative. That means we didn't find anything to show that cancer runs in their family. This means the person who has cancer can reassure their family.

Sometimes the tests show the family has a higher chance of getting cancers. This does not mean that every family member is affected. Each person would need their own test to find out. We can help people reduce their chance of getting cancer. Sometimes we can offer check-ups and treatments to help people reduce the chance of getting cancer or pick it up early and treat it quickly.

We can also offer support to help people come to terms with the information.

Do I need to tell my family that I am being tested?

No, you do not have to tell them you are having the test. It is up to you whether you share the result with them. We will support you in deciding whether you want to tell them or not.

What if I am not sure about being tested?

You can talk to a member of our team and take time to make up your mind. We can also refer you to the genetics team to talk about the tests, but this may take some time to arrange.

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. Only your care team and trained staff in the laboratory carrying out your genetic tests will know your identity.

How will the leftover samples be kept?

Any remaining samples may be stored in the laboratory. They may be used to repeat the tests or for further tests if needed.

Further information

You can find out more about cancer and genetic testing here:

- **Macmillan Cancer Support:** Family history, genetics and cancer risk: <https://bit.ly/3A0K08C> (Website checked 21st November 2022)
- **Ovacome:** Testing for BRCA gene changes: <https://bit.ly/3DSkuDO> (Website checked 21st November 2022)
- **Target Ovarian Cancer:** Hereditary ovarian cancer: <https://bit.ly/3A44TjA> (Website checked 21st November 2022)

Ovacome is a national charity that focuses on providing support and information to anyone affected by ovarian cancer. They run a number of support lines in English and other languages.

- English: 0800 008 7054 (Monday-Friday; 10am-5pm)
- Other languages (you will be greeted by a voicemail and asked to leave a message before a member of Ovacome support team returns your call with an interpreter):
 - Arabic: 0121 647 6630
 - Bengali: 0121 647 6631
 - Gujarati: 0121 647 6632
 - Polish: 0121 647 6633
 - Punjabi: 0121 647 6634
 - Urdu: 0121 647 6635

We have produced a set of videos to explain genetic testing for you. You can access this via this link: <https://ovarian.org.uk/demo-uk/>, or use the QR code.



Contact details

If you have any questions, please contact your clinical team.

This leaflet has been produced by Sandwell and West Birmingham NHS Trust in conjunction with the Cancer Research UK Cambridge Centre. To reproduce any part of this leaflet please contact elaine.leung@nhs.net.



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