

Oxford Regional Genetic Department

Diagnostic Genetic Testing

Information for people
who have a personal and
family history of cancer



What is involved in genetic testing?

After you have had a chance to discuss what genetic testing means for you, you may decide to give a blood sample. We will ask you to sign a consent form and we will take a small blood sample from you (about two teaspoons full).

The laboratory team will then search through the relevant genes in your blood sample to see if the code in these genes is different from what we would usually see.

What happens if I decide to be tested?

A genetic test involves taking a small sample of blood. We would look at your sample to see if we can find an alteration in one of the genes which is linked with inherited cancer. Such an alteration may explain the cancer in your family.

If we find that you have an altered gene, other members of your family can be tested to see if they have inherited the same altered gene as you.

If there is only a small chance that you have an altered gene, we may not test your sample now but suggest that we store a sample of your blood to test in the future when our understanding of the causes of cancer improves.

When will you hear from us?

Looking for alterations in genes can take quite a long time as they may be hard to find.

We will contact you when we have finished our analysis, usually within 3 months.

The result is confidential to you. However, we would discuss with you how the information could help other members of your family to make decisions about the best way to manage their risk of cancer.

What do the results mean if an altered gene is found in your sample?

For you

It would confirm that your cancer was probably due to an altered gene that has been passed down to you from one of your parents. You may be at an increased risk of getting a second cancer so we will talk to you about the best ways to reduce any risks. Some people find it helpful to know why they got their cancer. Some may feel guilty about possibly passing it on to their children. This is a very normal response and support is available from our genetic counsellors to help you deal with these feelings.

For your family

If you have any children each of them would have a 50% (1 in 2) chance of inheriting the altered gene from you. Your brothers and sisters would have the same 50% chance of having the altered gene. We would be able to offer testing to other members of your family to see whether or not they have inherited the same genetic alteration as you.

Having an altered gene does not mean you will get cancer, but the risks may be high. Therefore we will talk to you about the best ways to manage the risks.

What do the results mean if an altered gene is not found in your sample?

For you

Unfortunately, if we do not find an altered gene in your blood sample, we cannot give you a definite answer about whether or not your cancer is inherited. There are three reasons why we do not find gene alterations:

1. Your cancer may not have been inherited;
2. You may have an alteration in another cancer gene that has not been discovered yet;
3. You may have an alteration in one of the genes that we tested, but we have been unable to find the alteration.

We would store your sample unless you ask us not to. This is because if in the future we discover more cancer genes, we may be able to carry out further tests on your blood sample.

For your family

Even if we do not find an altered gene in your sample other members of your family may still be at an increased risk of getting cancer. We would not be able to offer them genetic testing because we have not found the underlying genetic cause in the family for the cancer, meaning no test would be available for unaffected relatives.

It would be important for them to continue with any screening that has been arranged for them.

What can be done to detect cancer early?

Screening

If you have had cancer and are still seeing a specialist, if necessary, he or she will help you to decide how often you should be screened.

If you are no longer seeing a specialist but there is a chance that your cancer could have been inherited, we will be able to help to arrange regular screening for you if this is necessary.

Awareness

It is important to know what is normal for you and if you notice any unusual symptoms to report them to your GP or specialist promptly.

What can be done to reduce cancer risk?

In some cases surgery may be an option to reduce the risk of cancer. If appropriate, we would discuss this option with you and refer to you to a specialist surgeon.

There is evidence that leading a healthy lifestyle can help to reduce the risk of cancer. In particular, a balanced diet rich in fruit and vegetables, combined with regular exercise is recommended.

Not smoking and reducing alcohol is a good idea, in line with general health advice.

How can you help?

There is still much we do not know about the genetics of familial cancer. There may be research studies which you could take part in to help with our understanding of inherited disease and in the early detection of cancer.

Please ask your genetic professional for information if this is something you are interested in.

Where can I get further information?

Some information about cancer can be found on the following websites. You may wish to wait until after your appointment so that we can direct you to information most appropriate to you.

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

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

If you need more advice please contact:

Oxford Cancer Genetics Service

Department of Clinical Genetics

Churchill Hospital

Old Road

Headington

Oxford

OX3 7LE

Telephone: **01865 226 034**

Fax: **01865 223 572**

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473** or email **PALSJR@ouh.nhs.uk**

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