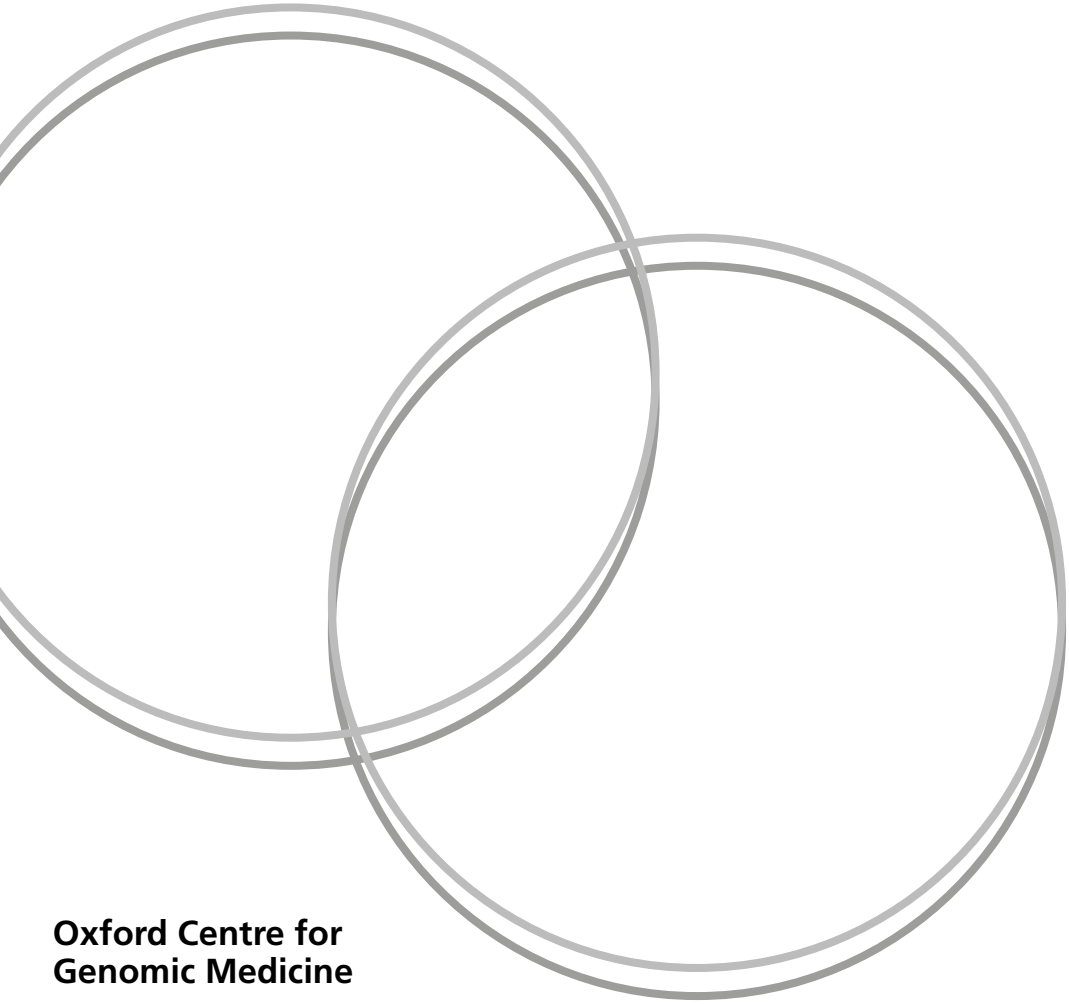
Oxford University Hospitals
NHS Foundation Trust

Predictive Genetic Testing

Information for people with a family history of cancer who have not had cancer themselves



Oxford Centre for
Genomic Medicine

What can we do at the Family Cancer Clinic?

From a family history, we can estimate how likely it is that there is an inherited chance of developing cancer in a family.

We can also estimate your chance of getting these cancers during your lifetime and talk to you about your options for screening and reducing your risk. In some families we can offer genetic testing which can help to clarify the chance of developing cancer.

Who can have a genetic test?

If there is a strong chance that there is an inherited risk of cancer in your family we may have talked to you about genetic testing.

Before we can think about testing you, we first need to look at the genes in a blood sample from your relative who has had

cancer. This is usually carried out after a full discussion about the implications of the testing. Testing an affected family member increases our chances of finding a gene alteration, if there is one there.

Depending on the result of this testing it may be possible to offer a genetic test to you.

In some families there is a low chance of finding a genetic alteration. We may have talked to you about storing a blood sample from your relative who has had cancer for possible testing at some time in the future, when our understanding of the causes of cancer improves.

How does genetic testing affect the family?

Having a genetic test can raise a number of psychological issues both for relatives who have not had cancer and for those who have had cancer.

It is therefore important for anyone considering genetic testing to have an opportunity to talk through the issues in order to help them to decide what they want to do.

What needs to happen before you can have a genetic test?

You would need to approach your relative who has had cancer to see if they would consider giving a blood sample for genetic testing.

This is not always an easy question to ask and it is up to your relative to decide whether to give us the blood sample or not.

Before genetic testing can go ahead it is important for us to discuss with your relative what it means for them and for the family. If they do not live in this region, we could arrange for them to see a genetics professional in another centre.

If your relative decides to go ahead, they could give the blood sample when they are seen in the clinic. Alternatively, we may be able to send them a kit to have their blood taken by their GP.

The laboratory team will look for alterations in the genes that are known to cause cancer in your relative's blood sample. We will contact your relative with the result when it becomes available. It may take 2 months before we have the result.

Any result will be confidential to your relative. It would be up to them to decide who they wish to share the information with.

What would it mean for you if we do not find an altered gene in your relative's sample?

This would mean that we could not offer genetic testing to you at the moment.

There are three reasons why we do not find gene alterations:

1. The cancer may not have been inherited;
2. There may be an alteration in another cancer gene that has not been discovered yet;
3. There may be an alteration in one of the genes that we tested, but we have not been able to find it.

This would mean that you are still at an increased risk of cancer. It would still be important for you to continue with any screening that has been set up for you.

We would store your relative's sample unless asked not to. This is because, if in the future we discover more cancer genes, we may be able to carry out further tests on the sample.

What would it mean for you if we do find an altered gene in your relative's sample?

This would mean that you could be tested to see if you have inherited the same altered gene.

Before you have a genetic test we would offer you the opportunity to come to a clinic appointment. We would discuss what genetic testing could mean for you and how you might be affected if you were found to have the altered gene. It is important to fully explore the pros and cons of testing to make sure that it is the right thing for you to do.

We would suggest you take some time to think about this and offer you another appointment if this is helpful for you. At the end of your appointment we could take a blood sample from you, if you still wish to go ahead.

Although at the moment there would not usually be insurance implications from genetic testing this may change in the future. This would be discussed with you during your genetic appointment.

We may ask you to come back to the clinic for your result four weeks later. Some people prefer to receive their result by phone or by letter. After the result, we would be happy to see you again, if helpful, and we could also arrange further support for you if necessary.

What would a genetic test tell you

A genetic test would tell you if you have inherited the altered gene or not. It would help to clarify your risks of developing cancer.

What does it mean if you are tested and find that you have inherited an altered gene?

This would mean that your chance of developing cancer during your lifetime would be significantly increased. Each of your children (if you have any) would have a 1 in 2 chance of inheriting the altered gene from you.

What does it mean if you are tested and you have not in-herited an altered gene?

As long as there is no cancer in the other side of your family, your risk of getting cancer during your lifetime would be similar to other people in the population. Your children would not be at an increased risk.

What can be done to detect cancer early or prevent the disease?

Screening

We will arrange for you to see a specialist who will advise you on how often you should be screened, if this is necessary. You may need to see more than one specialist.

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.

Risk reduction surgery

Some people may choose to have surgery to remove healthy tissue before cancer develops. Surgery does not completely remove the chance of developing cancer, although the risk of cancer is greatly reduced.

Further Information

Website: **http://www.macmillan.org.uk/Home.aspx**

Website: **http://www.cancerresearchuk.org/**

If you need more advice please contact:

Oxford Cancer Genetics Service

Oxford Centre for Genomic Medicine
ACE building (Room 33G16)
Nuffield Orthopaedic Centre
Oxford University Hospitals NHS Foundation Trust
Windmill Road
Headington
Oxford OX3 7HE

Tel: **01865 226 034**

Email: **orh-tr.churchill-clinicalgenetics@nhs.net**

Website: **http://www.ouh.nhs.uk/clinical-genetics**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

This leaflet is based, with permission, on a leaflet produced by the West Midlands Regional Genetic Service.

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