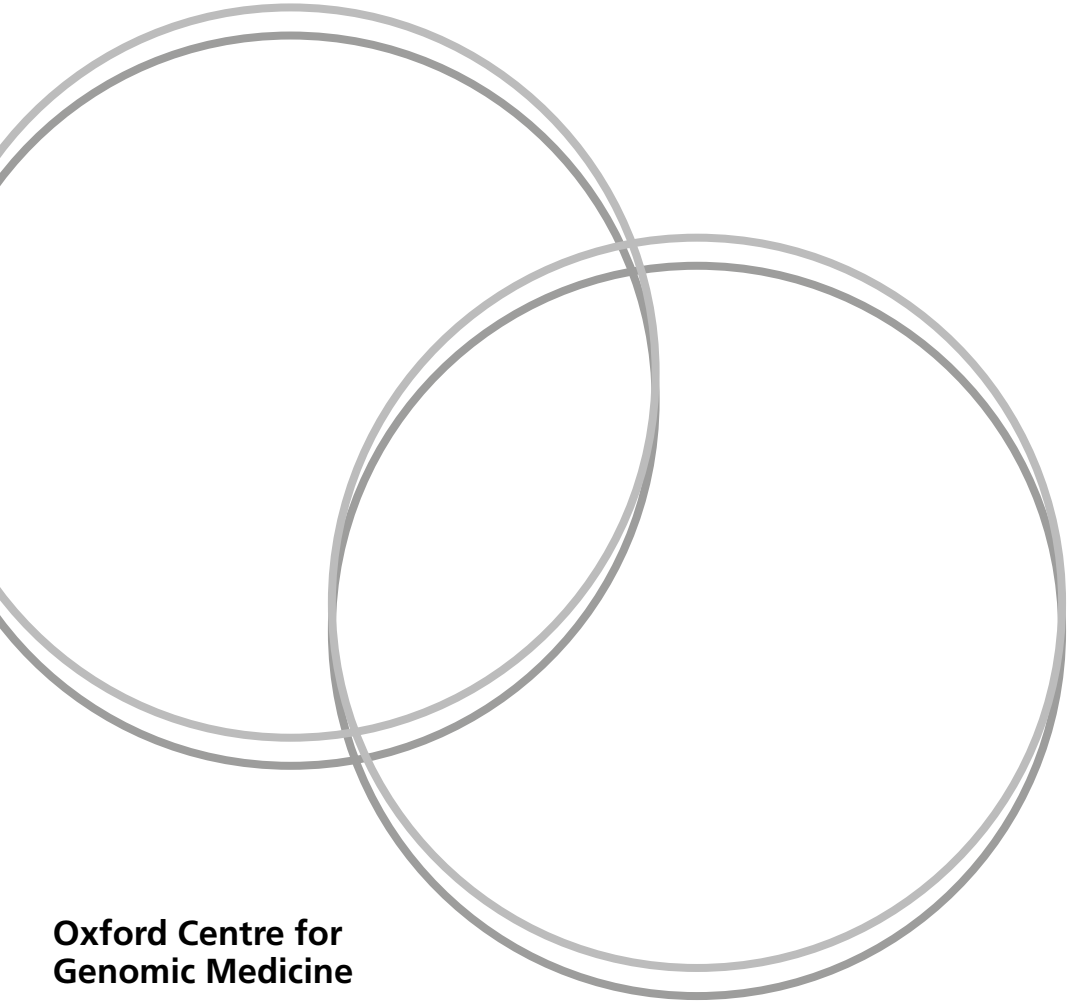
NHS
Oxford University Hospitals
NHS Foundation Trust

Cancer Tissue Studies

Information for individuals with a family history of cancer



Oxford Centre for
Genomic Medicine

Introduction

You, or your family member, have been referred to the Oxford Centre for Genomic Medicine because of your family history of cancer. We have suggested some further studies on cancer tissue samples either from you (if you have been affected by cancer) or from one of your family members. This leaflet explains more about this.

What are tissue studies?

Tissue studies are tests on samples of a cancer. These tests will allow us to give the best advice about the family history and the risks to family members. They can also help to identify the cancers which are more likely to be inherited. The results can help us recognise families where genetic testing may be useful.

Where does the tissue come from?

When someone has cancer removed or a biopsy (a small tissue sample used to help make a diagnosis) taken, small samples of the tissue are stored at the hospital. These samples can be useful if more tests are needed to help plan treatment. The samples are often kept for many years. We can ask the hospital to send some tissue samples to us to test. The tests are more likely to give results from cancer samples than on biopsies. Occasionally no tissue will be available at all.

What tests will be done?

There are two tests that can be done. They are called Immunohistochemistry (IHC) and Microsatellite Instability (MSI) testing.

What are the tests looking for?

The tests are looking for signs of an inherited cancer condition called Lynch syndrome. In families with Lynch syndrome there are usually several individuals with bowel, womb or other related cancers such as cancer of the stomach or ovary.

Lynch syndrome is caused by an alteration in one of a group of genes called *mismatch repair (or MMR)* genes. The two tests both look to see if these genes are working properly.

1. **IHC:**

   This test dyes the cancer cells. The dyes stick to the material produced by the Lynch syndrome genes. If one of the Lynch syndrome genes is not working no material will be produced and the dye will not stick.

2. **MSI:**

   This test looks at the DNA in the cancer cells to see if it is being repaired properly. If there are lots of mistakes in the DNA we know that the mismatch repair genes aren't working correctly.

What happens next?

If the MSI and IHC tests are normal it is much less likely that the cancers in the family are due to Lynch syndrome. They may be due to chance and not be inherited. Sometimes they may be due to another inherited cancer condition.

If the MSI and IHC tests show one of the genes are not working it is much more likely that the cancers in the family are due to Lynch syndrome. We may suggest some extra screening for you and your relatives. We may also be able to do further tests to try and find the exact gene alteration in the family.

What about the results?

The tests are complicated and the results can take up to a year. We will contact the person who has consented to the tests to give them the results. We will also update our advice about screening and whether any further testing could be useful.

Someone from the genetics team will contact you to discuss this further, if appropriate.

What if no tissue is available?

Sometimes we cannot get a tissue sample. However, it may be possible to get one from another relative who has had a related cancer. If we cannot get tissue from any relatives, we will give advice based on the information we already have.

What do I need to do?

To go ahead with these tissue studies we need permission from the individual who has had cancer. If this individual has passed away, a relative can give permission on their behalf. If they passed away after September 2006, the highest living person on the list below must give permission.

1. Legally nominated representative
2. Spouse or partner
3. Parent or child
4. Brother or sister
5. Grandparent or grandchild
6. Child of brother or sister
7. Stepfather or stepmother
8. Half brother or half sister
9. Friend of longstanding

If you want us to go ahead with these tissue tests, you need to complete and return the appropriate consent form. If you do not have one of these consent forms and would like one, please contact the department.

If you do not want us to go ahead with the tests please let us know so we can provide advice based on the family history you have given without delay.

Further information

Lynch Syndrome leaflet

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

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

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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