

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, then a legally nominated representative may provide consent (i.e. next of kin).

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 us. To discuss any aspect of testing further, please do not hesitate to contact us. 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.

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Cancer Tissue Studies



An information leaflet
for individuals with
a personal and/or
family history of cancer



ST. JAMES'S
HOSPITAL

Introduction

You, or your family member, have been referred to the Cancer Genetics Service 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 to recognise families where genetic testing may be useful.

Where does the tissue come from?

When someone has a cancer removed, or biopsy 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 on 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. Mostly, we only need to do the IHC test but sometimes we also do the MSI test.

What are the tests looking for ?

The tests are looking for signs of an inherited cancer condition called Lynch syndrome. Lynch syndrome is sometimes known as Hereditary Non Polyposis Colorectal Cancer (HNPCC). In families with Lynch syndrome there are usually several individuals with bowel, womb or other related cancers (e.g. Stomach, Ovary). Lynch syndrome is caused by an alteration in one of a group of genes called mismatch repair genes. The two tests both look to see if these genes are working properly within the tissue.

1. IHC:

This test dyes the cancer cells. The dyes stick to proteins 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 are not working correctly.

3. There may be other genetic tests undertaken on your tumour tissue, and your genetics team will discuss these with you if relevant.

What happens next ?

If the MSI and /or 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 /or IHC tests show one of the genes is 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 underlying genetic cause for the family history.

What about the results ?

The tests are complicated and the results can take several months. We will contact the family to discuss these in detail. We will also update our advice about screening and whether or not any further testing could be useful. Someone from the Cancer 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 regarding the family history.