NHS
Oxford University Hospitals
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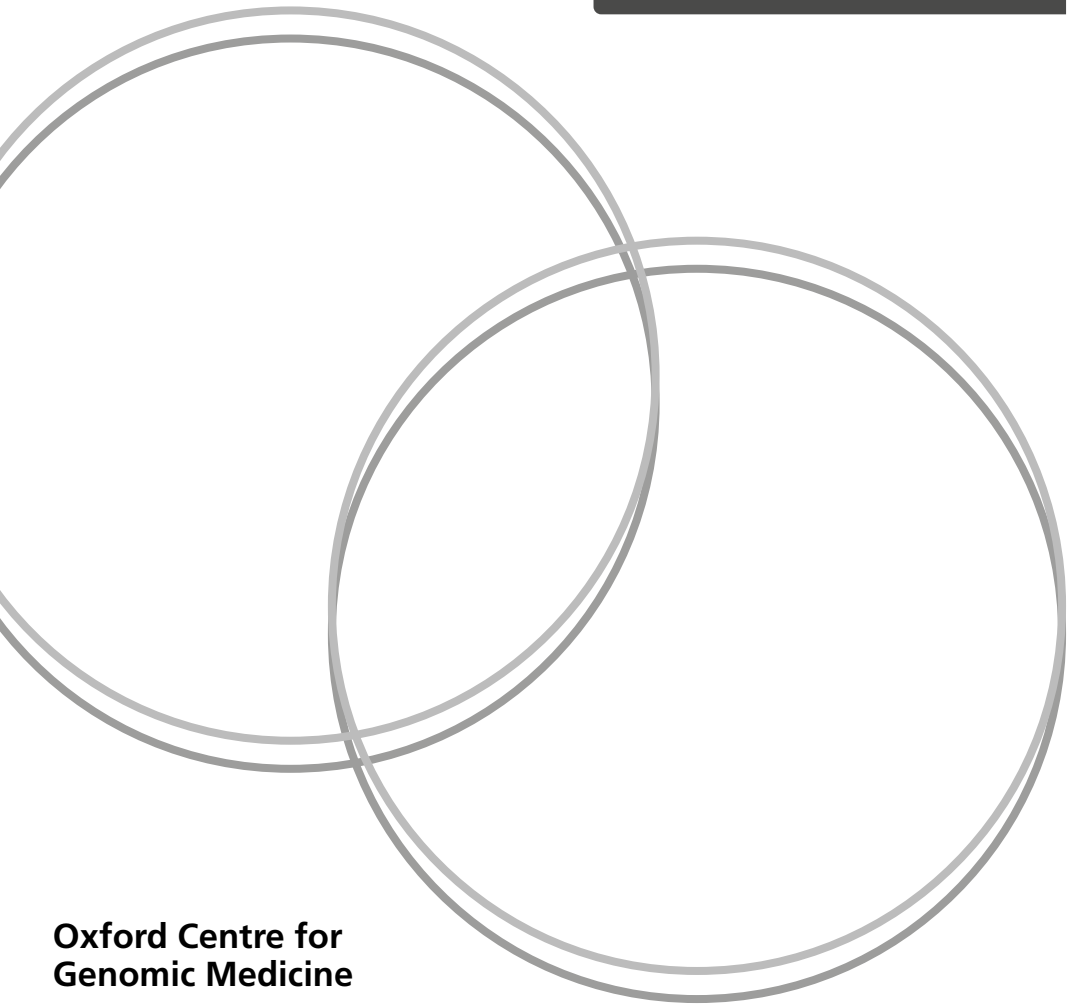
MUTYH-associated Polyposis (MAP)

Information for families with a history of bowel cancer or polyps



Oxford Centre for Genomic Medicine

What is MAP?

MUTYH-associated polyposis (MAP) is an inherited condition which gives people an increased chance of developing bowel polyps and cancer.

What is a polyp?

A polyp is a small non-cancerous growth. Polyps usually occur in the colon (large bowel). It is normal for an adult to develop 1 or 2 polyps as they get older but it is unusual to have lots of polyps. When lots of polyps occur we call this Polyposis.

Polyps are usually harmless. If they are left for several years some types of polyps can develop into cancers. If someone has lots of polyps it is more likely that one of them might develop into a cancer.

Some people are more prone to developing lots of polyps because of an inherited condition. One of these conditions is called MAP, after the gene which causes it.

What is the *MUTYH* gene?

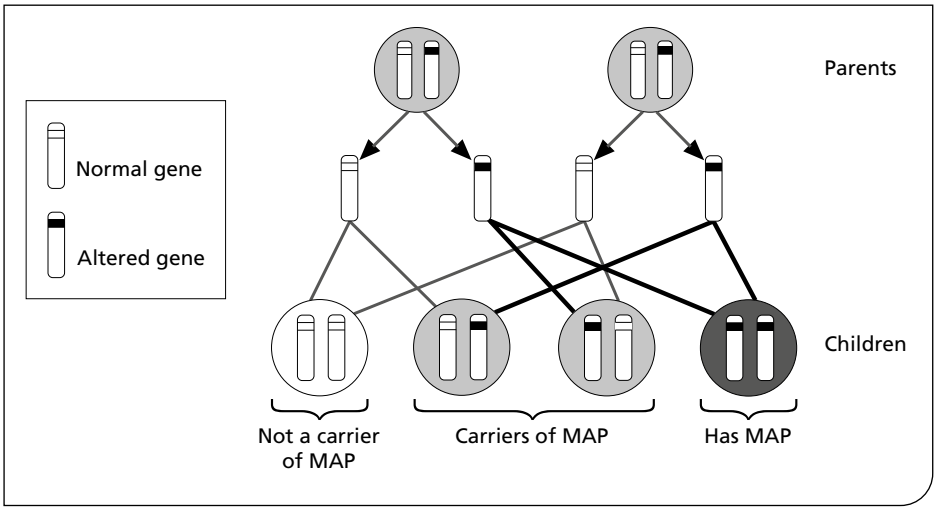
Genes are instructions which tell our bodies how to work. We each have about 20,000 genes. All our genes come in pairs as we get one copy from our Mother and one from our Father. Each gene has a specific job. The *MUTYH* gene is important in repairing damage to cells. If part of the gene is missing or altered it will not be able to do its job properly. If this happens in the *MUTYH* gene it can cause lots of polyps to develop, increasing the risk of bowel cancer.

How does MAP run in families?

MAP is inherited in an autosomal recessive way.

We each have two copies of the *MUTYH* gene. It is only if we inherit an alteration in both copies of the gene that problems occur. Lots of polyps develop because there is no working copy of the gene. People who have one altered and one working copy are carriers of MAP, but do not develop the condition themselves. This is because they still have a working copy of the gene which compensates for the altered one.

When a couple has a child they each pass on one copy of each gene at random. If both parents are carriers for MAP there are 4 possible combinations of the genes that the child may receive. This is shown in the diagram below.



Can you test for MAP?

It is possible to look at the *MUTYH* gene by taking a blood sample. If possible, it is best if this test is first done in someone who has had cancer or lots of polyps.

You may have been offered genetic testing of the *MUTYH* gene if:

- You have had between 5 and 100 polyps.
- The individuals affected with bowel cancer or bowel polyps at a young age in your family have been in one generation (brothers and sisters), rather than parents and children.
- Genetic tests for other inherited bowel cancer conditions have not found a cause for the pattern of cancers (or polyps) in your family.

What happens next?

If tests show that MAP is the cause of the cancers or polyps in your family, it is possible to offer genetic testing to other family members.

If the tests do not find any *MUTYH* alterations it is unlikely that MAP is the cause of the cancers or polyps in your family.

We would not be able to offer testing to family members. They should continue with any bowel screening already recommended.

What does it mean for my relatives?

We would be happy to discuss genetic testing with other family members. Relatives living outside this region could ask their GP to refer them to their local genetics service.

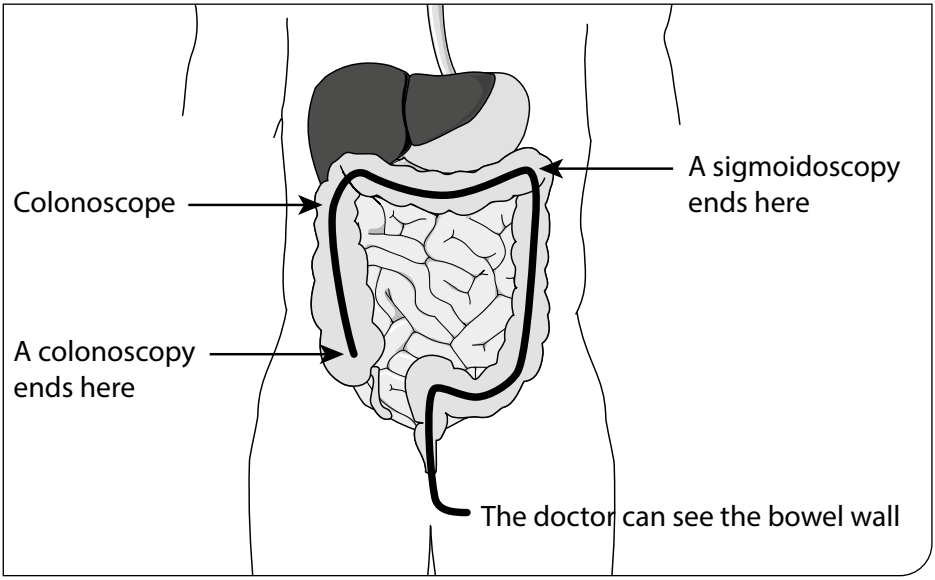
The genetic doctor or counsellor will organise a genetic blood test for your relatives to show if they also have MAP. If they do, they will be referred to the specialist bowel doctors to organise regular bowel screening with colonoscopy.

Family members who have only one altered copy of the *MUTYH* gene (carriers) are not thought to have a high enough risk for screening to be beneficial. Family members with two working copies of the gene have the same risk of bowel cancer as the general population.

In families with MAP, the risk for the next generation is often low, as the chances of both parents being carriers for MAP is small.

What does bowel screening involve?

Bowel screening involves a procedure called a 'colonoscopy' to be carried out. To have a colonoscopy you must first empty the bowel by taking strong laxatives. A colonoscope is a long flexible tube containing a tiny camera (about the thickness of your index finger). It is passed through the anus and along the bowel to look for polyps or abnormalities. You will be given mild sedation so it is not usually too uncomfortable.



There are two benefits of a colonoscopy. Firstly, it is able to detect cancers early when they are more treatable. Secondly, during the procedure, any polyps found can be removed. This reduces the chances of cancers forming.

What symptoms should I look out for?

You should be aware of any persistent unexplained tiredness or any unusual bowel symptoms. This might include blood in your stools, passing mucus, unexpected weight loss or persistent change in bowel habits. You should ask your GP for further advice about these. You should make your doctor aware of the family history and may wish to take this leaflet with you.

If anyone else in the family develops any cancers or polyps please let us know so we can update our advice.

Further Information

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

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

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

Telephone: **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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