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Genetic testing for inherited bowel and gynaecological cancers R210 (Lynch Syndrome)

This leaflet has been written for people who are considering a genetic test following a cancer diagnosis. It talks about testing for a genetic condition called Lynch Syndrome.

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Why have I been offered a genetic test?

You have been offered a test because your cancer shows signs that it might have a genetic cause called Lynch Syndrome. Most cancers are not genetic but the test can help to identify those that are.

The test could give us information about why you developed your cancer and about your risks of developing new cancers in the future. These results could help to inform the treatments you are offered.

As a genetic test, the results could have implications for your relatives, who may be eligible for extra screening or care.

If we find that you have an increased risk of future cancers, we will discuss treatment, screening and risk-reducing methods with you. You will be given a follow-up appointment with a genetic counsellor who can support you and your family.

What is Lynch Syndrome?

Lynch Syndrome is a genetic condition. People with Lynch Syndrome have a variant (a genetic change) in one of their mismatch repair (MMR) genes. These 'MMR' genes help to repair damaged DNA within our cells.

This gene variant results in a higher risk of certain cancers. The main cancers seen in Lynch Syndrome are bowel, womb, ovarian and stomach cancers. There can also be a smaller increase in the risk of some other cancers.

Lynch Syndrome is a ‘dominant’ genetic condition. This means that if someone has Lynch Syndrome, their children and siblings each have a 50% chance of also having the condition. Often, the condition has been inherited for many generations. If you are diagnosed with Lynch Syndrome, your relatives can choose to see a genetic counsellor and decide whether to be tested.

How high are the cancer risks in Lynch Syndrome?

In general, Lynch Syndrome is considered to cause a high risk of bowel, womb and ovarian cancers in adults. In some cases, the risk of stomach, prostate or urinary tract cancers may also be significantly raised. It is important to know that these risks vary, they depend on both the gene and your family history.

Bowel cancer risk is low before age 25. Womb and ovarian cancer risks are usually low before age 40.

There are five different genes which cause Lynch syndrome. Each gene carries slightly different pattern of cancer risk. The Lynch syndrome genes are: MSH1, MSH2, PMS2, MSH6 and EPCAM.

What will happen if I decide to have this test?

This test (Code R210) is carried out on a blood sample. All suspected bowel and womb cancers are now screened for signs of Lynch Syndrome. If the cancer shows signs of Lynch Syndrome, we can look in more

detail with a genetic test. This genetic test is done with a blood sample. Scientists will use this to look for any variation in the Lynch Syndrome genes.

Do I have to have a genetic test?

Please take the time to ask all the questions that you need to. If you do not feel ready to have a test right now, your team can store a DNA sample and revisit this with you at a later date. If you decide not to have genomic testing, you will still get the best possible health care, based on what we know about your cancer.

What results will I get from the genetic test?

There are three possible test results, the next section describes each result in more detail.

1. A gene variant is found: This confirms a diagnosis of Lynch Syndrome.
2. No gene variants were found: Lynch Syndrome is less likely.
3. Some genetic variation was found, but it is of uncertain significance: Further assessment is needed.

Sometimes families need a more detailed assessment to interpret their risk of Lynch Syndrome. Everyone who has this test will be referred to the Clinical Genetics service. Genetics can offer a personalised assessment and advice for families, taking into account their full history.

Result 1: A gene variant is found

This result tells us that you have a diagnosis of Lynch Syndrome. This is likely to explain why you developed cancer. Your oncology and surgical teams will take this into account when planning your care. Your specialist will refer you to a Genetic Counsellor for detailed personal and family advice.

Result 2: No gene variants were found

The sequence in your Lynch Syndrome genes seems to be normal. Lynch is unlikely, but we have not explained why your tumour showed signs of this condition. A Genetic Counsellor will see you to look at this in more detail. If they can't be sure whether you have Lynch Syndrome, they may recommend some screening for close family members.

Result 3: Some genetic variation was found but it is of uncertain significance

Our genes have many thousands of letters of code and variation is natural. Sometimes, it is hard to tell whether a particular gene change affects the gene (causing cancer risk), or whether it is just part of human diversity. A Genetic Counsellor will see you to look at this in more detail. If they can't be sure whether you have Lynch, they may recommend some screening for close family members.

What treatment or support is there for people with Lynch Syndrome?

If we know someone has Lynch Syndrome, we can take steps to reduce the risk of cancer developing. We can also offer screening to ensure early detection of cancers that do arise.

This can include:

- Colonoscopy screening every two years
- Aspirin medication to reduce the risk of cancers forming
- Treatment for common bacteria in the stomach
- Risk reducing surgery for women (removing the womb
- and ovaries after they have completed their family – not
- before age 35-40)
- Lifestyle advice

Important information about your data

Your genomic data and samples will be stored as part of your health record. DNA samples may be used anonymously for quality control. All data is kept securely and confidentially in line with UK law and NHS policy. More information can be found at www.england.nhs.uk/contact-us/privacy-notice

Information in this guide should be used to supplement professional advice specific to your circumstances. If you

have any questions, it is important to ask your medical team or contact.

Name

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Telephone Number

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Email

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Content reviewed: January 2026

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.

Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation.

***Ask 3 Questions** is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial.

Patient Education and Counselling, 2011;84: 379-85

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https://aqua.nhs.uk/resources/shared-decision-making-case-studies/

GHPI1932_01_26
Department: Gynaecology
Review due: January 2029
www.gloshospitals.nhs.uk