Healthier Communities, Outstanding Care

Sherwood Forest Hospitals NHS Foundation Trust

INFORMATION FOR PATIENTS WITH ENDOMETRIAL CANCER

Testing for Lynch syndrome

You have been given this leaflet because of your diagnosis of endometrial cancer (a type of womb (uterine) cancer). Initial testing of your cancer (tumour) suggests it might be due to an inherited condition called Lynch syndrome. We would like to offer you a genetic blood test to help determine whether you have Lynch syndrome.

This leaflet aims to answer some of the most commonly asked questions about Lynch syndrome. If you would like more information, you can visit: https://rmpartners.nhs.uk/lynch-syndrome-early-diagnosis-pathway/patient-information/

Lynch syndrome
Womb cancer is the fourth most common cancer in women in the UK, and most diagnoses are due to older age, increased weight or certain hormone therapies. However, a small proportion of womb cancer (specifically endometrial cancer) is caused by an inherited or genetic condition, called Lynch syndrome.

Most people with Lynch syndrome are well, but someone with Lynch syndrome has a higher chance of developing bowel cancer and also an increased risk of endometrial cancer for women. Both men and women with Lynch syndrome have a slight increased risk of developing cancers in other parts of the body than people in the general population. People with Lynch syndrome are monitored through colonoscopic surveillance to reduce the chances of bowel cancer developing and can discuss options to manage their endometrial cancer risk.

Genes and DNA
To understand genetic testing for Lynch syndrome and what it means for you, we need to look at your DNA and genes.

DNA is the code our bodies use to make genes. Genes are the instructions that tell our body how to grow and develop and each have their own job to perform. Some of our genes determine what hair and eye color we have, and some are responsible for protecting us against diseases like cancer.

Inherited conditions are due to an alteration change (also known as a change or variant) in a particular gene, which can be passed on in a family. An altered gene may change the level of protection a family has against diseases such as cancer.

The Lynch syndrome genes are genes that protect us against cancer by repairing DNA mistakes that can occur when our cells are made.

The genes are like police officers in our body, checking everything is working properly and protecting us against cancer. If these genes aren't working properly, then mistakes can occur in our DNA code, which can result in a cancer (a bit like having less police officers protecting us against cancer).

Inheritance pattern
When we are conceived, we inherit two copies of every gene, one copy from our mother and one copy from our father. If one of our parents has Lynch syndrome, at the point of conception, they have a 50% chance of passing on their altered copy and 50% chance of passing on their unaltered copy. If a person inherits the altered copy, they will have Lynch syndrome. This is also known as an autosomal dominant inheritance pattern. This also means a person with Lynch syndrome has a 50% chance of passing on their altered gene each time they have a child.

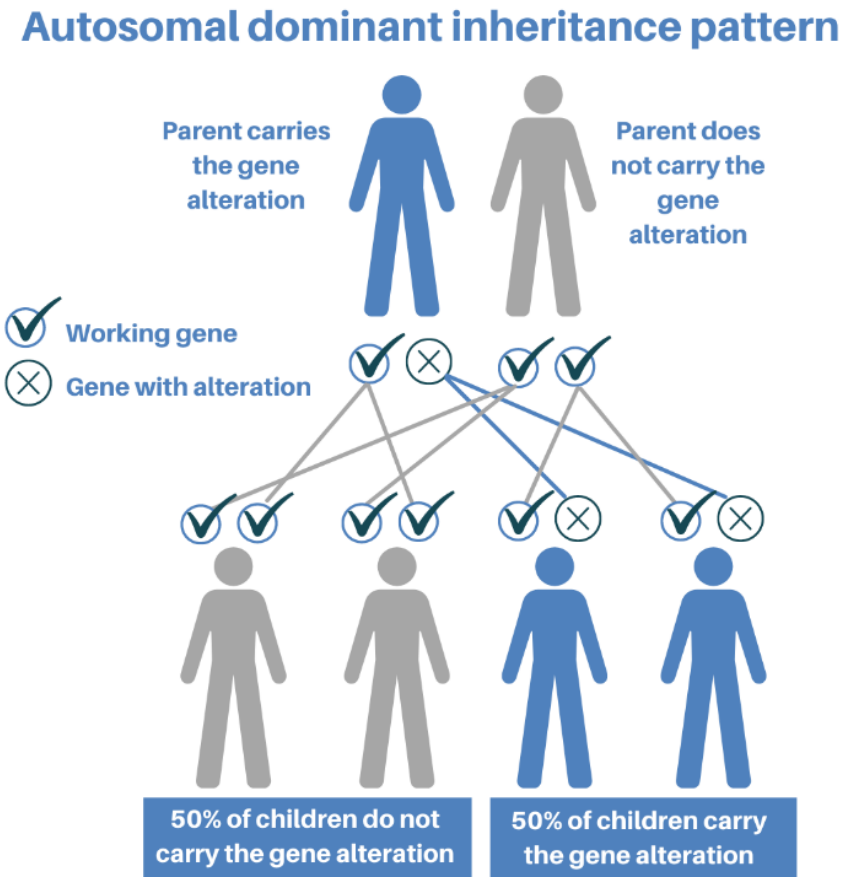

Figure created by North East Thames Regional Cancer Genetics Service

Genetic testing
Genetic testing for Lynch syndrome will involve having a blood test. DNA will be extracted from your blood to look for gene alterations (variants or changes) that cause disease or increase your risk of developing a disease. This testing takes approximately three months to complete.

Genetic testing for Lynch syndrome helps us to understand your and your family's risk of developing cancer in the future.

Positive test results will also help medical professionals understand the treatments you may require. There may be certain therapies available that can be tailored to you dependent on your test results.

Having genetic testing is optional. Your decision will not affect the standard of care you receive. However, knowing you have Lynch syndrome will give you and your family access to personalised treatments, advice and tailored surveillance programs. It will also enable testing of other family members to ensure they are kept safe and reduce the chance of further cancers developing in the family.

Genetic results
Genetic test results do not always give a clear answer. This is because the science of genetics is still in its infancy. For this reason, and for clarity, your results will be classified as: **positive, uncertain or negative.**

Positive - a disease causing genetic alteration (pathogenic variant) for Lynch syndrome is identified
This result would confirm the diagnosis of Lynch syndrome and provide an explanation for why you developed endometrial cancer. Your cancer team may use this information in their management decisions and will discuss this with you further. You might be considered for additional therapies. You will be referred to Clinical Genetics who can discuss your result with you further, particularly the implications this has for your family members. They can support you to discuss this result with your family and can offer predictive genetic testing to your relatives (starting with parents, siblings, and children) as they might carry the same genetic change (alteration).

Uncertain - a genetic alteration (variant) of unknown clinical significance is found
A genetic change is found, however, we cannot be certain it is the cause of your cancer, or if it is just a harmless change in the gene. You will be referred to Clinical Genetics who will assess your personal and family history to advise whether any further testing is possible and if any cancer screening is recommended to you or your family.

Negative - we do not find any genetic alterations (or variants)
This result **doesn't rule out an inherited condition**. It might be that the limited knowledge we have about genetics means we are unable find a genetic change currently. You might be referred to Clinical Genetics who will assess your personal and family history to advise whether any further testing is possible and if any cancer screening is recommended to you or your family.

Your results will be given by your cancer team, who will also refer you to your local Clinical Genetics department if required. They may suggest further testing to help clarify your results or may provide recommendations for your family members.

If you have any further questions about this test, or in relation to your ongoing cancer treatment, please contact your cancer team.

Further sources of information
NHS Choices: www.nhs.uk/conditions
Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)
PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222
Newark Hospital: 01636 685692
Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

To be completed by the Communications office
Leaflet code: PIL202405-01-LSEC
Created: May 2025 / Review Date: May 2026

This leaflet was adapted with the permission of Nottingham University Hospitals NHS Trust and St Mark's Hospital and RM Partners West London Cancer Alliance.