


NHS Bowel Cancer Screening
Programme
Colonoscopies for patients with
Lynch syndrome
Helping you decide

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It's your choice whether to take part in the NHS bowel cancer screening programme. This leaflet aims to help you decide.

About Lynch syndrome

Lynch syndrome (previously known as HNPCC - hereditary non-polyposis colorectal cancer) is an inherited condition which increases a person's chance of developing bowel cancer. It also increases the chance of developing other types of cancer, including cancer of the womb (endometrial cancer), ovary, stomach, and pancreas.

Lynch syndrome is caused by a change in one or more of the genes which usually work to prevent cancer. These genes are known as mismatch repair (MMR) genes. The genes are called MLH1, MSH2, MSH6, PMS2 and EPCAM. MMR genes usually work to correct mistakes in DNA, but when there's a change in these genes any mistakes in the DNA aren't corrected, which can lead to cancer developing.

Why we offer colonoscopies to people with Lynch syndrome

For people with Lynch syndrome, regular screening by having a colonoscopy has been shown to reduce the chance of becoming seriously ill or dying from bowel cancer, as well as reducing the chance of bowel cancer developing in the first place.

This is because screening through a colonoscopy can detect bowel cancer when it is at an early stage when treatment is more likely to be effective. It can also help to find polyps. These are small growths on the lining of the bowel. Polyps are not cancers but may develop into cancers over time. Polyps can be easily removed, which reduces the risk of bowel cancer developing.

Your clinical genetics team will continue to help you manage your other Lynch syndrome needs and risks (such as gynae and skin checks).

Who we invite

The NHS Bowel Cancer Screening Programme offers a colonoscopy every 2 years to people diagnosed with Lynch syndrome.

People with a MLH1 or MSH2 or EPCAM gene change will usually be invited just after their 25th birthday. People with a MSH6 or PMS2 gene change will usually be invited just after their 35th birthday.

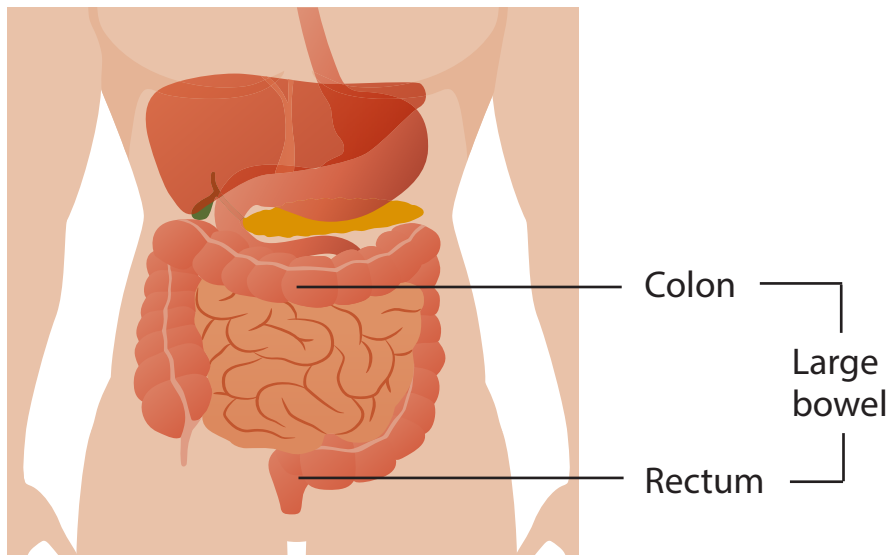
If you have previously had a colonoscopy, the NHS Bowel Cancer Screening Programme will send you an invitation when your next colonoscopy is due.

The NHS Bowel Cancer Screening Programme does not automatically invite people aged 75 or over, but they can request screening every 2 years by calling our free helpline on 0800 707 60 60.

You've received an invitation from the NHS bowel cancer screening programme because your genetics team has told us that you have Lynch syndrome. If you do not think you have Lynch syndrome or are unsure whether you have it, please call our free helpline on 0800 707 60 60.

How the bowel works

The bowel is part of your digestive system. It takes nutrients and water from food and turns what is left into poo (also known as faeces, stools or bowel motions).



The colon and rectum make up the large bowel, and are part of the digestive system

Risk (chance) of developing bowel cancer

People with Lynch syndrome are more likely to develop some (not all) types of cancer. Out of 100 people with Lynch syndrome between 15 and 80 will develop bowel cancer over their lifetime depending on which Lynch syndrome gene change they have. This is due to having less protection from the cancer mismatch repair genes. Having Lynch syndrome doesn't mean that you will definitely develop cancer, but having less protection makes it more likely.

Other things that can increase your chance of developing bowel cancer include:

- The specific Lynch syndrome gene that is altered in you
- Getting older
- Lifestyle factors (see below)

Reducing your risk of developing bowel cancer

Not everyone living with Lynch syndrome will develop cancer. The chance of developing cancer is much lower in people who know that they have Lynch syndrome and have regular colonoscopies, compared to people who have Lynch syndrome but are unaware. This is because knowing you have Lynch syndrome gives you the chance to take action in a timely manner and can help to ensure that cancer is found at an early stage so it can be treated more effectively.

You can also reduce your chance of getting bowel cancer by:

- keeping physically active
- keeping a healthy weight
- eating plenty of fibre, for example choose wholegrain and wholemeal foods
- eating plenty of vegetables and fruit
- eating less red meat and especially less processed meat such as bacon or sausages
- drinking less alcohol
- not smoking
- taking aspirin - research has shown that taking aspirin daily can help prevent cancer from developing in people with Lynch syndrome. You should speak to your GP or clinical genetics team if you want to know more about taking aspirin.

Possible benefits and risks of NHS bowel cancer screening

Being aware of the possible risks and benefits will help you decide whether to take part in the bowel cancer screening programme.

Benefits of having a colonoscopy:

- Reduces your chance of dying from bowel cancer. If you take part in the bowel cancer screening programme and have regular colonoscopies, your chance of dying from bowel cancer is more than halved.
- Out of 100 people with Lynch syndrome it prevents between 40 and 60 people from getting bowel cancer.
- Increases your chance of bowel cancer being found at an earlier stage, when it is more treatable.
- Allows us to remove any polyps found during colonoscopy, which reduces your chance of developing bowel cancer.

Risks:

In rare cases, having a colonoscopy might:

- Cause complications, for example, during or after colonoscopy

No screening test is 100% effective. This is because bowel cancer may develop in between tests. There is also a small chance that colonoscopy misses cancer or a polyp that could later turn into cancer

How the NHS bowel cancer screening programme works

We will offer you an appointment at a local screening centre (usually in a hospital). This is to discuss having a detailed examination of your bowel (colonoscopy). If you have been having regular colonoscopies outside of the NHS Bowel Cancer Screening Programme you may be offered an appointment at a different hospital to the one you usually attend.

The colonoscopy is to see if there are any polyps that need removing or any cancer that needs treatment. A specialist screening practitioner (SSP) will discuss the colonoscopy with you, answer any questions you have and check if you are fit enough for the procedure. You will need to attend an appointment with a specialist screening practitioner even if you have had a colonoscopy before.

If you are fit for a colonoscopy and want to go ahead with the examination, we will arrange an appointment for you. If we do not think you are fit enough for the examination, we may offer you a colonoscopy under general anaesthetic.

Colonoscopy

Colonoscopy takes place at NHS bowel cancer screening centres, usually in hospitals. A colonoscopist (someone specially trained in colonoscopy) carries out the examination.

The colonoscopist uses a thin flexible tube with a tiny camera on the end to look inside your bowel. Colonoscopy can find bowel cancer. It can also find polyps, which can usually be removed to stop them growing into cancers.

Colonoscopy usually takes 30 to 45 minutes, although the whole appointment may take around 2 hours.

Before your colonoscopy

The SSP (specialist screening practitioner) may give you a list of foods you need to avoid for several days before your colonoscopy. They will also give you a medicine to clear your bowel (a strong laxative). You need to have an empty bowel so the colonoscopist can see the bowel lining clearly.

When you take the medicine will depend on the time of your appointment. The SSP will give you written instructions. Please read and follow them carefully. It is important you take the medicine according to the instructions. It will cause diarrhoea, so you will need to stay close to a toilet.

If you choose to have a sedative you will need to arrange for someone to take you home after your colonoscopy as this could make you be drowsy. The SSP will discuss this with you at your appointment.

Having your colonoscopy

When you arrive for your appointment you will be able to talk to the nurses and doctors about any concerns or questions you have.

We will ask you to lie on a bed on your left side with your knees slightly bent up. We may give you a painkiller. We may also give you a sedative. It is your choice whether to have this. It is usually an injection into a vein in your arm or some pain-relieving gas to breathe. It is to relax you and make the colonoscopy more comfortable.

Following a sedative, you should not:

- drive home afterwards (you will need someone to take you home)
- drink alcohol for 24 hours
- operate machinery for 24 hours

A colonoscopist will perform your colonoscopy.

1. The colonoscopist will put a colonoscope (thin flexible tube) into your large bowel through your back passage (rectum).
2. They will then gently pump some harmless carbon dioxide gas inside. This opens up the bowel so they can see the lining clearly. It may cause a bloating or cramping feeling.
3. The camera on the colonoscope shows the inside of your bowel on a screen.

If you feel pain, let the colonoscopist know. They can change what they are doing to make you as comfortable as possible.

After your colonoscopy

The colonoscopist or SSP will tell you if they removed any polyps or pieces of bowel lining (biopsies). If they did, a pathologist will examine them and we will provide you with the results within 2 weeks. We will also send your GP a copy of your results. If you have not received your results after 2 weeks please contact our helpline on 0800 707 60 60 or your GP.

You will probably feel like resting after your colonoscopy. You may want to try and keep the whole day free of work or other commitments.

After the colonoscopy, you may feel sick or have some abdominal (tummy) pain or bloating for a day or so. You may also have some blood in your poo. If the symptoms are severe or do not go away in 2 days, you should see your GP. You can also contact the screening centre where you had your colonoscopy.

Reliability of colonoscopy

Colonoscopy is a good test for finding polyps or cancer in the bowel. But there is a small chance (about 3 out of every 100 colonoscopies) that colonoscopy misses cancer or a polyp that could later turn into cancer. This could be because:

- the bowel was not completely empty
- it was difficult to move the colonoscope around the bowel
- in rare cases, the colonoscopist could not see the polyp or cancer

Risk of colonoscopy

For most people, colonoscopy is straightforward. But as with most medical procedures, complications can happen. In rare cases, colonoscopy can damage the bowel. Possible complications include:

- a hole (perforation) in the bowel caused by the colonoscope (around 1 person in 1700); around half of people with a perforation will need surgery to repair it
- heavy bleeding needing a transfusion (around 1 person in 2,400)

If you have bleeding that is difficult to stop or a hole in your bowel that needs surgery, we will admit you to hospital straightaway.

In rare cases, colonoscopy complications may result in death. However, in a national audit of 20,085 colonoscopies carried out in 2011, no deaths were recorded.

Results

No polyps or small polyps that need no treatment:

If no polyps or only small polyps that are very unlikely to turn into cancer are found then no further investigation will be needed at this time. We will invite you for bowel cancer screening via colonoscopy in 2 years' time if you are still under 75 by then.

Polyps or other findings:

Usually we remove small polyps painlessly during colonoscopy using a tiny wire loop passed through the colonoscope. The colonoscopist may also take a tiny piece (biopsy) of bowel lining to look at afterwards under a microscope. Unless you require a site check (to check the site where the polyp was removed) you will be invited for bowel cancer screening via colonoscopy in 2 years' time if you are still under 75 by then.

Polyps needing removal:

Some polyps (called adenomas) are more likely to turn into cancer if they are not removed. These polyps may be too difficult to remove during colonoscopy. If we find one of these types of polyp you may need surgery or a further specialist colonoscopy at a later date.

Bowel cancer:

If a cancer is found we will refer you to a team of specialists who will look after you.

The main treatment for bowel cancer is surgery. In some cases, the specialists may offer you chemotherapy, immunotherapy or radiotherapy. Not all bowel cancers found are curable. But for every 100 people who have bowel cancer found at its earliest stage, over 90 are still alive 5 years later.*

* Office for National Statistics dataset 'Cancer survival in England - adults diagnosed', released August 2019. Available at: [Cancer survival in England - adults diagnosed - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk)

Bowel cancer symptoms

Having a colonoscopy does not guarantee that you do not have bowel cancer or that it will never develop in the future. It is still possible to get bowel cancer even if you had:

- no polyps found at colonoscopy
- small polyps found that we did not need to remove
- small polyps found that we removed

It is important to be aware of bowel cancer symptoms. These include:

- blood in your poo (faeces)
- looser poo, pooing more often (diarrhoea) and/or constipation
- a pain or lump in your abdomen (tummy)
- feeling more tired than usual for some time
- losing weight for no obvious reason

Please remember that these symptoms do not necessarily mean that you have bowel cancer. But if you have any of these symptoms for 3 weeks or more, please speak with your GP. It is important to do this even if you have recently had a colonoscopy or are due to have a colonoscopy in a few months.

Bowel cancer screening is not a test for when you have symptoms.

Further support

For more information about the NHS bowel cancer screening programme please call our free helpline on 0800 707 60 60.

You can also:

- talk to your GP
- talk to your genetics team
- visit www.nhs.uk/bowel
- visit www.lynch-syndrome-uk.org
- visit www.bowelcanceruk.org
- visit [Lynch Syndrome information - RM Partners](#)

If you are over the age of 75 and have been diagnosed with Lynch syndrome, you can request screening every 2 years by calling our helpline on 0800 707 60 60.

If you think you are due for a colonoscopy but have not received an invitation please call our helpline on 0800 707 60 60

Privacy statement

The NHS screening programmes use personal information from your NHS records to invite you for screening at the right time. NHS England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at: <https://www.gov.uk/government/publications/patient-confidentiality-in-nhs-population-screening-programmes>

How else can I view this?

Visit our website or call our helpline if you need screening information in a different language or format.

- Arabic إذا احتجت إلى معلومات بخصوص الفحوص بلغة مختلفة، يُرجى زيارة موقعنا أو الاتصال بخط مساعدتنا.
- Bengali আমাদের ওয়েবসাইট পরিদর্শন (ভিজিট) করুন বা আপনার যদি অন্য ভাষায় স্ক্রীনিং তথ্যের প্রয়োজন হয় তবে আমাদের হেল্পলাইনে কল করুন।
- Farsi در صورت نیاز به دسترسی به اطلاعات غربالگری به یک زبان متفاوت به تازمانی ما مراجعه کرده و یا با خط تلفنی راهنمایی ما تماس حاصل کنید.
- Gujarati જો તમને કોઈ જુદી ભાષામાં સ્ક્રીનીંગની માહિતીની જરૂર હોય તો અમારી વેબસાઇટની મુલાકાત લો અથવા અમારી હેલ્પલાઇનને કોલ કરો.
- Polish Jeśli potrzebujesz informacji o badaniach w innym języku, odwiedź naszą stronę internetową lub zadzwoń na infolinię.
- Portuguese Consulte o nosso site ou contacte a nossa linha de apoio se necessitar de informação sobre o rastreio numa língua diferente.
- Punjabi ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੱਖਰੀ ਭਾਸ਼ਾ ਵਿੱਚ ਸਕ੍ਰੀਨਿੰਗ ਜਾਣਕਾਰੀ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਸਾਡੀ ਵੈਬਸਾਈਟ 'ਤੇ ਜਾਓ ਜਾਂ ਸਾਡੀ ਹੈਲਪਲਾਈਨ 'ਤੇ ਕਾਲ ਕਰੋ।
- Chinese (Simplified) 如果您需要其他语言的筛查信息，请访问我们的网站或拨打我们的帮助热线。
- Chinese (Traditional) 如果您需要其他語言的篩查信息，請訪問我們的網站或撥打我們的幫助熱線。
- Urdu اگر آپ کو کسی دوسری زبان میں اسکریننگ کی معلومات درکار ہوں تو یا ہماری ہیلپ لائن پر کال کریں۔ ہماری ویب سائٹ ملاحظہ کریں

An HTML version of this leaflet is available. You can view and download it in large print, and use a screen reader for an audio version. Visit: www.gov.uk/lynch-syndrome

We can provide a braille version. Email: England.screeninghelpdesk@nhs.net

More information about bowel cancer screening: www.nhs.uk/bowel

Order this leaflet: <https://www.gov.uk/guidance/how-to-order-population-screening-leaflets>

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First published: March 2023

This version: March 2023

Leaflet reference: LYNCH01

PN-No

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