

Lynch syndrome Frequently Asked Questions (FAQs)

If you have any questions about Lynch syndrome, please refer to the FAQs below. If your query is not answered here, you can call the free Bowel Cancer Screening helpline on 0800 707 60 60.

Newly diagnosed Lynch syndrome patients

How will I be assessed for a colonoscopy?

You will have an appointment with a specialist (known as a Specialist Screening Practitioner or SSP). They will assess whether you should have a colonoscopy. They will also arrange any follow up appointments and procedures, including surgery if that is needed.

If it is appropriate, you can have a regular colonoscopy through the NHS Bowel Cancer Screening Programme.

A colonoscopy may not be right for you if you have a health condition. If so, your specialist will discuss this with you at the appointment.

Why do I need to have a colonoscopy?

If you have Lynch syndrome, you are at a higher risk than the average person of getting bowel cancer. Regular screening by having a colonoscopy picks up on any risks and therefore lowers your chance of becoming seriously ill or dying from bowel cancer. It also lowers the chance of bowel cancer developing in the first place.

How often will I need a colonoscopy?

People diagnosed with Lynch syndrome will be invited to have regular colonoscopies as part of the NHS Bowel Cancer Screening programme. This allows specialists to look for early changes in the large bowel before cancer develops.

If you have Lynch syndrome, you will be invited for a colonoscopy every 2 years which is the recommended guidance for surveillance. [Guidelines for the management of hereditary colorectal cancer from the British Society of Gastroenterology \(BSG\)/Association of Coloproctology of Great Britain and Ireland \(ACPGBI\)/United Kingdom Cancer Genetics Group \(UKCGG\).](#)

I'm anxious about having my first colonoscopy. What can I expect?

A colonoscopy examines your colon to check for polyps and signs of cancer.

Visit [Lynch Syndrome - GOV.UK](https://www.gov.uk/lynch-syndrome) for more information about having a colonoscopy. You can also call the screening centre and discuss your concerns with one of the Specialist Screening Practitioners or talk to them at your appointment.

Who will carry out my colonoscopy?

An NHS colonoscopist (a health professional specially qualified in carrying out colonoscopies) will carry out your colonoscopy at your local NHS screening centre.

Will I get a bowel cancer home testing kit?

No, people with Lynch syndrome do not receive a faecal immunochemical 'home testing' kit (also known as a FIT kit). These tests identify blood in poo which may result in a colonoscopy being needed. If you have Lynch syndrome, due to your higher risk of bowel cancer, you are offered a colonoscopy directly instead.

Where can I find out more about Lynch syndrome and bowel cancer screening?

The following websites provide information about bowel cancer screening and Lynch syndrome:

- www.nhs.uk/colon-cancer
- www.gov.uk/government/publications/lynch-syndrome
- www.lynch-syndrome-uk.org
- www.bowelcanceruk.org
- [Lynch Syndrome information - RM Partners](#)

Existing Lynch syndrome patients

I've had a colonoscopy before. Will I still be seen by the same person?

If you previously had a colonoscopy for Lynch syndrome, but not through the NHS Bowel Cancer Screening Programme, you may be offered an appointment at a different hospital to the one you usually attend. It's best to have your colonoscopy at the screening centre you're referred to, so you have it as soon as possible. Some people may see the same person if they perform colonoscopy as part of the NHS bowel cancer screening programme.

Will I need to travel to a different screening centre further away?

Not necessarily – where possible you will attend the screening centre nearest to your home. If you choose to remain under the care of your existing centre, you might need to travel further than for the screening centre you were invited to through the NHS Bowel Cancer Screening Programme.

I'd rather remain under the care of my current centre. What should I do?

You can choose where you have a colonoscopy. You can receive your care at the centre closest to your home as part of the NHS Bowel Cancer Screening Programme. If you prefer, you can request a transfer to another accredited screening centre, for example, to one you have been to before. This is called a 'screening centre transfer'.

If you decide to transfer to another screening centre, you should contact the NHS Bowel Cancer Screening Programme by calling the free helpline on 0800 707 60 60 for further advice.

This does not mean your surveillance will stop. You can also continue to receive your colonoscopies through your current hospital (even if they are not a bowel cancer screening centre), but your surveillance colonoscopies would not be arranged and managed through the NHS Bowel Cancer Screening Programme.

Why is my current Lynch syndrome screening centre not managed by the NHS Bowel Cancer Screening Programme?

Not all endoscopy units are screening centres managed by the NHS Bowel Cancer Screening Programme. If your current screening centre is not managed by the programme, you will be offered a centre close to your home that is managed by the NHS Bowel Cancer Screening Programme.

Why do I have to opt out of the NHS Bowel Cancer Screening programme if I want to stay with my current screening centre?

Not all endoscopy units are screening centres managed by the NHS Bowel Cancer Screening Programme. If your current screening centre is not managed by the NHS Bowel Cancer Screening Programme, you will be offered a centre close to your home that is managed by the programme. You can also choose an alternative bowel cancer screening centre if that is more convenient.

If you would prefer to have your colonoscopy at your current centre, you can choose to do that rather than through the NHS Bowel Cancer Screening Programme..

I previously had a colonoscopy every year. Why is this now every two years?

The decision to offer surveillance colonoscopies every two years was based on clinical advice and evidence by the [British Society of Gastroenterology](#) that it is safe to do so and in the best interests of people with Lynch syndrome.

However, you will have colonoscopies yearly if there are signs of bowel cancer.

I've had my colonoscopy recently. When will I be contacted under the new arrangement?

You might have received a letter to explain that your colonoscopies will be managed by the NHS Bowel Cancer Screening Programme. Your local screening centre will then call you to confirm the date of your last colonoscopy.

If you are not sure if you have been included, please call the free Bowel Cancer Screening helpline on 0800 707 60 60. **I'm due my colonoscopy in the next month. Why haven't I been contacted yet?**

If you haven't been contacted by the screening service, you can call the free Bowel Cancer Screening helpline on 0800 707 60 60.

If I move to the NHS Bowel Cancer Screening Programme, will my care change?

The NHS Bowel Cancer Screening programme will guarantee that you receive high quality colonoscopic surveillance at 2 yearly intervals. Other aspects of your Lynch syndrome care will not change.

Although you may be offered an appointment at a different hospital to the one you usually attend, your colonoscopies will be carried out by highly qualified colonoscopists at your local screening centre.

I opted out of the NHS Bowel Cancer Screening Programme but have changed my mind. Who should I contact to opt in?

You should contact the free Bowel Cancer Screening helpline on 0800 707 60 60 and explain that you want to opt back in to Lynch syndrome surveillance within the NHS Bowel Cancer Screening Programme.