NICE information for the public

Surveillance of the large bowel: preventing cancer in people at risk

Information for the public
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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about offering surveillance of the large bowel to prevent cancer in people at risk that is set out in NICE clinical guideline 118.

Inflammatory bowel disease or polyps (also called adenomas) affecting the large bowel can increase a person's risk of developing colorectal cancer. The specific types of inflammatory bowel disease considered in this information are ulcerative colitis and Crohn's disease. In this information, 'surveillance' means having regular checks to see if there are any changes or any early signs of disease suggesting cancer in the large bowel.

Does this information apply to me?

Yes, if you are an adult (age 18 and older):

- who has had symptoms of inflammatory bowel disease (ulcerative colitis or Crohn's disease affecting the large bowel) for at least 10 years
- who has polyps in the large bowel.

No, if you are:

- a child (younger than 18 years)
- an adult with cancer of the large bowel or rectum that has recently been diagnosed or has worsened
- an adult with polyps who has previously been treated for colorectal cancer
- an adult who is at risk of a certain type of colorectal cancer that runs in families (called hereditary non-polyposis colorectal cancer)
- an adult with polyps caused by a condition that runs in families (the most common of these conditions is called familial adenomatous polyposis).

Your care

If you think that your care does not match what is described in this information, please talk to a member of your healthcare team in the first instance.

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should discuss why surveillance of the large bowel is recommended and what it involves. They should cover possible benefits

and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review the plans for surveillance of your large bowel at any time. This may include changing your mind about surveillance.

If you have made an 'advance decision' (known as a 'living will' in the past) in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103643) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

Surveillance of the large bowel

Some people with conditions affecting the large bowel (also called the colon) are at higher risk of developing colorectal cancer than other people in the general population and should be offered surveillance. These conditions include:

- ulcerative colitis or Crohn's disease of the large bowel that started at least 10 years ago. These types of inflammatory bowel disease cause inflammation and damage to the lining of the large bowel
- fleshy growths (polyps or adenomas) in the lining of the large bowel.

Surveillance involves regular checks to detect any pre-cancerous changes in the cells of the large bowel (called dysplasia). If dysplasia is found, early treatment can stop it progressing to colorectal cancer. These checks can also pick up early signs of cancer, before the person has any symptoms. This is important because colorectal cancer can be treated successfully if found early enough.

Surveillance of the large bowel is not the same as the NHS bowel cancer screening programme, which is offered to all men and women aged 60–74 in England and Wales. The NHS bowel cancer screening programme involves testing stool samples to see if there is any blood, which could be a sign of bowel cancer. It does not diagnose bowel cancer but shows whether the person needs further tests.

Questions you might like to ask your healthcare team

- Can you tell me more about the link between inflammatory bowel disease or polyps and colorectal cancer?
- What is my risk of developing colorectal cancer?
- Are there any support organisations in my local area?
- Can you provide any information for my family?

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Deciding whether to have surveillance of the large bowel

To help you decide whether to have surveillance of the large bowel, you should be given information that you can understand (for example with illustrations, in large print or in your first language). Your specialist should discuss the risks, benefits and limitations of the tests with you. They should explain how surveillance can detect early signs of disease and how early treatment can prevent these progressing to colorectal cancer. You should be given the opportunity to discuss the implications of being on a surveillance programme (such as whether it might reassure you or make you feel worried and how it might affect your quality of life).

If you decide to have surveillance, you and your family should be given the opportunity to talk to a healthcare professional about your concerns at any time during the surveillance programme. You should be able to discuss the benefits, risks and limitations of ongoing surveillance with your specialist when you get the results of your surveillance test. If your specialist thinks that surveillance is no longer of benefit to you, the decision to stop surveillance should be made jointly with you and if appropriate, your family and carers.

Questions you might like to ask about having surveillance of the large bowel

- Why have you decided to offer me surveillance?
- What does having surveillance involve?
- Is there some written material (like a leaflet) or audio information about surveillance of the large bowel that I can have?
- How often should I have surveillance?
- Where will surveillance be carried out? Will I need to have it in hospital?
- Will I be able to carry out my usual activities in the days before having surveillance and straight after surveillance?
- When will I get the results of surveillance?

- What happens if I want to stop having surveillance?
- What happens if I have signs of colorectal cancer? Am I likely to need surgery or other treatment?

People with inflammatory bowel disease

If you have had symptoms of inflammatory bowel disease for at least 10 years your specialist should offer you a test called a colonoscopy (see 'Surveillance tests').

The colonoscopy will show how much of your large bowel is affected by inflammatory bowel disease and how active the disease is. It can also detect signs of dysplasia or early colorectal cancer in the large bowel. Your specialist will look at the findings of the colonoscopy and consider any history of colorectal cancer in your family and whether you have any other conditions, such as narrowing of your large bowel or a type of liver disease called primary sclerosing cholangitis, to determine your risk of developing colorectal cancer. If your risk is higher than people in the general population, you should be offered surveillance at 1 year, 3 years or 5 years, depending on your level of risk.

If there are any signs of dysplasia or early colorectal cancer in your large bowel, you should be offered treatment or you may be referred to another specialist. Your options should be discussed with you.

If you have a condition called proctitis, when only the lowest part of the bowel is inflamed, you should not be offered surveillance.

People with polyps

If you have been diagnosed with polyps, it is likely that they were removed when you had your colonoscopy. Your specialist should be able to work out your risk of developing colorectal cancer based on the number and size of the polyps found. Depending on your risk, you should be offered surveillance at 1 year or 3 years. If your risk is low, your specialist will consider offering you surveillance at 5 years.

If there are any signs of dysplasia or early colorectal cancer in your large bowel, you

should be offered treatment or you may be referred to another specialist. Your options should be discussed with you.

Surveillance tests

Some tests may not be suitable for you, depending on your exact circumstances. If you have questions about specific tests and options, please talk to a member of your healthcare team.

There are different types of surveillance test and these are described in the box below. The test usually offered is colonoscopy.

Your specialist should give you information about what to expect during and after the test and whether you will need a sedative. They will also discuss with you any risks of the test and how to prepare for it, for example, what you can eat before the test and when, or whether you need to take a laxative to empty your bowel.

Each time you have a surveillance test, the results will help your specialist decide (in discussion with you) when you should come for your next surveillance test, or if you need to have another surveillance test.

Surveillance tests

The NICE guideline recommends the following tests to look for changes in the large bowel, including signs of colorectal cancer.

- **Colonoscopy:** a thin flexible tube containing a tiny video camera is inserted through the rectum (also called the back passage) into the large bowel. This shows any abnormal areas or polyps inside the large bowel. Tissue samples, known as biopsies, can be taken during the procedure. You should be offered this test if you have had polyps removed. Sometimes a colonoscopy may need to be repeated if it has not examined all of the large bowel.
- **Chromoscopy:** a dye is used during colonoscopy to show up any abnormal areas. You should be offered chromoscopy if you have inflammatory bowel disease.

- **Computed tomographic (CT) colonography:** a CT scan of the large bowel that produces two- and three-dimensional images. You may be offered this test if you have had polyps removed and a colonoscopy is not suitable for you.
- **Barium enema:** an X-ray is taken after the large bowel is filled with barium fluid inserted through a tube into the rectum. Barium shows up any abnormal areas when the X-ray is taken. You may be offered this test if you have had polyps removed and a colonoscopy is not suitable for you.

More information

The organisations below can provide more information and support for people with inflammatory bowel disease or polyps having surveillance of the large bowel. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Beating Bowel Cancer, 0845 071 9301 www.beatingbowelcancer.org
- CancerHelp UK – the patient information website of CancerResearch UK, 0808 800 4040 www.cancerhelp.org.uk
- Crohn's and Colitis UK (working name for the National Association for Colitis and Crohn's Disease – NACC), 0845 130 3344 www.crohnsandcolitis.org.uk
- Macmillan Cancer Support, 0808 808 0000 www.macmillan.org.uk

You can also go to NHS Choices (www.nhs.uk) for more information.

Accreditation