

Guidelines for the management of hereditary colorectal cancer from the British Society of Gastroenterology (BSG)/ Association of Coloproctologists of Great Britain and Ireland (ACPGBI)/ United Kingdom Cancer Genetics Group (UKCGG)

Lay summary

What do these guidelines cover?

Bowel cancer is a common disease which will affect approximately 1 in 20 people in their lifetime. In the United Kingdom there is a national screening programme available for the whole population at a certain age (beginning in people in their 50s or 60s depending on where they live). This is usually a stool test perhaps followed by a colonoscopy.

In some people there are genetic ('hereditary') factors which may increase this lifetime risk of cancer. This may include those with a family history of bowel cancer, or those with genetic conditions which increase the risk of cancer of the gut. In some people with increased hereditary risk of cancer, we would suggest additional check-ups, surgical procedures, genetic testing or other interventions including medications or lifestyle advice.

A colonoscopy test uses a thin flexible tube with a tiny camera on the end to look inside your bowel. This test can find bowel cancer, or polyps (pre-cancerous growths) which can usually be removed to lower the risk of bowel cancer.

We address the issue of person-specific care (sometimes called 'personalised' care) in such individuals at increased risk of cancer of the gut.

This includes the choice of surgical procedures, made between clinicians and patients, which may be different from those without genetic risk factors for bowel cancer.

Gene testing for inherited risk factors for cancer is usually performed after some counselling, followed by a blood test. In this guideline we discuss the best ways to improve identification of people who might have increased genetic risk of bowel cancer, in order to prevent cancer, or better treat those with cancer who also have genetic risk factors.

These guidelines are primarily aimed at healthcare professionals and address:

- Who should have surveillance?
- When should surveillance take place?
- What else can we do to prevent cancer?
- What kind of surgery should we perform in people with hereditary cancer risk?
- Who is eligible for gene testing, and what kind of testing should we perform?

These guidelines were written by the British Society of Gastroenterology (BSG), the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the United Kingdom Cancer Genetics Group (UKCGG).

Common questions that patients and their relatives ask are outlined below.

If I have a family history of bowel cancer, do I need a colonoscopy?

It is not unusual to have a family history of bowel cancer. For most people the usual screening offered for those at average lifetime risk is adequate as a means of surveillance. However if a close relative was diagnosed under age 50 years, or if you have more than one close relative with bowel cancer, you may benefit from additional tests and/or procedures.

What is the purpose of surveillance?

The main purpose of surveillance is to find and remove polyps so that they are prevented from potentially developing into cancer in the future. If a cancer does occur, surveillance may also find it at an earlier stage when it is easier to cure.

Who can I ask about genetic testing?

You can talk to your GP about whether you should be referred to a specialist for genetic testing. It can be helpful to have genetic testing, but it is not always appropriate. With scientific advances more genetic testing is possible however.

Why have these guidelines on surveillance been updated?

New evidence has allowed medical professionals to improve the previous guidelines which were published a decade ago. New genetic tests are available which help us make decisions about how we may prevent cancer. Moreover, since the last guidance, national bowel screening has been introduced which provides a useful check-up for low-risk people. The updated guidelines aim to make surveillance, surgery, genetic testing and other more personalised. This ensures that such procedures or tests are recommended for people who need it, and not recommended to those who do not. Therefore for some people the need for and timing of surveillance colonoscopies has altered in this updated guidance.