When you will receive a screening invitation

The bowel cancer screening programme was paused in March 2020 in response to the coronavirus pandemic. Screening colonoscopy services were reintroduced by Trusts from June 2020, for those who had had a positive screening result and were on a waiting list for this investigation.

Routine invitations for bowel cancer screening started again from week commencing 17th August 2020, beginning with those who were due to be sent a test at end March 2020. All routine invites will continue to be delayed by approximately five months until the programme has the capacity to catch up.

Completing your screening test kit

When you receive your test kit, you should follow the instructions of how to collect your sample and return it to the laboratory in the envelope provided.

The test used within the bowel cancer screening programme has recently changed. The new test is called a Faecal Immunochemical Test (FIT). This test is easier to use and is better at detecting individuals who require further investigations.

Please post your completed test kit it as soon as possible. Delays in returning your kit may prevent the sample from being processed. You should receive your screening test result within 2 weeks.

What to do while you wait for your screening invite

While you wait for your invite it is important to be symptom aware. If you are concerned about symptoms of bowel cancer you should seek advice from your doctor. Symptoms may include:

- unexplained bleeding/blood in your stools
- a change in bowel habit
- pain or swelling in your abdomen
- unexplained weight loss
- unexplained tiredness.

Your safety if you need further investigations

If your screening test shows traces of blood in your bowel motion, you will be asked to contact the freephone helpline on 0800 015 2514. Appointments with the Specialist Screening Practitioner (nurse) have mostly moved to telephone appointments. A suitable time for the nurse to call you will be arranged by the helpline staff.

The Specialist Screening Practitioner will assess your fitness for further investigations and will advise you on all the measures the Trust is taking to keep you and their staff safe at this time. The Trust will advise you of all safety requirements and instructions for attending your investigation.

When attending the hospital for any investigations you will be asked to wear a face covering, you may be asked to attend alone and you may have to wait outside until the time of your appointment.

If you have symptoms of coronavirus, or have been in contact with someone who does, you must **not** go to your colonoscopy appointment. Contact the Trust and let them know you have coronavirus symptoms. Your appointment can be rearranged for a time after you have isolated.

'Taking the test could save your life'

Bowel cancer is a significant cause of ill health and premature death. Over 1,000 people every year in Northern Ireland are diagnosed with the disease and over 400 will die. Symptoms often develop late in the disease, leaving limited scope for treatment and potential cure. If detected at a very early stage bowel cancer treatment can be 90% successful.

The bowel cancer screening programme, which allows early detection and treatment, significantly improves outcomes for those with the disease which will save approximately 60 lives a year.

Bowel cancer screening is the third cancer based screening programme in Northern Ireland, following breast cancer and cervical cancer screening. It is the only cancer screening programme in Northern Ireland to include men.

The bowel cancer screening programme started in Northern Ireland in 2010 and it is for people who have no signs or symptoms of bowel cancer. The programme covers all of Northern Ireland. All people aged between 60 and 74 registered with a GP are automatically sent a screening kit every two years.

The bowel cancer screening programme involves the use of a home testing kit to collect a sample of bowel motion. Completed tests kits are returned to a laboratory which looks for traces of blood in the sample. Blood indicates that further investigations, usually a colonoscopy, are required.

For further information on bowel cancer screening please see:

Bowel cancer screening: the facts

- BeCancer Aware | Be Cancer Aware
- Bowel cancer screening: how to take the test
- Bowel cancer screening: the next step
- Cancer Research UK animated video on how to complete the bowel screening test in NI
- Bowel cancer screening | nidirect

Resources for health professionals can be found on <u>Bowel Screening | Cancer</u> Screening Northern Ireland

About bowel cancer

What does the bowel do?

The <u>bowel</u> is part of our digestive system and is divided into the small and large bowel. The large bowel is made up of the <u>colon</u> and <u>rectum</u>. Food passes from the stomach to the small bowel. After the small bowel takes nutrients into the body any undigested food passes through the large bowel where water is removed from the waste matter. This waste matter is held in the rectum (back passage) until it leaves the body as bowel motions (also known as stools or faeces).

What is bowel cancer?

Bowel cancer is also known as colon, rectal or colorectal cancer. The lining of the bowel is made of cells that are constantly being renewed. Sometimes these cells grow too quickly forming a clump of cells known as a bowel <u>polyp</u> (sometimes known as an <u>adenoma</u>). Polyps are not bowel cancers (they are usually <u>benign</u>) but they

can change into a <u>malignant</u> cancer over a number of years. A malignant cancer is when cancer cells have the ability to spread beyond the original site and into other parts of the body.

How common is bowel cancer?

Bowel cancer is the second most common type of cancer found in men and women in Northern Ireland. About 1 in 20 people will develop bowel cancer in their lifetime. Bowel cancer is more common in older people, with around 80% bowel cancers occurring in people over 60 or over.

What are the symptoms of bowel cancer?

Bowel cancer can develop at any time between screening tests. Do not ignore the following symptoms:

- Unexpected, painless bleeding from your back passage, or blood in your stools. If you see blood in your stools, you should see your GP immediately. Finding a little bright red blood just on the toilet paper probably does not matter. If it continues for two or three weeks, see your GP.
- A change in your bowel habit. You may develop loose bowel motions, or you may pass a slimy substance called mucus. Sometimes you may become constipated. Look out for constipation and diarrhoea combined. If you experience these symptoms for more than six weeks, you should see your GP. If you have these symptoms as well as others in this list, see your GP as soon as possible.
- Pain or swelling in your abdomen (belly or tummy).
- Unexplained weight loss.
- Unexplained anaemia (thinning of the blood). This can make you feel extremely tired. It is usually discovered by a blood test done by your GP.

All these symptoms can be caused by other conditions. For example, <u>haemorrhoids</u> (piles) often bleed.

Why screen for bowel cancer?

Why screen for bowel cancer?

Bowel cancer screening aims to detect bowel cancer at an early stage (in people with no symptoms) when treatment is more likely to be effective. Screening can also detect polyps. Polyps are clumps of cells that are not cancer but may develop into cancer over time. If polyps are picked up early they can easily be removed reducing the risk of bowel cancer developing.

Regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by 16%.

Who is screening aimed at?

The Northern Ireland Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 74. People in this age group will automatically be sent an invitation and a screening kit so they can do the test at home. Your GP will provide your contact details so it is important that he or she has your correct name and address. After your first screening test you will be sent another invitation and screening kit every two years for as long as you remain within the screening age group.

How does the screening test work?

- The Faecal Occult Blood Test (FOBT) detects tiny amounts of blood which you cannot normally see in your bowel motions. ('occult blood' means hidden blood)
- Polyps and bowel cancers sometimes bleed which is why we screen for blood in your bowel motions.
- If the test picks up some bleeding this does not mean that you definitely have bowel cancer. It just means you should be checked out to find the cause.

How reliable is bowel cancer screening?

A screening test cannot tell if you have bowel cancer. It simply sorts people into two groups – those who do not need any more tests and those who should have further

tests. No test is 100% reliable so if you are concerned about bowel symptoms you should contact your GP, even if your last test was negative.

Is screening for bowel cancer appropriate for everyone?

Bowel cancer screening may not be appropriate for everybody. Individuals may not need to complete the test kit if they:

- · Have had their large bowel removed;
- Have had a colonoscopy or a barium enema plus a Sigmoidoscopy within the last two years;
- Are on a bowel polyp surveillance programme;
- Are currently being treated for bowel cancer;
- Are currently being treated for ulcerative colitis or Crohn's disease;
- Are currently awaiting bowel investigations.

If you are unsure whether you need to complete the test kit or not you should speak to your GP or call the freephone helpline on 0800 015 2514.

How do I do the screening test?

How do I do the screening test?

The test is done in the privacy of your own home. The screening kit provides a simple way for you to collect a very small sample of your bowel motion (stools) onto a special card. A detailed instruction leaflet 'Bowel cancer screening – how to take the test' is available to show you how to take the test. Once you have collected a sample, the card is placed in a special envelope and posted to the screening laboratory. It is safe to send in the post. You may think that doing the test sounds a bit embarrassing or unpleasant but it will only take a few minutes. If you have any

questions about how to use the test kit please call the Freephone Helpline number 0800 015 2514.

When will I get my results?

You should get your results within two weeks of sending in your test. If you don't get your results within two weeks, call the freephone helpline on 0800 015 2514

What do the results mean?

- A negative result means that blood was not found in your sample. Most people (about 98 out of100) will receive a negative result. You will be offered bowel cancer screening again in two years time provided you remain within the screening age group.
- An unclear result means there was a slight suggestion of blood in your sample.
 Receiving an unclear result does not mean you have cancer, just that you need to do a Repeat Test (<u>FIT Faecal Immunochemical Test</u>) to double check for any blood.
 About four people out of every 100 will receive an unclear result. Most people who do the repeat test will then receive a negative result.
- A positive result means that blood has been found in your sample. It is not a diagnosis of cancer but it does mean that you will be offered an appointment with a Specialist Screening Practitioner (SSP) to talk about further tests. About 10 in every 500 people tested will have a positive result. Even then, 9 out of every 10 of these will not have cancer. Blood in your bowel motions can also be caused by small growths called polyps or other conditions such as haemorrhoids (piles).

What happens if my test result is positive?

A positive test result means that blood has been found in your stools. You will be offered an appointment with a Specialist Screening Practitioner who will explain what further tests can be done. The most common test is called a colonoscopy. The Specialist Screening Practitioner will fully explain the colonoscopy procedure to you and assess your fitness for it. If you want to go ahead with the colonoscopy the nurse will book an appointment for you.

What happens to my sample once it has been tested?

Once the sample has been tested at the laboratory, the result is recorded onto a computer database and the sample card is destroyed.

What happens to my information

- A copy of your results will be sent to your GP.
- The bowel cancer screening programme office needs to keep records of all people who have been screened and their results. Staff working for the programme may see your records. This information is used to make sure the programme is working to the high standard it should be. The information also shows how many cases of cancer have been picked up and makes sure that people are followed up with proper treatment.

If you need any further information on how your records are kept and used, you should contact the Freephone helpline 0800 015 2514.

Frequently asked questions

1. I'm within the age range. What do I have to do to take part in the Bowel Cancer Screening Programme?

As long as you are registered with a GP you will automatically be sent your screening invitation through the post so that you can do the screening test at home. All you need to do is make sure that your GP has the correct address details for you. In the meantime, if you have any concern about your bowel health, you should see your GP in the usual way.

2. I have a family history of Bowel Cancer, can I be tested earlier?

Eight out of ten people who get bowel cancer are over the age of sixty so the Bowel Cancer Screening Programme is aimed at people aged 60 to 71. If you are concerned about your family history, or risk of developing bowel cancer, or if you have any symptoms you should see your GP in the usual way.

3. I fall outside the age range, can I still have the test?

The target age range for the Northern Ireland Bowel Cancer Screening Programme is 60 – 71. Screening is not available to people outside of the age range. If you are worried about possible symptoms of bowel cancer you should contact your GP in the usual way.

4. I'm worried about constipation / diarrhoea - can I have the test?

If you have symptoms or are worried about a change in your bowel habit, then you should see your GP.

5. I'm within the age range and screening has started where I live - why haven't I been invited yet?

Once screening starts, it will take 2 years to invite everyone within your Health and Social Care Trust to participate. To ensure that that you will be invited make sure that your GP has your correct address and details and you will receive your bowel cancer screening invitation and kit in due course. Please note invitations are issued based on your birthday as opposed to age. As always, people worried about possible symptoms shouldn't wait for screening, but should speak to their GP

6. How do I get my screening kit?

If you are in the screening age range of 60-74 you will automatically be sent your screening invitation through the post. All you need to do is make sure that your GP has the correct address details for you.

7. I take care of the toilet needs of an infirm/disable person - can I complete the screening kit for them?

If the person has asked for help, understands the screening process (including colonoscopy), and does not have a medical condition that means they shouldn't be screened, then yes, you can assist them to complete the test kit.

8. I am a carer, looking after someone who lacks the mental capacity to make their own decisions about screening - how should I deal with their invitation?

If the person you care for is unable to make their own decisions about screening, then you, as their carer, should make what is called a 'best interests' decision on their behalf, in the same way as you may be making other decisions about their care and treatment. You will need to weigh up the benefits of screening, the possible harm to them and what you think the person would have wanted to do themselves. Whether you are a paid carer, or an unpaid carer, family member or close friend, the process is the same. You may find it helpful to speak to the persons GP to discuss.

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