

# BowelScreen

# Important information about your bowel screening





#### What is BowelScreen?

BowelScreen is the National Bowel Screening Programme, which is part of the National Screening Service. It is funded by the Government.

The programme offers people in the eligible age range a free home screening test called the FIT test every two years. (FIT stands for faecal immunochemical test.) (Read more about this test on page 4.)

The age range of BowelScreen is changing. This will make the free home screening programme available to more people. To find out if you can take part visit <a href="https://www.bowelscreen.ie">www.bowelscreen.ie</a>.

If you are outside the eligible age range, please contact your GP (family doctor) with any concerns you have about your bowel health.

If you are having treatment for a bowel condition, ask your GP if it is appropriate for you to take part in the BowelScreen programme.

If you would like to consent (agree) to take part in the BowelScreen programme, please call Freephone 1800 45 45 55 or email us <a href="mailto:info@bowelscreen.ie">info@bowelscreen.ie</a>. You can also register for BowelScreen online. Please visit <a href="https://www.bowelscreen.ie">www.bowelscreen.ie</a> for more information.

# What is bowel screening?

Bowel screening aims to detect signs of bowel cancer at an early stage, where there are no symptoms. (You can read more about symptoms on page 10.) Around 2,600 people are diagnosed with bowel cancer in Ireland every year.

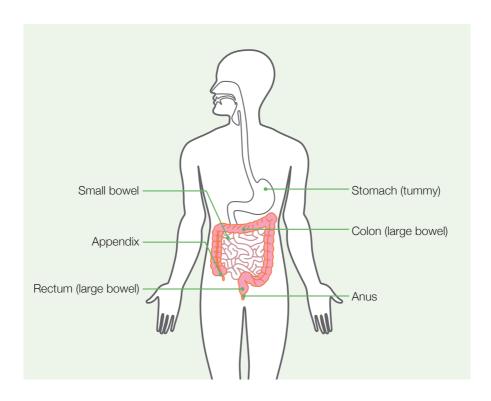
Bowel cancer is the second most common cancer in men and the third most common cancer in women in Ireland. If we find bowel cancer early, it is easier to treat and there is a higher chance of recovery.

Bowel screening uses a home test kit that looks for a level of blood in your stool (poo). If the amount of blood found in your stool sample is above the screening limit, BowelScreen will refer you for a further test called a colonoscopy. (Read more about this test on page 7.)

# What is bowel cancer and why do we screen for it?

Bowel cancer is also known as colon, rectal or colorectal cancer. It affects the lower part of the digestive system (gut).

 People of any age can get bowel cancer but the risk increases as you get older.



#### How is the BowelScreen test done?

Screening involves taking a sample of your stool (poo) at home using a home test that we post to you.

The FIT test kit provides a simple way for you to collect a small sample of your stool (poo) at home. This may sound embarrassing or unpleasant, but it only takes a few minutes.

You can collect the sample at any time of day or night. Follow these three steps:

- 1. Collect a sample by scraping the sampling stick on your stool until the end of the stick is covered
- 2. Put the sample stick in the tube we sent you and seal the tube in the plastic bag provided
- 3. Use the pre-paid envelope to send the sample back to us on the same day you take the sample or the next day. We will then test it.



This test we do (FIT test) looks for a level of blood in your stool. If the level of blood in your stool sample is above the screening limit, BowelScreen will refer you for a further test called a colonoscopy. (You can read more about this test on page 7.)

Blood can be present in your poo for many non-serious reasons. But it could also be an early warning sign that you may be at risk of bowel cancer.

# Your bowel screening results

You will get a letter with the results of your BowelScreen FIT test in about four weeks.

There are two types of results.

#### 1. Normal

Most people (96%) will get a normal result. This means that no blood was detected, or the amount of blood in your stool sample is below the screening limit.

If you are within the eligible age range you will be invited to take the test again in two years.

It's important to be aware of your bowel health as changes can happen at any age. Please visit your GP (doctor) straight away if you notice any symptoms. Do not wait for your next screening test.

You can find more information on symptoms of bowel cancer on page 10.

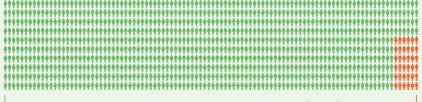
#### 2. Not normal

This means that the amount of blood in your stool sample is above the screening limit. To find out why this is, BowelScreen will refer you for a test called a colonoscopy.

(You can read more about this test on page 7.)

Higher levels of blood in your stool doesn't mean you have bowel cancer. There could be blood in your stool for other reasons – for example, you might have haemorrhoids (piles). More information on haemorrhoids is available on the HSE website.

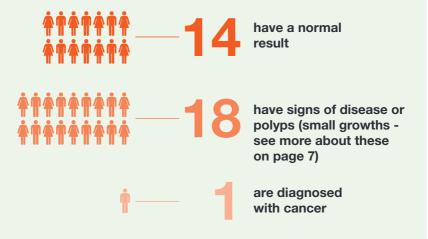
# On average, out of every 1,000 men and women screened for bowel cancer\*



About 967 have a normal result

About 33 have a not normal FIT result

Of the 33 people who have a not normal FIT result and go to colonoscopy, about:



<sup>\*</sup> According to our most recent BowelScreen data

# If you need a colonoscopy

A BowelScreen nurse will phone you to talk about what happens during the colonoscopy. The nurse will ask you a number of questions about your general health and about any medication you may be taking.

If it is clear that you are suitable to have a colonoscopy, the nurse will offer you one within about four to six weeks. Before this, you will also get information about the benefits and risks of the procedure.

A colonoscopy is an examination of your bowel using a small camera on the end of a thin flexible tube. The tube is inserted into your bottom, passed through the back passage (also known as the rectum) into the large bowel or colon.

A colonoscopy is done in a hospital in an endoscopy unit. BowelScreen will organise this appointment.

#### **During the colonoscopy**

During the examination a small sample of the lining of your bowel may be taken to be looked at more closely. This is called a biopsy. The test looks for any polyps or signs of disease in the lining of your bowel.

Polyps are small growths that are not cancer but, if not removed, might turn into cancer over time. If polyps are found, they are usually removed during the colonoscopy. This is to reduce the risk of cancer developing. This is painless.

A colonoscopy is the best way to find bowel cancer, the presence of polyps and other conditions.

BowelScreen will send you and your GP a letter with your results.

If you need help to understand your results or you want to talk about them, you can ring our Freephone 1800 45 45 55, email <u>info@bowelscreen.ie</u> or contact your GP.

#### Benefits of bowel screening

#### Bowel screening:

- saves lives
- can detect bowel cancer early
- improves bowel cancer survival cancer rates.

If bowel cancer is found early through regular screening:

- it is easier to treat
- there may be more treatment options
- your chances of surviving it is greater.

# Limitations of bowel screening

A screening test does not diagnose (confirm) if you have or do not have a condition. Like all screening tests, it is carried out on people who seem to be healthy. They don't have symptoms.

The bowel screening test looks only for a higher level of blood in your stool than normal. However, even if the amount of blood in your stool is below the screening limit, this is not a guarantee that you don't have bowel cancer. This is because not all cancers or polyps bleed all the time.

#### No screening test is 100% reliable.

Changes in your bowel health can also happen between screening tests. This is why it is so important to have the screening test every two years.

Always see a GP if you have any concerns or symptoms of bowel cancer at any time. (Read more about symptoms on page 10).

#### Interval cancer is not common

An interval bowel cancer is a cancer that is diagnosed within three years of having a colonoscopy. Interval cancers are unavoidable because we know that screening tests cannot detect every cancer. Interval cancers are not common.

For every 1,000 people screened, around two of these will have interval cancer. This is a low rate that compares well internationally.

# Why interval cancer happens

In most of these cases, there was no sign of cancer seen during the colonoscopy. Instead, the signs of cancer developed after the colonoscopy. In some interval cancers, some signs of cancer were there, but they were not found when the colonoscopy was done.

This does not necessarily mean there has been a mistake. It is a stated limitation of the screening test that it will not pick up all signs of cancer (find out more about the limitations of bowel screening on page 8).

#### Screening review

If you develop bowel cancer between screening tests (an interval cancer), and you have had a BowelScreen colonoscopy, you can ask for a review. Contact <a href="mailto:review.request@screeningservice.ie">review.request@screeningservice.ie</a> or National Screening Service, King's Inns House, 200 Parnell St, Freepost FDN7612, Dublin 1, D01A3Y8.

# Review your screening history after interval cancer diagnosis

Anyone diagnosed with bowel cancer can request a review of their screening history.

We are putting in place a new review process at the moment.

You can read more about the expert panel review of our interval cancer review process on <a href="www.bowelscreen.ie">www.bowelscreen.ie</a>. We will update our website with details of how to request a review when this process has been finalised.

# How can you reduce your risk of developing cancer?

It's important to stay aware of your bowel health as changes can occur at any age. A healthy lifestyle can reduce the risk of bowel cancer.

#### Try to:

- be more physically active
- eat a diet with plenty of dietary fibre such as fruit, vegetables and wholegrain bread, brown rice and cereals
- eat less processed food and red meat
- keep a healthy weight
- limit the amount of alcohol you drink

# Symptoms of bowel cancer

The most common symptoms of bowel cancer are:

- a change in your bowel habits such as going to the toilet more often or diarrhoea that lasts for a number of weeks
- bleeding from the back passage (also known as the rectum)
- pain or lump in your stomach (tummy)
- loss of weight when you are not trying to lose weight.

A number of conditions can cause these symptoms. But, if you have one or more of these symptoms, you should see your GP.

# If you need additional support

If you or someone you care for has a disability, or needs additional support to take part in BowelScreen, we can help.

Please contact our **access officer**. You can email them at: <u>access@bowelscreen.ie</u> **or** call the Freephone number on 1800 45 45 55 and ask to speak to them.

#### Information in other languages

For information about bowel screening in other languages visit www.hse.ie/bowelscreenvideos

# Communicating with you

We will communicate with you in an open, honest, timely and transparent manner if:

- something goes wrong with your care
- you experience harm as a result of your care
- we think that harm may have occurred.

This means that we will keep you fully informed of the facts and details related to your participation in the BowelScreen programme.

# Where did BowelScreen get your details?

BowelScreen puts together a list of people who qualify for screening. We get these details from the Department of Social Protection and from people who register for the screening programme themselves over the phone or online. We gather this information under the Health Provision of Information Act, 1997. This Act covers collecting necessary personal information of people who are invited to take part in screening programmes.

# What is included in your personal information?

Your personal information includes your name, address, phone number, date of birth, Personal Public Service (PPS) Number and mother's maiden name. It also includes your bowel screening history. Your bowel screening history relates to your participation in BowelScreen.

This personal information can also include your bowel screening results, colonoscopy attendances, treatments and biopsy (test sample) results.

BowelScreen takes and securely stores your personal information. Your personal information is not a medical record.

If you have had a screening test as a private patient, we will **not** hold this information. We are also unable to access any information or results of tests you have had as a private patient.

#### How do we use your personal information?

We will use your information to contact you when your next screening test is due or when your results are available. We also exchange your information with the other health services that deliver the BowelScreen programme. This includes your GP.

If you have a colonoscopy, your data will also be shared with the colonoscopy clinic, the National Cancer Registry of Ireland as well as other healthcare professionals. This is to enable us to provide you with a quality healthcare service.

We may use your screening test sample in teaching, in reviews and audits and to check the quality and effectiveness of the programme. We may also use your information to invite you to take part in research. It is your choice to take part or not.

We will never use your name in any reports, when teaching or in reviews.

We will keep your personal information safe, secure and confidential in line with current data protection regulations.

You will have full and open access to your personal information held by BowelScreen upon request.

You can find out more about data protection rights and how to use them at <a href="https://www.hse.ie/gdpr">www.hse.ie/gdpr</a>.

#### Change in details

It is important that you let BowelScreen know if your personal details (such as your address) change. You can do this by contacting us on Freephone 1800 45 45 55 or emailing <a href="mailto:info@bowelscreen.ie">info@bowelscreen.ie</a>.

# Giving your consent

Remember: Only you can give your consent to be part of our programme.

You have to give your consent before you have your first screening FIT test at home.

You can withdraw your consent at any time by contacting us on Freephone 1800 45 45 55 or emailing info@bowelscreen.ie

This means we will not contact you about BowelScreen in the future.

#### More information

Visit <u>www.bowelscreen.ie</u>, Freephone 1800 45 45 55 or email <u>info@bowelscreen.ie</u> if you would:

- like more information
- like to register for the bowel screening programme
- want to check if you are on the register

The National Bowel Screening Programme, King's Inn House, 200 Parnell Street, Dublin 1 D01 A3Y8. Email: <a href="mailto:info@bowelscreen.ie">info@bowelscreen.ie</a>



