



National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport

Bowel Cancer Screening Programme

2017



Why this brochure?

In this brochure, you will find information about the screening for bowel cancer. The purpose of this brochure is to give you information about the screening, so you can decide whether or not you wish to participate in it. Bowel cancer is a serious illness. Four to five individuals out of every 100 people will get bowel cancer during their life. In 2015, 15,500 people in the Netherlands were diagnosed with bowel cancer, 8,800 men and 6,700 women. In 2014, this disease killed 4,950 people. Source: IKNL & CBS- Mortality statistics, preliminary results. Bowel cancer can be detected and treated at an early stage, thanks to screening. If bowel cancer is detected early on, there is a better chance of curing it. The treatment is also less arduous. Possible precancerous stages may also be discovered. The treatment of a precancerous stage can prevent bowel cancer from developing. In the long term, this screening programme can help to prevent 2,400 deaths from bowel cancer each year.

For whom?

Screening is intended for men and women from 55 to 75 years of age. They receive an invitation every two years. The screening programme will be introduced incrementally up until 2019. Not everyone will receive an invitation immediately.

This is because it takes time to train sufficient numbers of care providers to carry out the follow-up examination involved.

Your year of birth determines when you will receive an invitation.



You can find the invitation summary at www.bevolkingsonderzoekdarmkanker.nl



What causes bowel cancer?

Bowel cancer often has a lengthy precancerous stage. It usually starts as a polyp. A polyp is a bulge on the wall of the colon. There are early-stage and advanced-stage polyps. Polyps are fairly common in people above the age of 55. Most polyps are benign and will always stay that way. Some polyps can develop into malignant tumours: bowel cancer.

For more details about bowel cancer see:

- www.kanker.nl, maintained by organisations in the field of cancer (Dutch Cancer Society (KWF), Dutch Federation of Cancer Patient Organizations (NFK), Association of Comprehensive Cancer Centres (IKNL))
- www.maagleverdarmstichting.nl

Can bowel cancer be treated?

Polyps are easily recognisable and relatively easy to treat. There are early-stage and advanced-stage polyps. Polyps are usually removed during an internal surveillance examination, known as a colonoscopy. During this examination a doctor examines the colon, using a small camera. The camera is mounted on a tube and is passed into the colon through the anus. Polyps are usually removed immediately, during the colonoscopy. These polyps will then no longer be able to develop into bowel cancer. If bowel cancer is detected, the treatment will depend on the stage of the cancer in question. Another deciding factor is the patient's state of health. Initial treatment usually involves surgery, to remove a section of the colon. In some cases, supplemental chemotherapy may be needed.



What is this screening actually testing for?

Bowel cancer screening involves tests for traces of blood in your stool (poo). The presence of blood in stool can be caused by polyps in the bowel and by bowel cancer. Blood in the stool is usually not visible to the naked eye. This is why your stool will be tested in a laboratory.

What does the screening involve?

The invitation is accompanied by a sampling tube, the self-sampling test kit. You take samples at four different places in your stool. You do this using the stool sampling stick that is attached to the green cap of the self-sampling test kit. Even a tiny amount of stool material is sufficient to carry out the test effectively. If too much stool material is placed in the sampling tube, it will become unusable for the screening. First read all of the instructions. When you have finished, fill in the reply form and post it back in the return envelope, together with the sampling tube. Your stool will be tested in a laboratory. At www.bevolkingsonderzoekdarmkanker.nl, you can watch a video clip that shows you how to perform the test correctly.

In what situations would it be better for you not to take part?

- You do not need to take part in the screening if you are already being treated for bowel cancer.
- If you have had a colonoscopy in the past five years, it is better to discuss your participation in this programme with your GP.
- If you are currently being treated by a gastroenterologist or internal specialist, please discuss your participation with this physician

Do you have doubts about participating in the screening programme?

Please consult your GP or the attending physician.

Do you currently have symptoms?

The most common symptoms that may indicate bowel cancer are:

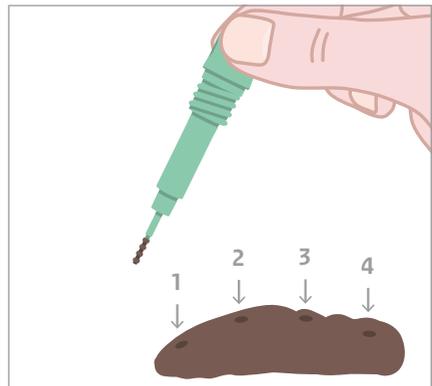
- an unexplained and persistent change in the pattern of bowel movement, such as constipation or diarrhoea;
- blood in the stool.

Are you currently experiencing symptoms that might be related to bowel cancer?

If so, first consult your GP. The GP can determine the most suitable examination in your situation.

If you will not be participating in the screening, please fill in the cancellation form on the back of the reply form and post the form off in the return envelope.

Dip the ribbed section of the sampling stick into your stool. Only a small amount of stool material is needed. If too much stool material is placed in the sampling tube, it will become unusable for the screening.



The results

Within one to two weeks after you have returned the sampling tube, a letter containing the results will be sent to your home address. There are two possible results:

The result is favourable

Further examination is not required. You do not need to do anything. In two years' time you will receive another invitation for screening. If you are above the age of 75, you will not receive any more invitations. The test does not provide complete certainty. Are you experiencing symptoms that might be related to bowel cancer? Please contact your GP and do not wait for an invitation for the screening programme.

Your stool has been found to contain blood

The test does not detect bowel cancer, just the presence of blood in the stool. There are also other possible causes. Further examination in the hospital is needed to find out what is causing the presence of blood in your stool. The result letter will inform you about your appointment for the intake interview at the hospital. It also contains details of how you can change the date of this appointment. If your stool has been found to contain blood, your GP will be informed about this.

It is important to repeat the screening **every two years**. If you get your stool tested every two years, the risk that a polyp or tumour might be missed will be smaller.





Follow-up examination

The letter containing the screening results will also indicate if further examination is needed. The further examination consists of an intake interview and examination of the colon, using a small camera, a colonoscopy. The colonoscopy takes place in a colonoscopy centre. This is usually a hospital unit. Enclosed with the letter containing the screening results is your invitation to the intake interview and a leaflet giving details of the intake interview and the colonoscopy. You can find further details at www.bevolkingsonderzoekdarmkanker.nl.

Costs

Participation in the screening programme is free of charge. Further examination (intake interview and colonoscopy) is not part of the screening. The costs of these tests are covered by your health insurance. You may be obliged to pay the costs, or a part of them, yourself. This depends on your excess amount and how much you have already used of this. For questions about this, please contact your health care insurer.

Deciding whether or not to participate

The bowel cancer screening programme is organised by the government. Participating in a screening programme has benefits and drawbacks. Research has shown that the benefits of such screening, to the target group as a whole, outweigh the drawbacks involved. For you, personally, this may not be the case. It is, of course, up to you to decide whether or not you wish to participate in the screening.

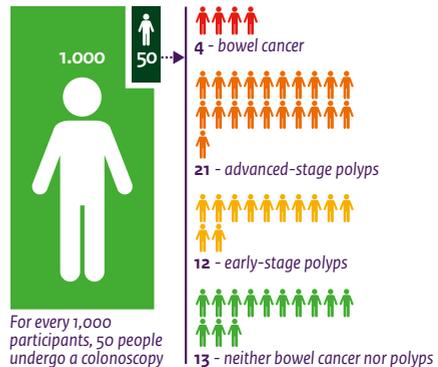
The risk of bowel cancer

Four to five individuals out of every 100 people will get bowel cancer during their life. If blood is found in the stool, further examination is required (colonoscopy). A small number of people undergoing a colonoscopy are diagnosed with bowel cancer.

For every 1,000 people who take part in the screening programme, 50 undergo a colonoscopy.

For each 50 people who undergo a colonoscopy:

- 4 of them will be diagnosed with bowel cancer.
- 21 people will be found to have advanced-stage polyps.
- 12 people will be found to have early-stage polyps.
- The remaining 13 people will be found to have neither bowel cancer nor polyps.



It is up to you to decide whether you want to undergo this examination. The main benefits and drawbacks of screening are described below.

Benefits

- Bowel cancer can be detected and treated at an early stage, thanks to screening. If bowel cancer is detected early on, there is a better chance of curing it. The treatment is also less arduous.
- The screening programme may reveal a precancerous stage of bowel cancer. The treatment of a precancerous stage can prevent bowel cancer from developing.
- This screening programme will reduce the number of people dying from bowel cancer. The screening programme will ultimately help to prevent 2,400 deaths from bowel cancer each year.
- It is a self-sampling test. You can determine the time of the test.
- The screening programme is directly linked to the healthcare system. If a further examination is needed, you can quickly get an appointment.

Drawbacks

- Screening does not always detect bowel cancer. In addition, screening is just a snapshot, it does not guarantee that bowel cancer will not develop in future. You may, therefore, be mistakenly reassured.
- The screening results may cause you some anxiety. People who are found to have blood in their stool must cope with a temporary period of uncertainty. Blood on your stool does not have to mean bowel cancer; there are other potential causes.
- Both preparing for colonoscopy and actually undergoing this procedure can be an unpleasant experience.
- If any polyps are found during this follow-up examination, they will be removed immediately. Not all polyps cause bowel cancer. It is, therefore, possible that it was not necessary to remove the polyps.
- If any anomalies are found during this further examination (colonoscopy) in the hospital, a surgical procedure is usually required. This involves a degree of risk. There may be complications, for example. Complications occur in two out of every 1,000 colonoscopies. The risk of dying is likely to be between 1 in 400,000 and 1 in 10,000.
- Depending on the amount of your health insurance excess, you may have to pay (part of) the cost of the follow-up examination yourself (intake interview and colonoscopy).

How did we obtain your details?

We obtained details of your name, address, date of birth, and country of origin from your local authority. By returning the sampling tube for testing, you are consenting to the use of this information within the screening programme.

What else do we do with your details?

The exchange of digital data

We comply with the legislation that protects your privacy. If you participate in the screening programme, we will process your details digitally. If blood is found in your stool, we will also send your digitised data to the colonoscopy centre where the further examination is to take place. By participating in the screening programme, you are giving the screening organisation permission to exchange your details, in digital form, with the caregivers who are involved, if this is necessary for the further examination. The screening organisation uses secure systems for this purpose. If you are not prepared to allow your details to be processed digitally, this means that you cannot participate in the screening programme.

Your GP

Has your stool been found to contain blood? The screening organisation will pass this result on to your GP. This will not happen if you object to this. If the results are favourable, your GP will not be informed. Thus your GP will not be informed that you have taken part in the screening programme.

The hospital

If blood is found in the stool, the screening organisation sends the results to the hospital where the further examination is to take place. The hospital needs your details in order to schedule an appointment. If you do not respond to the referral to the hospital, your GP will be informed. If you object to this, your GP will not be informed.

If there is no need for a follow-up examination, you will receive another invitation in two years' time. Consult your GP if you experience symptoms during those two years. It may be that a colonoscopy is needed.

The results of the screening and treatment of patients with severe intestinal symptoms are used to continually improve the bowel cancer screening programme. These results are obtained from other care providers, such as hospitals. In exceptional situations, your details may be used for scientific research. Your privacy will be thoroughly protected. The researcher will never know your identity. The screening organisations and researchers will comply with the applicable legislation.

Objection

Do you not agree to the screening organisation exchanging data with your GP, or do you object to your details or screening results being used for quality improvement and scientific research? If so, you can object to this. You can request an objection form from the screening organisation for this purpose, or you can download one from the website. You can find the address of your screening organisation's website at www.bevolkingsonderzoekdarmkanker.nl. Whatever your decision, this will not affect the way you are treated before, during, or after the screening. You can find further information at the website about how we deal with your personal details and screening results.

Digital access to your data

You can access your personal data through 'Mijn bevolkingsonderzoek'. You can view and change your data. You can also use 'Mijn bevolkingsonderzoek' to object. You can access 'Mijn bevolkingsonderzoek' through the website of the screening organisation that is responsible for the screening programme in your region.

Where can you get further information?

Do you have questions about your health? If so, consult your GP. On behalf of the government, RIVM instructs the five regional screening organisations to set up and manage the bowel cancer screening programme. Do you have any complaints, tips, or questions about the screening? Please contact the screening organisation in your region. The screening organisations have a complaints procedure.

For contact details and information: www.bevolkingsonderzoekdarmkanker.nl.
You can obtain details of the screening organisation's telephone number and address at this website.

You can identify the screening programmes by this logo:
bevolkingsonderzoek

This is a publication of:
National Institute for Public Health and the Environment
P.O. Box 1 | 3720 BA Bilthoven
www.rivm.nl

RIVM. Committed to *health and sustainability*

Great care and attention was devoted to the contents of this brochure.
You cannot derive any rights from it.

Edition 2017