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Statement of intent

CRUK is committed to informed choice with respect to screening participation. Screening has both benefits and harms, and these must be communicated appropriately.

Cancer Research UK aims to share examples of good practice in this guide. It is up to each individual practice to explore what methods they wish to facilitate and to take responsibility for compliance with data protection processes as appropriate.
Background

We know that primary care involvement in the bowel cancer screening programme can really drive engagement so we have prepared this guide to help brief you on the latest developments in the programme and suggest ways that you can support your eligible population to make an informed choice about their participation in bowel cancer screening.

Bowel cancer screening aims to detect bowel cancer at an early stage before symptoms have a chance to develop. It may also help to prevent bowel cancer through the identification and removal of potentially harmful adenomas. When diagnosed at its earliest stage, survival is much higher compared to when it is diagnosed at a late stage (below).

Bowel cancer 5 years survival by stage at diagnosis

Diagnosed at earliest stage

More than 9 in 10

Diagnosed at latest stage

Around 1 in 10

Earliest stage = stage 1; latest stage = stage 4.

Data is age-standardised net 5 years survival for adults (aged 15 to 99 years) in England in 2012-2016 followed up to 2017.


Eligible population:

- In Scotland all people who are registered with a GP between the ages of 50-74 years are invited
- In England and Wales, as a phased approach over the next few years, people age 50-59 year olds will be invited to participate in the bowel cancer screening programme. Therefore, people may now receive a test before they turn 60. Check with your local Public Health teams to get the latest information
- Those aged 75 and over can request a kit by ringing or by emailing the screening hub* – see Appendix 5
- People are invited by letter to their home address every 2 years and are asked to complete a FIT test by providing a sample from one stool and then posting it back to the programme for analysis in a sealed envelope. They receive their result by letter and their GP is informed

*may not be available in all nations

Statistics

Bowel cancer screening uptake increased after the introduction of FIT in England in June 2019. Uptake fell during the COVID-19 pandemic to its lowest point (since the introduction of FIT) but has now recovered and is exceeding pre-pandemic levels with uptake at 71.0% in Jan-Mar 2021¹.

Uptake of bowel cancer screening in Scotland has been increasing since FIT was introduced, from 56.3% in between 2015/17* to 63.2% in 2018/20².

While FIT is making a positive contribution to bowel cancer screening uptake, we’re still seeing a short fall of that seen in other cancer screening programmes and inequalities in uptake may still exist.

* Two-year reporting period is from 1st of May to 30th of April in given years.

See here for an overview of the latest statistics for bowel cancer screening programmes across the UK.

Role of primary care in supporting informed participation

What the evidence says

Studies have shown the positive impact that primary care engagement can have on increasing the uptake of cancer screening with eligible populations. The studies described in this section were undertaken when the primary test was gFOBt.

A study found that sending people eligible for bowel cancer screening a letter from their GP endorsing the screening programme, increased bowel cancer screening uptake by up to 6%¹, and by up to 12%¹ when sent in combination with enhanced patient information. Since this study, a GP endorsement banner has been introduced on both pre-invite and invite letters across England.

The same study also found that phoning people to provide information about bowel cancer screening and offering to answer questions, used in combination with a GP letter, increased bowel cancer screening uptake by around 8%.²

Providing the opportunity to speak to a trained bilingual advocate from a person’s own GP practice may help increase awareness of bowel cancer screening and overcome barriers to participation.²

For details of more interventions see CRUK’s Bowel Cancer Screening Hub.

Endorsement

Endorsement by a primary care team increases the uptake of screening.

Explaining what the test is for and how to do it will help people decide whether they wish to participate.

Any additional endorsement may be better targeted to previous non attenders so that subjects are not over contacted.

See flowchart to engage first timers and non responders for some suggested approaches (page 6).

Around 80% of people who have completed the kit once will do so again when they are invited in the future.

Quality improvement

In England, the Primary Care Network (PCN) GP Contract for Early Diagnosis requires PCNs to:

Contribute to improving local uptake of National Cancer Screening Programmes by working with local system partners to agree the PCN contribution to local efforts to improve uptake in bowel cancer screening and follow up on non-responders to invitations.

This must build on any existing actions across the PCN’s Core Network Practices and include at least one specific action to engage a group with low participation locally.

For more information see CRUK’s GP Contract Hub.


What you can do to support your practice population

Key questions you could consider:

- How many eligible people do you have?
- What % of people have not responded to their bowel cancer screening invitation?
- Who knows about bowel cancer screening in your practice. Could you train staff (including non clinical) to support participation?
- Do you have a dedicated member of staff who could lead on reviewing/engaging bowel cancer screening non-responders? (e.g. results, READ codes, health promotion, communication)

Use practice data

It could be helpful to review the bowel cancer screening data within your practice and/or across your Primary Care Network/Cluster. Reviewing the data will give you an understanding of the particular population groups who may need more support.

This information can be used to contact people, encourage them, and offer them further advice/signposting (i.e. to request a screening kit).

Actions

- For PCN or practice level data you could access:
  - OHID Fingertips Public Health Data
  - NHS Digital Cancer Screening Programme National Statistics
  - NHS Scotland
  - Public Health Wales
  - Northern Ireland - NISRA/HSC
  - CRUK Early Diagnosis Data Hub

- Regularly review your practice lists and check people's contact details are up to date
- Review your practice data to understand those that are eligible and are being invited for screening for the first time and engage early with them
- Review your practices' non-responders to understand the profile of those not attending their screening and then identify methods to engage with these people
- Access the online Gateway C (England only) FIT (bowel cancer screening) module here. Continuing Professional Development (CPD) points are available in the module

Training

Providing training to all of your staff (clinical and non clinical), will help them understand and be able to explain to your eligible population, the importance of bowel cancer screening in diagnosing bowel cancer early and giving people the best chance of successful treatment.

Training can also help ensure the whole practice team are aware of the different uses of FIT for screening vs symptomatic.

Know the test

Being familiar with the FIT kit can help practice staff explain and support people to complete the test.

- You could watch this useful video produced by CRUK. It addresses practical issues and patients’ potential concerns about the test. You can access the video here
- Keep a test kit for demonstration at your practice (the kit may look different to the one they receive in the post)
- Information can be displayed in the practice to alert eligible people to bowel cancer screening

FIT test

![FIT test image](image-url) Image will differ depending on nation

Results

Results are sent to individuals by post. GPs are informed of all results either electronically or by letter. Screening results do not provide a quantitative value, and rather indicate where further investigations are needed. For more information about results see here.

A negative result does not guarantee the person not having or developing bowel cancer in the future. Being aware of the symptoms of bowel cancer is important too. Click here to find out more about the symptoms of bowel cancer.
You can encourage informed participation in bowel cancer screening by:

- Making sure people are aware of the programme and the eligible age for participation
- Asking people if they have taken part, and encouraging them to participate every two years, even if previous results have been negative
- Encourage people to read the information pack carefully, to help them make their decision and inform them about the **benefits and harms** of screening
- Ensuring that any barriers to participation are minimised

**Actions**

- Recognise those that may need some additional support
- Use your practice IT system to identify those eligible for screening from the lower participation groups:
  - who are not likely to engage
  - who are approaching the age of their first invitation
  - who have not responded to their invitation
  - who have not participated in screening previously
- Agree a protocol to discuss bowel cancer screening with those who may require further support to access and complete their bowel cancer screening
- If a patient requires additional support to complete their bowel cancer screening, contact your local screening hub to record this information

**Identify inequalities in your local population**

Understand who are your lower participation groups in bowel cancer screening:

- People with lower socioeconomic status
- Men
- People from ethnic minority communities
- People who do not read or write English or where English isn’t their first language
- People with learning disabilities
- People with physical disabilities
- People with sensory impairment
- People with severe mental illness

Understand the barriers to participation. These may include:

- Language and literacy
- Fear
- Practicalities and ease of use
- Cultural barriers

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1. [https://www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf](https://www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf)
Flowchart to engage first timers and non-responders to screening

**Identify**
- Ensure letters from bowel cancer screening service are coded in people's records

**Use practice data to identify first timers to screening**
- Search for people approaching their first invitation

**Use practice data to identify non-responders to screening**
- Search for the eligible population with a non-response result in the last 2 years. See READ codes

**Review lists** to exclude people for whom it may be insensitive for the practice to endorse screening
(Note: they will still be invited by the national programme)

**Code**
- All first timers and non-responders
  - Add alerts/prompts to identify people and support discussion
  - Familiarise yourself with the READ codes used

**Contact**
Consider the intervention that would work best for your practice(s) to engage first timers and non-responders to screening e.g.
- Letter
- Text
- Telephone call

**You could also:**
- Display information in your practice
- Leaflet from receptionist
- Discuss with clinical staff
- Remind people of the phone number to request another kit if lost or discarded (hand them a bowel screening information card. You can order CRUK’s bowel cancer screening information cards here.)
- Opportunistically check details at routine appointments

**Check**
Evaluate effectiveness of the invention
- Code engagement methods used for each person
- Review which methods have been most effective

[Click here](#) to order CRUK resources about bowel cancer screening for your practice(s)
Safety netting

People and health professionals should be aware that a previous negative bowel cancer screening test result does not rule out cancer. If a person has any symptoms or changes that are not normal for them they should contact a health professional.

Is the person eligible for the bowel cancer screening programme?
Use clinical IT systems to flag up people due or non responders who have not completed their bowel cancer screening

- Yes
  - Encourage participation and assess removing any barriers to participation.
  - Consider approaches outlined in this guide, to support participation

- No
  - N/A

Has the person participated in the screening programme?

- No

What was the result of the test?

- No further tests are needed at this time
  - Educate person about red flag symptoms.
  - Reinforce importance of repeat screening (i.e. taking part in the next screening round)
  - Avoid over reassurance by maintaining vigilance for symptoms

- Further tests needed
  - Did the person attend for colonoscopy?
    - Yes
      - Address barriers to accessing colonoscopy e.g. correct details, explain process

    - No
      - Safety net around symptoms/awareness and let them know how they can opt back in if they change their mind

  - Safety net around symptoms/awareness and remove barriers to improve participation. Provide info on how to opt out if they do not wish to participate in the future

- Have the person opted out?
  - Yes
    - Provide info on how to opt out if they do not wish to participate in the future
  - No
    - Reinforce importance of repeat screening (i.e. taking part in next screening round)
    - Avoid over reassurance by maintaining vigilance for symptoms

Ensure person enters correct pathway

Positive

Negative
Appendix 1

Sample telephone script – A guide to having a conversation with a person who has not completed their bowel cancer screening.

Before the call, it might be a good idea to have the following in front of you:

- Benefits/harms of bowel cancer screening
- Practical tips/how to collect poo

Introduction
Hello, ☑️ Verify who speaking with
My name is... I am phoning from... ☑️ Insert name of GP practice
There’s nothing to worry about, I’m phoning about the bowel cancer screening programme. Is it okay to have a chat with you about this? ☑️ If not, arrange convenient time to call back

Receipt of bowel cancer screening kit
We have received information from the bowel cancer screening service that you didn’t return your bowel cancer screening test kit.
Can I just check that you received your kit? ☑️ Mention date it was sent from the screening service

Yes ☑

No ☒

Can I ask your reasons why you didn’t return the kit? ☑️ Record why and provide non patient identifiable feedback (general themes) to: earlydiagnosis@cancer.org.uk*

Wants to participate but didn’t get round to it
Unsure whether to complete or not
 Doesn’t want to participate

☑️ Suggest practical tips to complete the kit
☑️ Discuss benefits and harms of screening

Common issues:
How to collect poo

Benefits:
Bowel cancer screening saves lives from bowel cancer
Harms:
- Screening can miss bowel cancers
- You may have to have further tests before finding out you don't have cancer
- If you get a positive result, you’ll be invited for a colonoscopy
- In a very small proportion of cases this can lead to bleeding or tearing of the wall of the bowel

☒ Order replacement kit (see appendix 5)

*We would be interested to hear what the barriers to screening are.
Appendix 2

Sample GP endorsement letter for non-responders

Building on the endorsement templates used in peer review studies, Cancer Research UK has produced a version that incorporates elements to promote informed consent.

Example letter

Dear <Patient Name>,

We are writing to you to express our support for the NHS Bowel Cancer Screening Programme. This is in follow-up to the bowel cancer screening kit that you would recently have received through the post.

Bowel cancer is the forth most common cancer in the UK. The aim of the Bowel Cancer Screening Programme is to discover bowel cancer at an early stage before symptoms have a chance to develop. The sooner it’s caught, the easier it is to treat, and treatment is more likely to be successful.

Bowel cancer screening involves a simple test that you carry out in your own home.

We encourage you to consider doing this screening test, which you then send off in the envelope.

Whether or not to do the test is your choice, so you should read the information you were sent with your screening invitation to help you decide.

If you have not received your screening pack or wish to have another sent out to you, please telephone the following number, which is the bowel cancer screening helpline:

<Insert your hub’s telephone number> or email <insert your hub’s email address (Appendix 5)>.

If you’re not sure how to complete the test itself, and have access to the internet, this link will give you further information:

https://www.cancerresearchuk.org/about-cancer/bowel-cancer/getting-diagnosed/screening or speak to your practice nurse who can show you how to complete the kit.

If there is anything else that you’d like to know or discuss about bowel cancer screening, please do not hesitate to contact the surgery for further advice.

Yours sincerely

Dr <insert name>

You might want to consider sending a copy of the how to do your kit infographic with this letter - you can find them here.

Appendix 3

Use of SMS texts

Texts can be used as an alternative to letters for people. Primary care can use it for engaging non-responders as well as using it for general promotion of the programme to all eligible people. Some screening services have started to encourage the use of text reminders in practices. This is an emerging intervention that we are closely monitoring to build an evidence base.

Sample text

Dear <Patient Name>,

we have been informed that you have not yet completed your bowel cancer screening test. The Doctors at <XXXX> Surgery encourage you to complete the test ASAP. If you are unsure about the test please talk to your practice.
Appendix 4

READ codes

Appropriate READ codes are useful when recording activity relating to bowel cancer screening and the results of the screening test kits. Consider working with your data quality team to understand how to carry out searches. Here are some suggested codes*:

<table>
<thead>
<tr>
<th>Read Description</th>
<th>V2</th>
<th>CTv3</th>
<th>SNOMED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel cancer screening programme invitation letter sent</td>
<td>9Ow5</td>
<td>XaZx5</td>
<td>862031000000107</td>
</tr>
<tr>
<td>Advice given about bowel cancer screening programme</td>
<td>8Ca</td>
<td>XaPyB</td>
<td>38216100000102</td>
</tr>
<tr>
<td>Bowel cancer screening declined</td>
<td>8A3</td>
<td>XaN4r</td>
<td>294201000000109</td>
</tr>
<tr>
<td>BCSP faecal occult blood test negative</td>
<td>686A</td>
<td>XaPkd</td>
<td>37521100000108</td>
</tr>
<tr>
<td>BCSP faecal occult blood test positive</td>
<td>686B</td>
<td>XaPke</td>
<td>37524100000109</td>
</tr>
<tr>
<td>BCSP faecal occult blood testing kit spoilt</td>
<td>6867</td>
<td>XaPka</td>
<td>37512100000106</td>
</tr>
<tr>
<td>Bowel cancer screening programme faecal occult blood testing incomplete participation</td>
<td>686C</td>
<td>XaQ1z</td>
<td>38424100000100</td>
</tr>
<tr>
<td>Provision of written information about BCSP</td>
<td>8OA5</td>
<td>XaZu9</td>
<td>860781000000108</td>
</tr>
<tr>
<td>No response to bowel cancer screening programme invitation</td>
<td>9Ow2</td>
<td>XaPf6</td>
<td>37325100000108</td>
</tr>
<tr>
<td>Bowel cancer screening programme telephone invitation</td>
<td>9Ow4</td>
<td>XaZx4</td>
<td>86201100000104</td>
</tr>
<tr>
<td>Not eligible for bowel cancer screening programme</td>
<td>9Ow3</td>
<td>XaX8y</td>
<td>75885100000101</td>
</tr>
</tbody>
</table>

* Please note, these codes may be subject to change during our next review.

Appendix 5

Key screening contacts

England – Bowel cancer screening helpline (all hubs) 0800 707 6060

- Midlands & North West (Rugby)
  Hospital of St Cross
  Barby Road
  Rugby, Warks, CV22 5PX
  Email: bowelscreening@nhs.net

- Southern
  20 Priestley Road
  Surrey Research Park
  Guildford, GU2 7YS
  Email: rsc-tr.BCSPSouthernHub@nhs.net

- London
  Level 5V 013 St Mark’s Hospital
  Watford Road
  Harrow, Middlesex, HA1 3UJ
  Email: lnwh-tr.bcsp@nhs.net

- Eastern
  University Hospital Queens Medical Centre
  Nottingham, NG7 2UH
  Email: nuhnt.bcsp.eastern@nhs.net

- North East
  Queen Elizabeth Hospital
  Sheriff Hill
  Gateshead, NE9 6X
  Email: gan-tr.north-east-bowel-hub@nhs.net

Scotland – Bowel cancer screening helpline 0800 0121 833 or email bowelscreening.tayside@nhs.net

Wales – Bowel cancer screening helpline 0800 294 3370

Replacement test kit: if you would like to request a replacement test kit please visit here

Northern Ireland – Bowel cancer screening helpline 0800 015 2514
Appendix 6
The bowel cancer screening pathway in England

Programme hub

**Invitation** to participate in bowel cancer screening by FIT test 60-74 Years old*

- Kit dispatched by FIT supplier
- Reminder sent if no return within four weeks

Receipt and analysis of FIT kit

- **No further tests needed** at this time (below FIT threshold)
- **Further tests needed** (at or above FIT threshold)
- **Spoilt kit/technical fail**

Local screening centre

- **SSP appointment made** – offer colonoscopy if suitable

- **Does not accept/is not fit**
- **Accepts colonoscopy**
- **Medically unsuitable** – referred for CTC

- **FOBT offered in two years if <75**
- **Non-attendance**
- **Nothing abnormal detected**
- **Polyp**
- **Cancer**
- **Other pathology**

- ** LNPCP (with histological R0 en bloc excision?)**
- **High risk findings?**

This pathway was produced by NHS England and NHS Improvement

* As a phased approach over the next few years, people age 50-59 year olds will be invited to participate.
**The FIT screening pathway in Scotland**

1. **Bowel cancer screening test** aged 50-74 every 2 years
   - Test returned
     - No response
     - 6 weeks reminder
     - No response
     - 2nd test spoiled or expired
       - Non responder (3 months)
         - Notifications are received via mail manager
   - Negative result
   - Positive result
   - 2nd test spoiled or expired
     - Referred to local board for pre-colonoscopy assessment
   - 2 year recall
   - Colonoscopy appointment

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This pathway was produced by Health Scotland. The supplementary comments (below) are provided by CRUK.

1. The 6 week reminder is provided by the bowel cancer screening programme.
2. If a 2nd test is spoiled or expired or the person does not respond at 3 months, then no further action is required. This person is re-invited at the next round (Rounds are two yearly intervals.)
3. After the colonoscopy appointment, those with an abnormal result undergo further tests to receive a diagnosis and treatment.
The FIT screening pathway in Wales

Invocation to participate in bowel cancer screening by FIT test 55-74 Years old*

FIT test kit returned and tested

- Negative: FIT test result lower than 150ug of Hb per gram of faeces
  - Recall 2 Years for FIT test
  - Unfit for colonoscopy
    - Refer to clinician for management
    - Consider CT colonogram
- Positive: FIT test result of 150ug or higher of Hb per gram of faeces
  - Screening assessment
    - Fit enough for colonoscopy
    - Refer to Colonoscopy
      - Complete
      - Incomplete
        - Consider repeat or CT colonogram

Surveillance programme
- High – colonoscopy 1 year
- Intermediate – colonoscopy 3 years
- Low – recall FIT in 2 years

Cancer
- Refer to Health Board MDT for symptomatic treatment and surveillance

* As a phased approach over the next few years, people age 50-54 year olds will be invited to participate.
The FIT screening pathway in Northern Ireland

Coming soon