

Together we are beating cancer

# Bowel cancer screening Primary care good practice guide



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### **Statement of intent**

Cancer Research UK is committed to informed choice with respect to screening participation. Screening has both benefits and harms, and these must be communicated appropriately. We aim 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**

Primary care can play an important role in increasing public engagement with the bowel cancer screening programmes. We have prepared this guide to help brief you on the latest developments in the programmes 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 polyps. When diagnosed at its earliest stage, survival is much higher compared to when it is diagnosed at a late stage (see below).

Across the UK, the bowel cancer screening programmes use the Faecal Immunochemical Test (FIT). FIT looks for hidden traces of blood in poo. View our **Bowel cancer screening programmes at a glance** summary to see how FIT is used in bowel cancer screening programmes across the UK.

Some people may experience barriers to informed bowel cancer screening participation, which their GP and wider practice team could help them overcome.



For more information about FIT please see our **Bowel Cancer Screening webpage**.

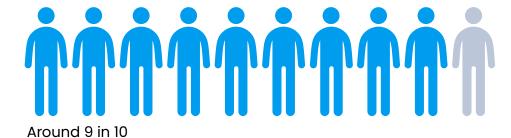
## Bowel cancer survival

by stage at diagnosis in England

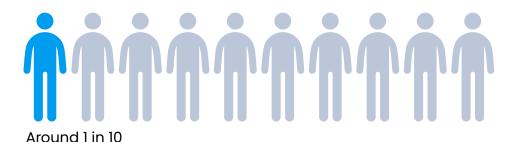
Proportion of people surviving their cancer for five years or more\*



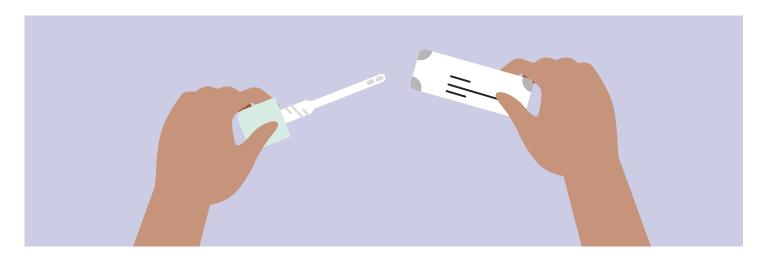
Survival when diagnosed at earliest stage (stage 1)



Survival when diagnosed at latest stage (stage 4)



\* Data is age-standardised net survival for adults (age 15 to 99 years) diagnosed in England between 2016-2020, followed up to 2021. Source: NHS Digital, Cancer survival in England, Published 2023.



### Eligible population for bowel cancer screening

### Bowel cancer screening is available to people in the following age groups:



- In England, people aged 60–74 years who are registered with a GP are invited. Over the next few years, people aged 50–59 years will also be invited to participate as the bowel cancer screening programme expands. So, people may now receive a test before they turn 60. Check with your local Screening Hub to get the latest information.
- In Northern Ireland, all people aged 60–74 years who are registered with a GP are invited.
- In Scotland, all people aged 50–74 years with a CHI (Community Health Index) number are invited.
- In Wales, everyone aged 55–74 years who are registered with a GP and living in Wales will be invited. Over the next few years, people aged 50–54 years will also be invited to participate as the bowel cancer screening programme expands.
- People aged 75 years and over in England and Scotland can request a FIT kit by ringing or emailing the screening hub—see Appendix 5.

People are invited by letter to their home address every two years. They are asked to complete a FIT kit 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.

## Lynch syndrome surveillance in England

The NHS Bowel Cancer Screening
Programme (BCSP) is now managing
colonoscopies for people with Lynch
syndrome in England. Lynch syndrome is a
hereditary condition that increases a
person's risk of bowel and other cancers
due to inherited faults in specific genes
(MLH1, MSH2, MSH6 and PMS2).

The NHS BCSP will invite people with Lynch syndrome to a specialist screening practitioner consultation followed by a surveillance colonoscopy every two years to help reduce their lifetime risk of bowel cancer.

We are not aware of upcoming plans to include people with Lynch syndrome in the Bowel Cancer Screening Programmes in Wales, Scotland and Northern Ireland.

### **Statistics**

Bowel cancer screening uptake has been increasing across the UK since the introduction of FIT. The most recent data shows that yearly uptake was 69.6% in England for 2021/22 [1], 62.1% in Northern Ireland for 2021/22 [2], 66.7% in Scotland for 2020–2022 [3], and 67.1% in Wales for 2020/21 [4]. We know there is regional variation in uptake within these nations.

While FIT is helping to improve bowel cancer screening uptake, it is still lower than other cancer screening programmes and variation in uptake across different demographic groups and geographies still exist.

## Role of primary care in supporting informed participation

### **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 people are not over contacted.

See <u>'Steps to engage first timers and</u> <u>non-responders'</u> for some suggested approaches (page 9).

Bowel cancer screening has harms as well as benefits, which is why it is important to assist people in making an informed decision about whether to take part. Some harms people should be aware of include false positives and negatives, over-reassurance following a normal result, and the risks associated with follow-up colonoscopy.

You can find more public-facing information on the possible risks and benefits of bowel cancer screening **here**.

### 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 the guaiac fecal occult blood test (gFOBT), prior to the introduction of FIT.



## GP endorsement letter

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% [5], and by up to 12% when sent in combination with enhanced patient information [5]. See our <u>sample GP endorsement letter</u> for non-responders on page 12.



## Telephone support

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% [6]. See our **sample telephone script** to support GP conversations with patients around bowel cancer screening (page 11).



## Text reminders

Evidence has suggested that **text reminders** increase uptake in first time invitees, although it does not appear to improve overall uptake [7]. The use of text reminders is increasing. Further evaluation will enable us to understand their role in supporting bowel cancer screening uptake. See a **sample text message** practices can send to patients who have yet to return their FIT kit (page 12)



## Language support

Providing people with the opportunity to **speak to a trained bilingual advocate** from their own GP practice may help increase awareness of bowel cancer screening and overcome barriers to participation [6].



For details of more interventions see our **Bowel Cancer Screening webpage.** 

### **Quality improvement**

In England, the Primary Care Network (PCN) GP Contract 2023/24 for Early Cancer 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 our **GP Contract Hub**.

## What you can do to support your practice population

## ? Key questions to consider

- How many eligible people do you haven for bowel cancer screening?
- What percentage of people have not responded to their invitation?
- Who knows about bowel cancer screening in your practice? Could you train staff (including non-clinical staff) to support participation?
- Do you have a dedicated member of staff who could lead on reviewing/ engaging bowel cancer screening nonresponders? (eg by reviewing results and READ codes, leading health promotion activities and communications)

### Use practice data

It could be helpful to review the bowel cancer screening data within your practice and/or across your region. This 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 (ie, to request a screening kit). We encourage practices to routinely check that patient contact details are up to date to ensure they receive this information.

## Actions

- For regional or practice level data you could access:
  - OHID Fingertips Public Health Data
  - NHS Digital Cancer Screening Programme National Statistics
  - Local Health Board Public Health departments (Scotland)
  - Public Health Wales
  - Northern Ireland NISRA and HSC
  - Our Early Diagnosis Data Hub
- Regularly review your practice lists, checking people's details are up to date
- Review your practice data to note people who are eligible for their first screening invitation and engage with them early

## Actions

- Review your practices' non-responders to understand the profile of those not attending their screening and then identify methods to engage with these people
- Visit the <u>Doctors.net.uk Bowel Cancer</u> <u>Screening Hub</u> (login required)
- Access the online <u>GatewayC Faecal</u>
   <u>Immunochemical Test module</u>
   (England and Wales only, login required).
   Continuing Professional Development
   (CPD) points are available in the module

### **Provide training**

Provide training to all your staff (clinical and non-clinical) to help them understand - and explain to your eligible population - the importance of bowel cancer screening in diagnosing bowel cancer early and increasing the chance of successful treatment.

Training can also help ensure that the whole practice team are aware that there are key differences in how the FIT is used when screening asymptomatic patients versus investigating symptomatic patients. For example, the bowel cancer screening programmes use a much higher FIT threshold for referral into diagnostic testing than FIT symptomatic. For more detail, download <u>our infographics</u> which highlight the different uses of FIT.

### Know the test

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

- View our <u>our patient videos</u>, which addresses practical issues and patients' potential concerns about the test.
- Keep a test kit for demonstration at your practice (the kit may look different to the one people receive in the post).
- Information can be displayed in the practice to alert eligible people to bowel cancer screening.
- Note that FIT kits vary across the UK (eg Scotland's kits are not labelled and participants are expected to label their own kits).

### **FIT kit**



The FIT kit will vary by nation.

### Results

Results are sent to people by post. GPs are informed of all results either electronically or by letter. Screening results do not always provide a quantitative value, and rather indicate where further investigations are needed. Find out more about screening results here.



A negative result does not guarantee the person not having or developing bowel cancer in the future. Being aware of the signs and symptoms of bowel cancer is important too. See CRUK's information on bowel cancer symptoms.

### **Encourage participation**

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 from either a screening or symptomatic FIT 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.
- helping to minimise any other known barriers to participation where feasible

## Identify inequalities in your local population

Understand who may be less likely to participate in bowel cancer screening:

- people with lower socioeconomic status [4, 8-10]
- men [4, 9, 11]
- people from non-white ethnic minority communities [10, 12, 13]
- people who do not read or write English or where English isn't their first language [12]
- people with learning disabilities [12, 14]
- people with physical disabilities [14]
- people with sensory impairment [14]
- people with severe mental illness [10, 14]
- people invited for the first time [4, 9]

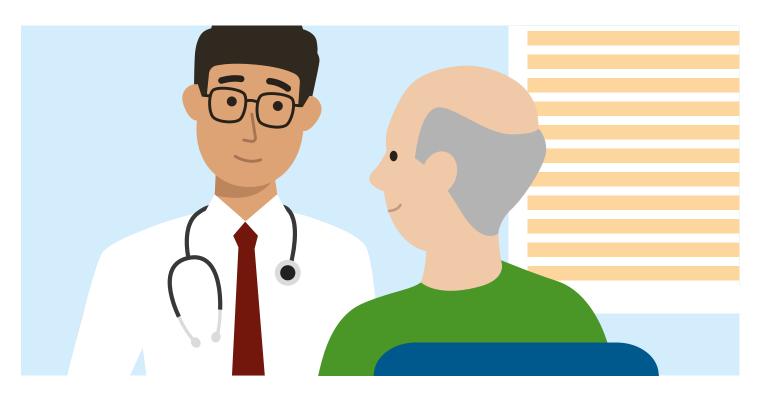
## Understand the barriers to participation. These may include:

- lack of knowledge/awareness [15, 16]
- language and literacy [15, 16]
- stigma and/or embarrassment [15–18]
- fear, or screening anxiety [15-18]
- practicalities and ease of use, including finding the test too messy to complete [16, 18]
- cultural and/or religious beliefs [15]
- the lack of bowel cancer symptoms (misconception that should have symptoms to participate in screening) [16, 18]

## The benefit of tackling inequalities



Bowel cancer screening uptake is higher in the least deprived areas. We estimate that there would be a 7% increase in the number of bowel cancers diagnosed through screening if the proportion of eligible patients in England (aged 60–74 years) who took up their bowel cancer screening invitation was similar to that of patients at GP practices in the least deprived areas. This would mean that around 400 extra bowel cancers could be detected each year [19].



## Actions

- Recognise those that may need some additional support.
- Recognise that faith groups may benefit from co-designed, community outreach interventions [15, 20].
- Use your practice IT system to identify those eligible for groups with lower participation:
  - · 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 test.
- If a patient requires additional support to participate in bowel cancer screening, contact your local screening hub to record this information.
- For more information about tackling screening barriers, read NHS England's guide, <u>Bowel cancer screening:</u> identifying and reducing inequalities

### Colonoscopy attendance

People with a positive FIT for bowel cancer screening will be offered follow-up investigation, usually a colonoscopy. However, a proportion of people may not attend their appointment. In Scotland (2020-2022), a study reported that 25% of people with a positive FIT did not attend their follow-up colonoscopy [3].

There is evidence to suggest that inequalities in screening colonoscopy attendance exist, with some groups experiencing more barriers to attending, including those from a non-white ethnic minority, and/or from areas of higher deprivation [21–23].

To help overcome these barriers and improve uptake, primary care health professionals and the wider practice team should be available to have conversations with patients about what a colonoscopy is and what it involves. They should be able to discuss what a person might expect before, during and after their appointment, and able to talk through any concerns a patient may have around attending a colonoscopy. To support you with these conversations, see our patient-facing information on colonoscopies.



Access our 'Reducing inequalities in cancer screening' resource **for more tips here**.

## Steps to engage with first timers and non-responders



### Identify

• Ensure letters from bowel cancer screening centres are **coded** in patient records if relevant.



## Use practice data to identify first timers to screening

 Search for people approaching their first invitaiton.



 Search the eligible population with a non-response result in the last two 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.)

This may include people who have experienced the following:

- · palliative care
- bowel cancer
- chronic inflammatory bowel disease
- · a colonoscopy in last two years
- · have opted out of screening
- are coded as ineligible



### Code

- Code first timers and non-responders.
- Add alerts or prompts to identify patients and support discussion.
- Familarise yourself with the READ codes used, if relevant.



### Contact

Consider the intervention that would work best for your practice(s) to engage first timers and non-responders to screening, for example:

- letter
- text
- telephone call



### You could also:

- display information in your practice.
- hold leaflets at reception.
- ensure opportunities for patients to discuss screening with clinical staff.
- remind people of the phone number to request another kit if lost or discarded (hand them a bowel cancer screening info card).
- check details at routine appointments.



#### Check

Evaluate effectiveness of the intervention.

- Code engagement methods used for each patient.
- Review which methods have been most effective.



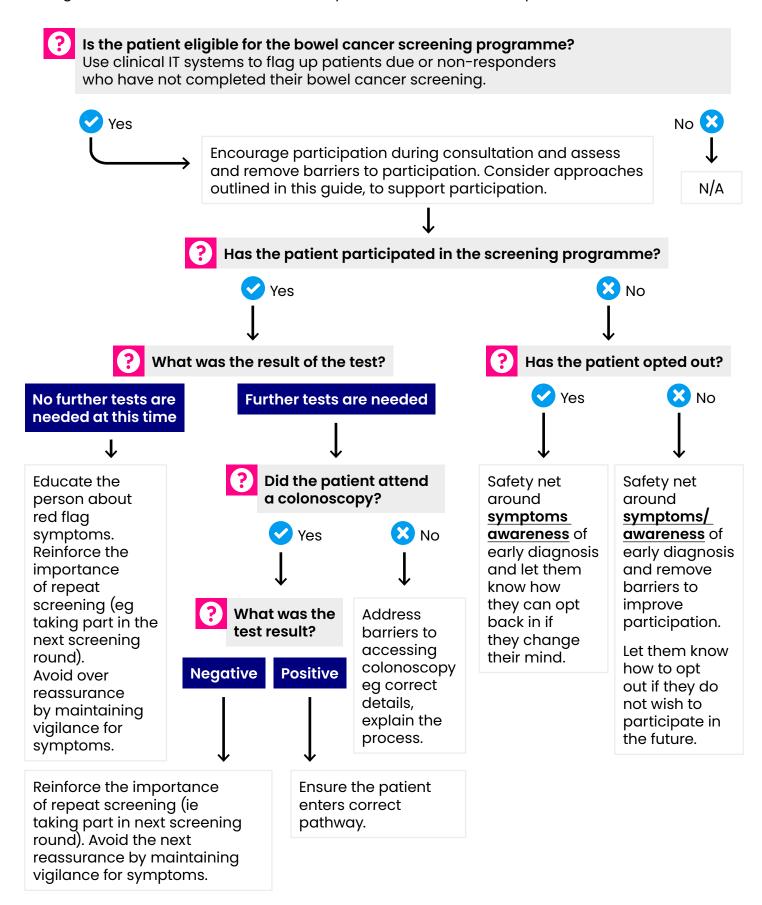
Order our free <u>bowel</u> <u>cancer screening</u> <u>resources</u> for your practice.

Please note these are suggested steps, and they may vary by nation.

## Safety netting



The public 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.



## Appendix 1: Sample telephone script



### A guide to having a conversation with a patient 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: the benefits and harms of bowel cancer screening and Tips for collecting your poo

#### Introduction



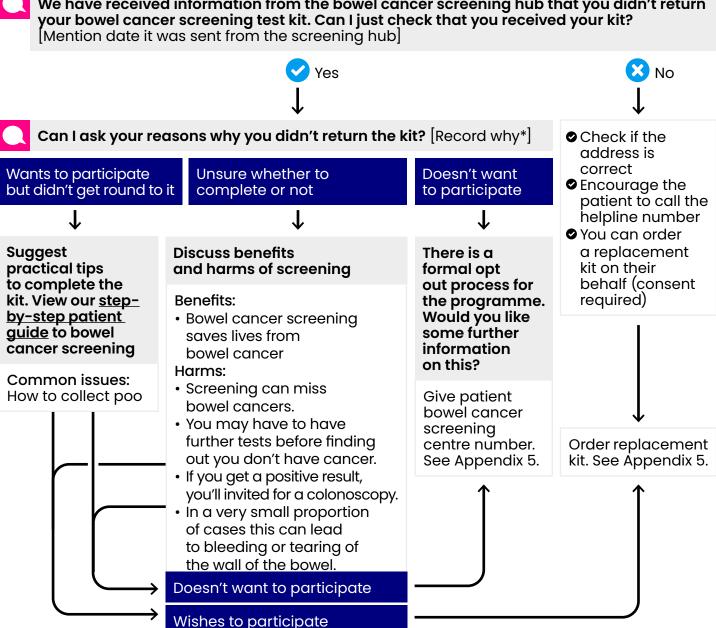
**Hello**, [verify who speaking with] My name is... I am phoning from... [insert name of GP practice] There's nothing to worry about, I'm phoning about the bowel cancer screening programme.

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 hub 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 hub]



<sup>\*</sup>We would be interested to hear about any barriers to screening you encounter. Email SEinbox@cancer.org.uk to let us know.

## Appendix 2: Sample GP endorsement letter for non-responders



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

<Insert GP letterhead including GP practice phone number>
Freephone – <see Appendix 5 and include number relevant to nation>

#### Dear < Patient - insert 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: **cruk.org/bowel-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 <Surgery Name> encourage you to complete the test ASAP. If you are unsure about the test please talk to the 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\*:

Read Description	V2	CTv3	SNOMED
Bowel cancer screening programme invitation letter sent	90w5.	XaZx5	862031000000107
Advice given about bowel cancer screening programme	8Cay.	ХаРуВ	382161000000102
Bowel cancer screening declined	8IA3.	XaN4r	294201000000109
BCSP faecal occult blood test negative	686A.	XaPkd	375211000000108
BCSP faecal occult blood test positive	686B.	XaPke	375241000000109
BCSP faecal occult blood testing kit spoilt	6867.	XaPka	375121000000106
BCSP faecal occult blood testing incomplete participation	686C.	XaQlz	384241000000100
Provision of written information about BCSP	8OA5.	XaZu9	860781000000108
No response to bowel cancer screening programme invitation	90w2.	XaPf6	373251000000108
BCSP Telephone Invitation	90w4.	XaZx4	862011000000104
Not eligible for bowel cancer screening programme	90w3.	XaX8y	758851000000101

<sup>\*</sup> 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 and North West (Rugby) Hospital of St Cross Barby Road Rugby, Warks, CV22 5PX Email: bowelscreening@nhs.net

Southern 20 Priestley Road Surrey Research Park Gulldford, GU2 7YS

Email: rsc-tr.BCSPSouthernHub@nhs.net

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

Eastern

University Hospital Queens Medical Centre Nottingham, NG7 2UH

Email: nuhnt.bcspeastern@nhs.net

North East Queen Elizabeth Hospital Sheriff Hill

Gateshead, NE9 6SX

Email: gan-tr.north-east-bowel-hub@nhs.net

### Scotland

Bowel cancer screening helpline 0800 0121 833 or email <a href="mailto:bowelscreening.tayside@nhs.net">bowelscreening.tayside@nhs.net</a>

### 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

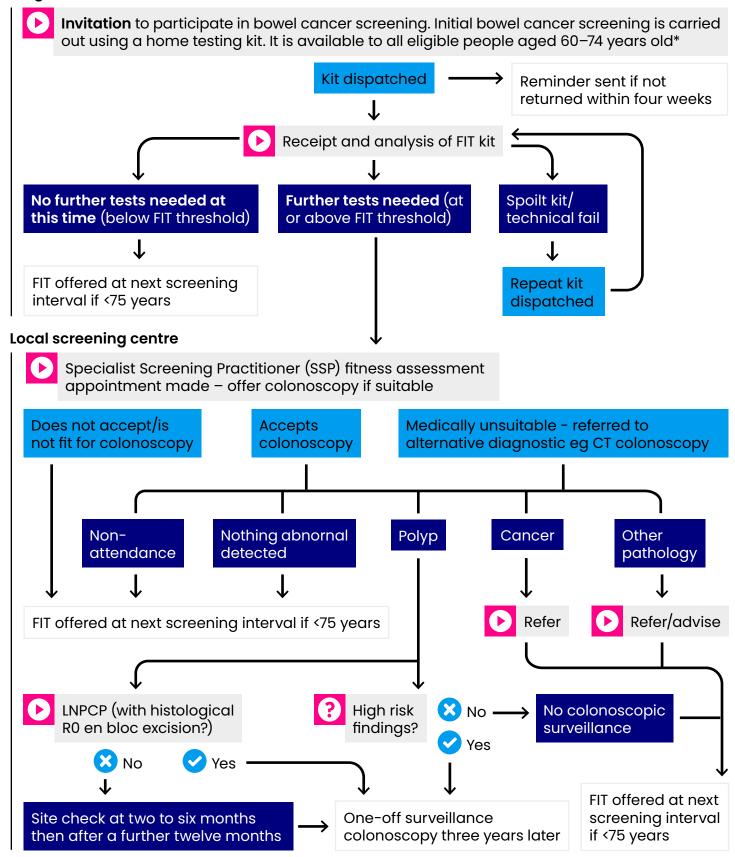
Bowel cancer screening helpline 0800 015 2514

## Appendix 6: National screening pathways

### The bowel cancer screening pathway in England



### Programme hub



This pathway was produced by NHS England. \*As a phased approach over the next few years, people age 50–59-year-olds will be invited to participate.

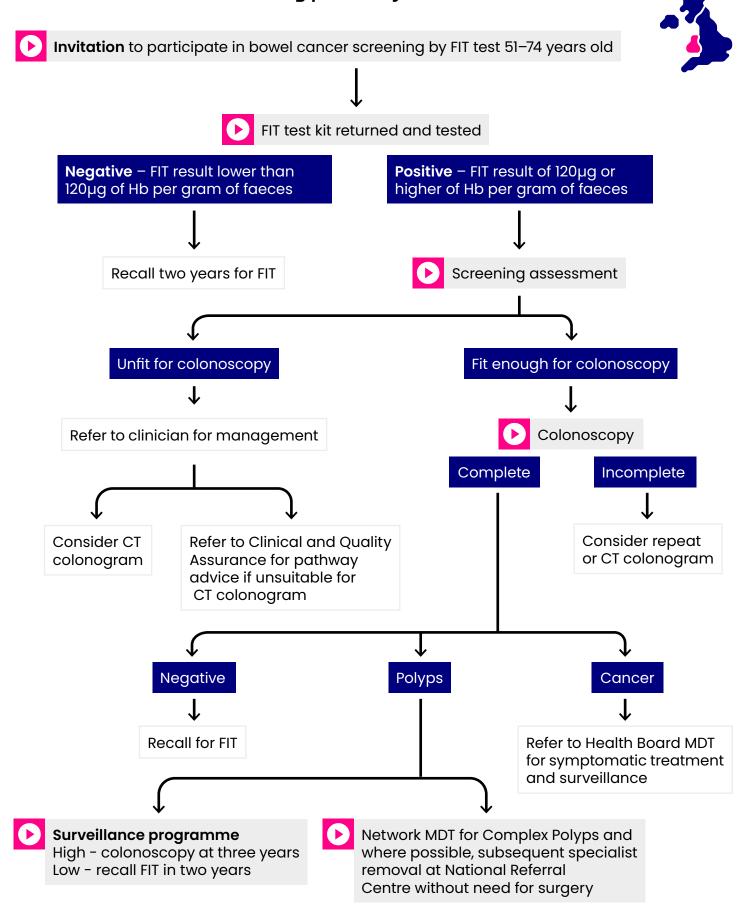
## The bowel cancer screening pathway in Scotland **Bowel cancer screening test** aged 50–74 every two years Test returned No response **Bowel cancer screening** laboratory Six-week reminder [1] The central laboratory carries out the tests on home test kits and the centre refers positive screening test results via the No response Repeat the Bowel cancer screening IT test once System (BoSS) directly to the relevant local colorectal service for further investigations. Test spoiled or expired Message to GP Negative result Positive result Non responder (three months). Second test spoiled Notifications are received or expired [2] via mail manager [2] Referred to local Two year recall board for precolonoscopy 1. The six week reminder is provided by the assessment bowel cancer screening programme.

This pathway was produced by NHS National Services Scotland. The supplementary comments (right) are provided by Cancer Research UK.

Colonoscopy appointment [3]

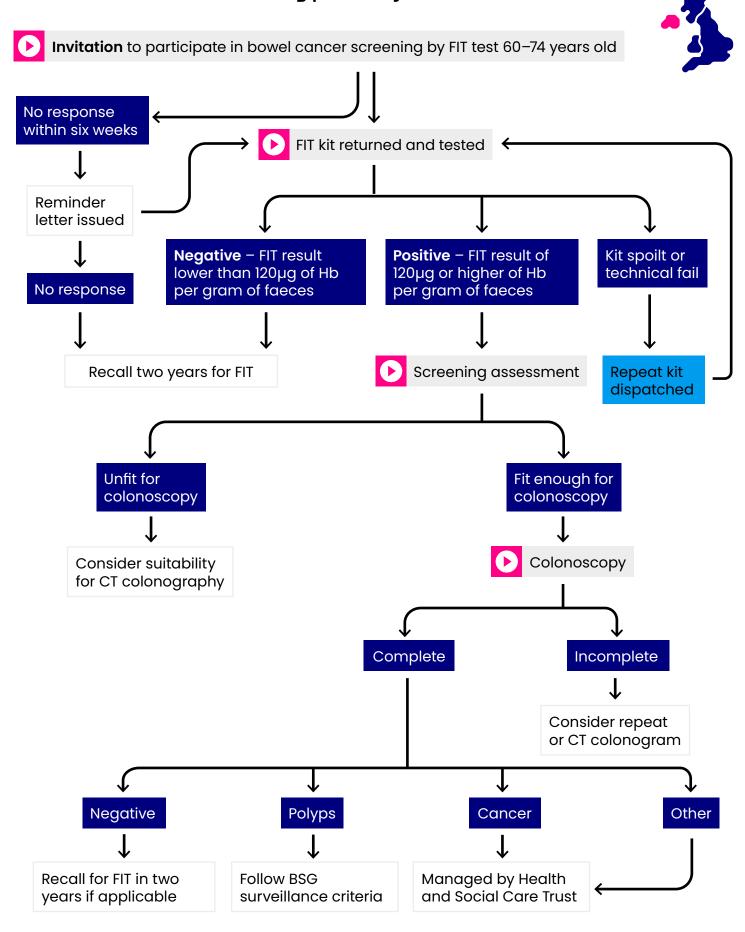
- 2. If a second test is spoiled or expired or the person does not respond at three months, then no further action is required. This person is re-invited at the next round (Rounds are two yearly intervals.)
- 3. After the colonoscopy appointment, those with an abnormal result undergo further tests to receive a diagnosis and treatment.

### The bowel cancer screening pathway in Wales



This pathway was produced by Public Health Wales. \*As a phased approach over the next few years, people age 50–54-year-olds will be invited to participate.

### The bowel cancer screening pathway in Northern Ireland



This pathway was produced by Public Health Agency

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