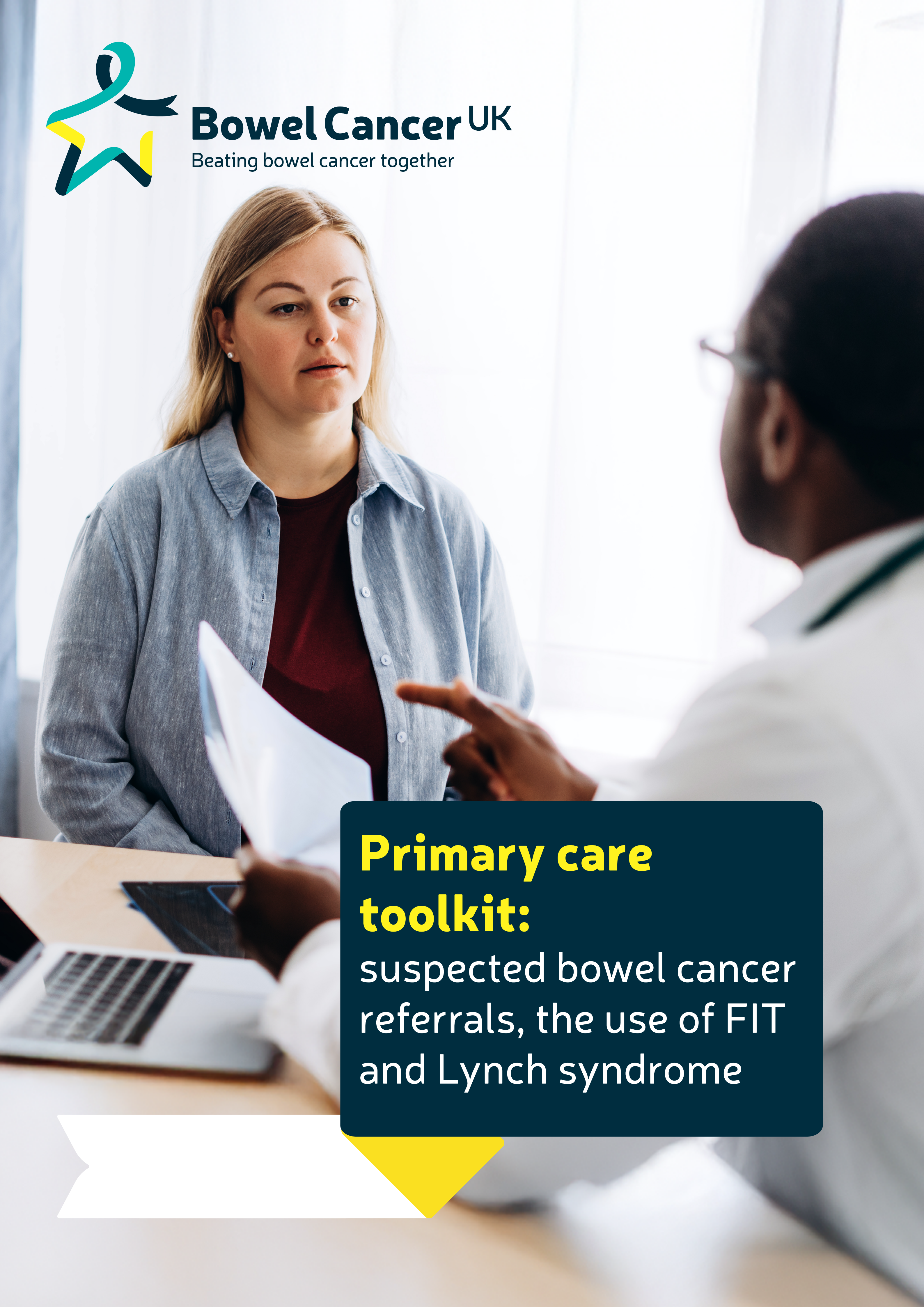

Bowel Cancer UK
Beating bowel cancer together

Primary care toolkit:

suspected bowel cancer referrals, the use of FIT and Lynch syndrome

Contents

Referring people for bowel cancer investigation in England and the role of faecal immunochemical testing (FIT)

This factsheet provides best practice guidance for GPs on the monitoring and referral of people with bowel problems in England.

- Bowel cancer is the fourth most common cancer in England.
- Every year, around 38,000 people in England are diagnosed with bowel cancer.
- Bowel cancer is England's second biggest cancer killer. However, it shouldn't be because it is treatable and curable especially if diagnosed early.

Risk factors

People are at higher risk of developing bowel cancer if they have one or more of the following risk factors:

- Aged over 50
- A strong family history of bowel cancer
- A history of non-cancerous growths (polyps) in their bowel
- Longstanding inflammatory bowel disease such as Crohn's disease or ulcerative colitis
- Type 2 diabetes
- An unhealthy lifestyle

Referral for suspected colorectal cancer

Knowing when to refer a patient using the suspected cancer pathway will help them to receive a diagnosis earlier and potentially save their life.

Whilst people aged over 50 are at increased risk of developing bowel cancer, it is important to note that more than 2,700 people under the age of 50 are diagnosed with bowel cancer in the UK every year, and early-onset cases have doubled since the 1990s.

Offer faecal immunochemical testing (FIT) to guide referral for suspected colorectal cancer in adults with abdominal mass, or

- with a change in bowel habit, or
- with iron-deficiency anaemia, or
- aged 40 and over with unexplained
- weight loss and abdominal pain, or

aged under 50 with rectal bleeding and either of the following unexplained symptoms:

- abdominal pain
- weight loss, or

aged 50 and over with any of the following unexplained symptoms:

- rectal bleeding
- abdominal pain
- weight loss, or

aged 60 and over with anaemia even in the absence of iron deficiency.

Symptomatic use of FIT in primary care

What is FIT?

The faecal immunochemical test (FIT) detects traces of blood in faeces and is used to guide the management of patients with lower gastrointestinal (GI) symptoms.

Symptomatic use of FIT in primary care

FIT should be used at a sensitivity level of 10 ug/g (micrograms of blood per gram of faeces) in primary care to select patients with lower gastrointestinal symptoms for an urgent referral pathway for further investigation. FIT should be offered to symptomatic patients regardless of their age.

FIT should be offered even if the person has previously had a negative FIT result through the NHS bowel cancer screening programme. It's important to remember that the sensitivity level of FIT for the bowel cancer screening programme is set at 80 ug/g (micrograms of blood per gram of faeces) therefore someone may present with symptoms but had a recent negative screening result.

Patients should not be excluded from referral from primary care for symptoms on the basis of FIT alone. People with a rectal mass, an unexplained anal mass or unexplained anal ulceration do not need to be offered FIT before referral is considered.

For people who have not returned a faecal sample or who have a FIT result below 10 ug/g (micrograms of blood per gram of faeces):

- Safety netting processes should be in place
- Referral to an appropriate secondary care pathway should not be delayed if there is strong clinical concern of cancer because of ongoing unexplained symptoms (for example, abdominal mass)

Example of a faecal immunochemical test (FIT)

For safety netting, clinical teams should consider:

- Using a symptoms diary and providing the patient with clear information about who to contact if they develop new symptoms or if their existing symptoms worsen
- Using advice and guidance via the electronic referral service (eRS) to guide management of patients with persistent or troublesome symptoms
- Offering a second FIT if ongoing clinical concerns remain
- Referral to a non-specific symptoms urgent cancer pathway, if appropriate and there are ongoing concerns about possible cancer
- Management of FIT negative patients in an outpatient setting following referral on a non-urgent pathway
- Maintaining continuity of care by adopting Jess's rule:
    - **Reflect:** Think back on what the patient has said and consider what has changed or been missed. Offer ongoing episodic continuity of care for future direct patient care. If previous consultations have been remote, see the patient face-to-face and conduct a physical examination
    - **Review:** Where underlying uncertainty exists, consider seeking a view from a peer and review any red flags that may suggest another diagnosis, regardless of the patient's age or demographic
    - **Rethink:** If appropriate, refer onwards for further tests or for specialist input

Keeping your patients informed

Being referred for further investigation can be a worrying time. It's important to give your patient, or their guardian or carer, clear information about what to expect.

For more information visit **bowelcanceruk.org.uk**

Lynch syndrome is a genetic condition with no known cure, that increases a person's lifetime risk of bowel cancer by up to 80%. It is estimated to cause around 3% of bowel cancer cases in the UK every year, many of them in people under the age of 50.

Currently, less than 5% of people with Lynch syndrome have been diagnosed. It is estimated that around 175,000–200,000 people across the UK have Lynch syndrome and are unaware they are at high risk of developing bowel, and other cancers.

People with Lynch syndrome have a 50% chance of passing the condition on to their children, meaning whole families can be devastated by the impact of bowel cancer.

Lynch syndrome predisposes to certain cancer types

The main concerns are:

- Colorectal
- Endometrial
- Other associated cancers:
- Ovarian
- Urinary tract
- Gastric
- Small intestine
- Hepato-biliary and pancreatic
- Sebaceous gland (and adenoma)

Underlying flags for a genetic diagnosis include:

- cancer diagnosis at an early age;
- multiple affected family members (two or more first-degree relatives or one first-degree relative diagnosed at under 50 years of age);
- personal or family history of bowel polyps at an early age; and
- presence of other associated cancers such as endometrial, liver, gastric or brain.

Diagnosing Lynch syndrome

Diagnosing Lynch syndrome begins with molecular testing of tumours for specific genes related to DNA repair. Mismatch repair (MMR) genes are responsible for fixing DNA errors in the body. If these genes have faults, DNA mistakes can build and lead to cancer over time.

Lynch syndrome is caused by germline pathogenic variants in one of the DNA Mismatch Repair (MMR) genes: **MLH1, MSH2, MSH6, PMS2, EPCAM**: which may inactivate MSH2.

Around 15% of people with bowel cancer are estimated to have defects to these genes, and approximately 25% of those with MMR defects have Lynch syndrome. Because these faults can happen in cancers unrelated to Lynch syndrome, two more tests are carried out. If no changes are found, further testing of DNA called germline testing is necessary to definitively diagnose Lynch syndrome.

Before getting a diagnosis, every patient must undergo genetic counselling. Counselling helps people to make informed decisions by providing information on the genetic condition, the implications of being diagnosed, and the measures that would be put in place to care for them after a Lynch syndrome diagnosis (also known as 'wraparound care').

Preventing bowel cancer

The new bowel cancer screening programme will offer a colonoscopy to people with Lynch syndrome every two years. They will be eligible to join the programme from age 25 or 35, depending on the gene variant they have that causes the condition, as some variants can result in the disease developing at a younger age than others.

Offering people with Lynch syndrome regular colonoscopies will allow precancerous cell changes to be identified and treated before cancer develops, as well as diagnosing cancers that do arise at the earliest possible stages, when treatment outcomes are best.

Identifying those at risk

Bowel cancer is the fourth most common cancer in the UK, with 29% of the population having a family history in a first- or second-degree relative.

When a family member has a known hereditary bowel cancer syndrome, referral to local clinical genetics services is indicated.

Even when hereditary bowel cancer syndromes have not been identified, if a patient has a family history of bowel cancer, they themselves carry an increased risk of up to six times that of the general population.

Effect of aspirin on the chance of getting bowel cancer: results of the CaPP3 study

CaPP3 is the third trial in the Colorectal Adenoma/Carcinoma Prevention Programme.

The CaPP2 trial showed aspirin reduced the risk of CRC in people with Lynch syndrome, however, CaPP2 did not identify the best dose, meaning people could be taking unnecessary high doses of aspirin.

Following the results from CaPP2, the CaPP3 trial was established to compare 3 doses of aspirin, with the aim to reduce the risk of potential harm from high dose aspirin. The results of CaPP3 show that taking as little as 75 to 100mg of aspirin each day can halve the risk of CRC in people with Lynch syndrome.

We're now engaging with regulators to change prescribing guidelines so that aspirin can be used more widely for people with a high risk of bowel cancer.

Scan this QR code to access free training on Lynch Syndrome from RM Partners:

Scan this QR code to read more about how we can support you and your patients, or visit **bowelcanceruk.org.uk/health-professionals**

References available upon request

About Bowel Cancer UK

We're the UK's leading bowel cancer charity.

We're determined to save lives and improve the quality of life of everyone affected by bowel cancer.

We support and fund targeted research, provide expert information and support to patients and their families, educate the public and professionals about the disease and campaign for early diagnosis and access to the best treatment and care.

Bowel Cancer UK
@bowelcanceruk

Registered Charity Number 1071038 (England and Wales) and SC040914 (Scotland)