



Bowel Cancer UK

Beating bowel cancer together

Sharing learning, saving lives

21 January 2019

Our projects which focus on learning disabilities

Sharing learning

Today:

- An introduction to Bowel Cancer UK
- Our projects which focus on bowel cancer and learning disabilities
 - Accessible information
 - Training for health and care professionals (a project funded by the Scottish Government)

About us

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



Bowel Cancer UK
Beating bowel cancer together



We provide expert **information** and **support** to patients and their families



We **campaign** for early diagnosis and access to best treatment and care



We support and fund **research** to help stop people dying of bowel cancer

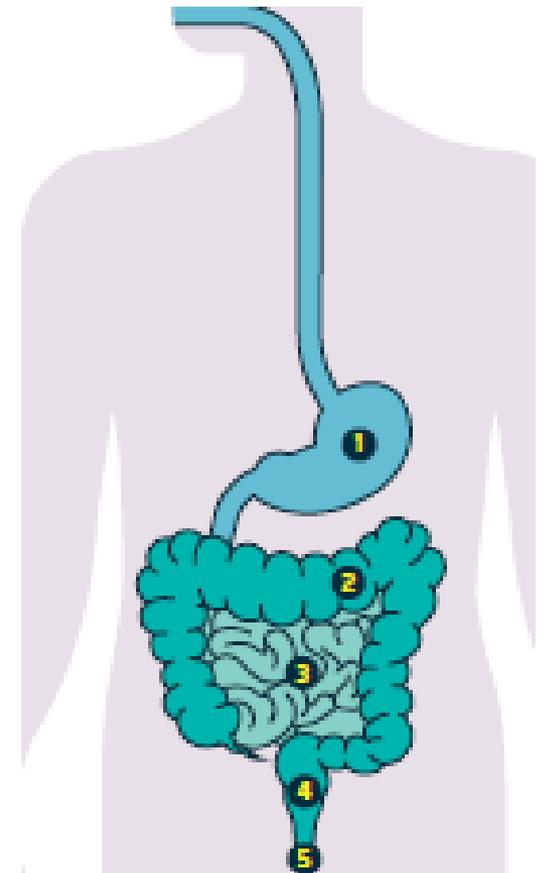


We **educate** the public and professionals about the disease

Bowel cancer: the facts

Bowel cancer is also called colorectal cancer. It affects the large bowel, which is made up of the colon and rectum.

1 in 15 men and
1 in 18 women will be
diagnosed with bowel cancer during
their lifetime



- 1 Stomach
- 2 Colon
- 3 Small bowel
- 4 Rectum
- 5 Anus

Bowel cancer: the facts

**Bowel cancer is the
fourth most common
cancer in the UK**

4th



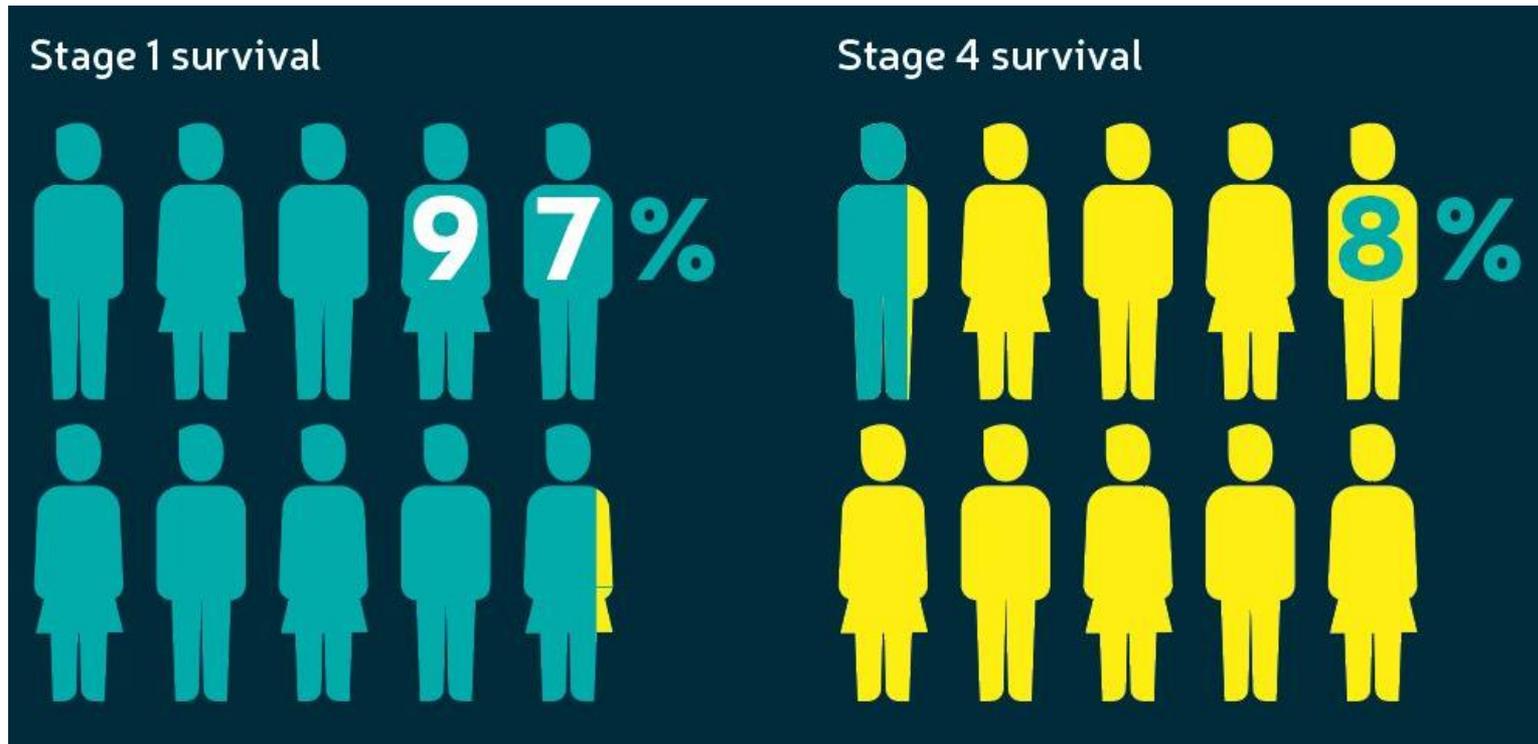
Every **15 minutes**
someone is diagnosed.
That's almost **42,000 people every year**

**Bowel cancer is the UK's
second biggest cancer killer**



Early diagnosis saves lives

Bowel cancer is both treatable and curable, especially if diagnosed early





**A focus on bowel
cancer and learning
disabilities**

People with a learning disability



- Now living longer, thus **incidence of cancer is increasing**
- **Different pattern of cancers** than that of general population - a higher risk for digestive tract / gastrointestinal cancers e.g. oesophagus, stomach and gall bladder
- Bowel cancer in people with a learning disability (PWLD) has rarely been specifically studied and has not been extensively reviewed.
- A useful paper published in 2018. . .

People with a learning disability



- **Rates of bowel cancer are at least equivalent** (similar) to that found in the general population
- **Often diagnosed late:** “Clinical presentation is frequently masked, particularly by challenging behaviours”
- **PWLD have a number of risk factors:** E.g. a high incidence of being overweight and obesity; limited access to exercise and physical activity; poorer dietary intake of fibre

Source: Willis D, Samalin E, Satgé D: *Colorectal cancer in people with intellectual disabilities*; Oncology 2018; 95(6): p323–336

Screening inequalities



Screening is underused by PWLD compared to the general population

A number of recognised barriers, including

- Difficulties in obtaining informed consent
- Lack of accessible information
- Inadequate support to complete the test
- Lack of knowledge about cancer and cancer screening in health and social care staff

Source: Willis D, Samalin E, Satgé D: ***Colorectal cancer in people with intellectual disabilities***; Oncology 2018; 95(6): p323–336

A decorative graphic consisting of a teal rectangle in the top left, a dark teal triangle pointing downwards from the top right, and a yellow banner-like shape at the bottom right containing text.

**Accessible information
for people with
learning disabilities**

Screening



Bowel Cancer UK
Beating bowel cancer together

- Bowel cancer screening **saves lives**
- Screening can **detect bowel cancer early** before any symptoms appear, when it is **easier to treat**
- Each of the screening programmes in the UK use home screening tests
- Either a Faecal Occult Blood Test (FOBT) or, more recently, a Faecal Immunology Test (FIT)
- FIT introduced in Scotland in November 2017. Commitment to introduce in England and Wales



Accessible resource pack



- Building on a **clear need** for accessible information and the **success of previous accessible information** (supported by NE & Cumbria LD network)
- NHS Health Scotland commissioned Bowel Cancer UK to **nationally produce an accessible information pack**
- Designed to support informed choice and optimise access to screening for PWLD

Right to best possible health information



Principles applied in information development

- Accurate and balanced
- Personal informed choice
- **Accessible formats** - easy read guide tailored for PWLD; Carers guide – for paid & family carers
- **Stakeholder involvement** - working group, health professional reviewers, robust approval process
- **User testing** - information was tailored for, and developed in closely with PWLD (focus groups x5 / 40)
- **Proactive dissemination** - to support national invitation system. Available on request and to download. Reprint.

Feedback

“Providing easy read materials supported an individual to undertake the bowel screening test for the first time (refused 3 before)”



Photo permission, Community Connections West Dunbartonshire

“The accessible information available has enabled me to increase clients understanding of importance of screening and what it involves”

A teal rectangle is positioned in the top-left corner. A dark teal shape, resembling a triangle with a rounded top-right corner, overlaps the teal rectangle and extends towards the center of the slide.

**Training for health and
care professionals**



Bowel Cancer UK
Beating bowel cancer together

Bowel Screening: Tackling inequalities in uptake in adults with learning disabilities

Our objective

- **“Train public health and allied health professionals so that they can effectively promote early diagnosis and cascade our key messages effectively”**
- In March 2018, we successfully gained Scottish Government funding to deliver a targeted training programme focused on driving improvements in access to bowel screening for PWLD

About the training



Bowel Cancer UK
Beating bowel cancer together

- The training is informative, interactive
- It takes an integrated approach, covering the facts, symptoms, early diagnosis, risk factors and screening
- As well as informed choice & person-centred support



A practical look at screening – key messages, uptake, minimising the barriers



New test is being well received

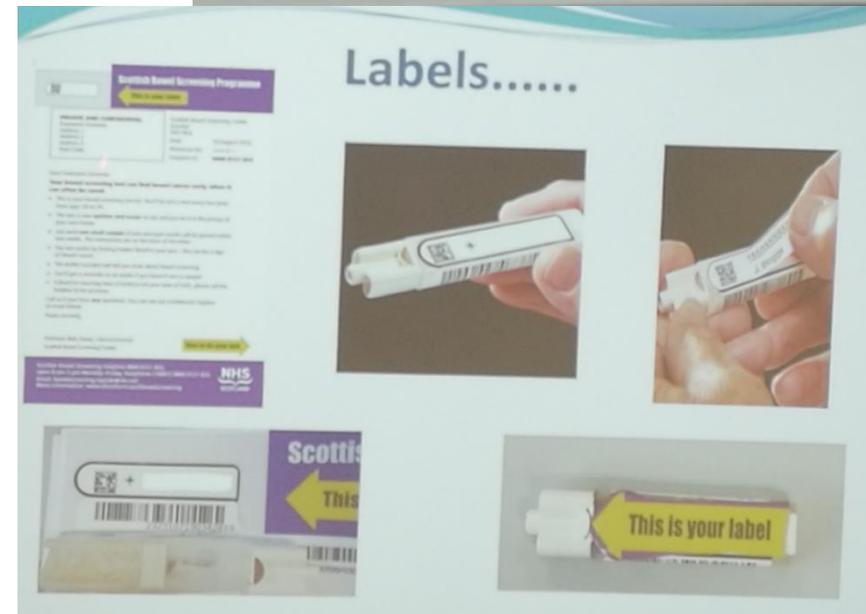
- Quicker, easier
- Just one small poo sample
- More acceptable 'looks more medical'
- Quantifies blood - detects and measures the amount of blood in a sample
- Increase in uptake (no official stats but operational data around 60%)



Ongoing challenges

- Holes in lid >
- Labels >
- Screw on lid
- Old kits still being returned
- Damaged post – new envelopes
- Incontinence pad instead of going to the toilet, you can take the poo sample from pad

Image credit, Judith Strachan, NHS Tayside



Snapshot of results



**Together we're driving
positive change.**

Beating bowel cancer together

Progress

A great demand for the training across our target audiences

Up to November 2018,
19 training sessions in 9 health board areas to 265 attendees, across Scotland

Who we have trained so far:

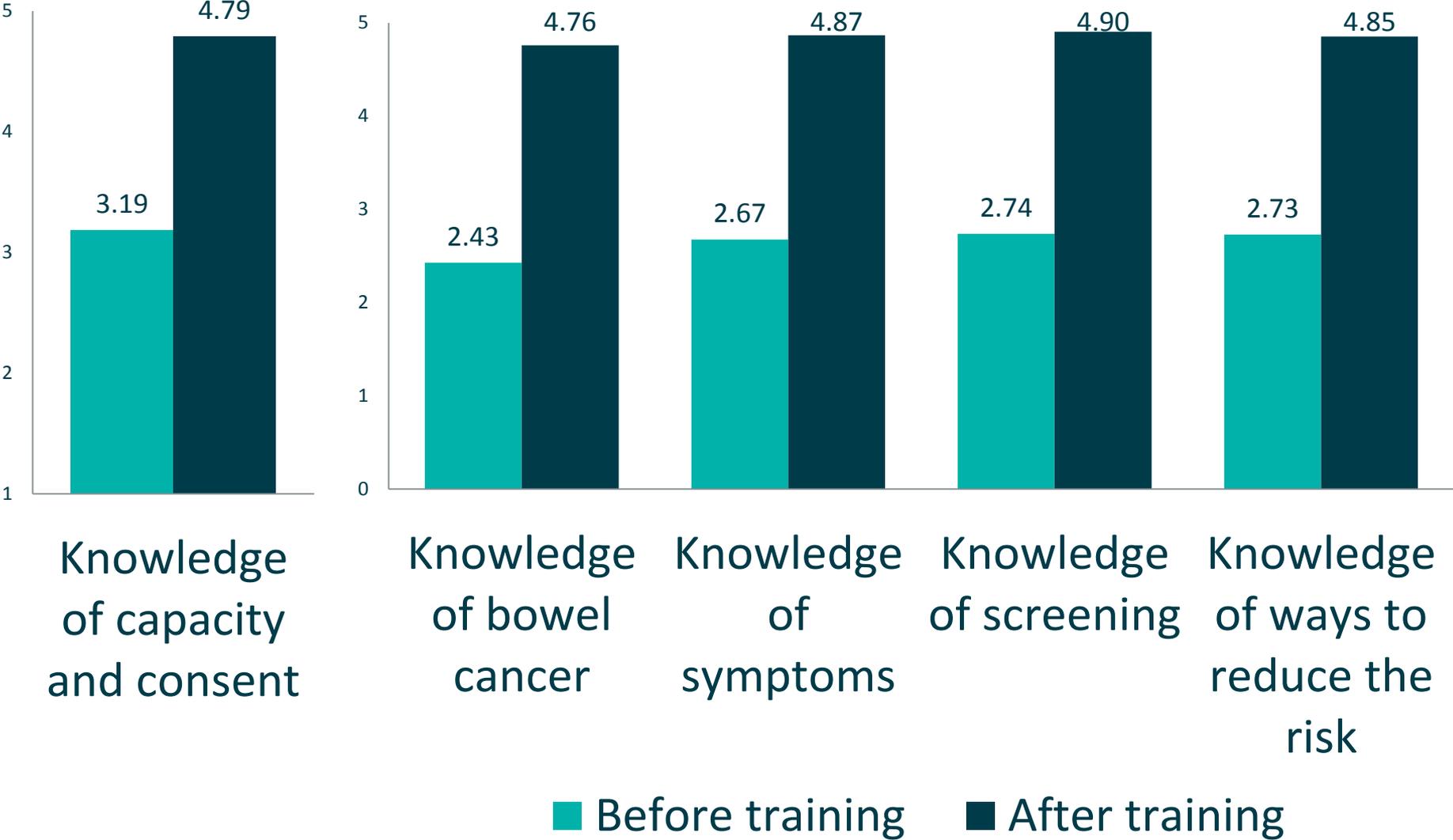
136 third sector care

42 local authority care

53 nurses



Increases in knowledge



Knowledge of bowel cancer, **an average increase of 96%**

“I now have awareness which I can put into practice and I am now knowledgeable of the signs/symptoms”

“We did a morning training ... The ladies really enjoyed it and were able to talk openly about bowel function without embarrassment, this was a major step as at the beginning they were all a bit coy when I mentioned poo!”

100% of attendees felt confident explaining the NHS Bowel Screening Programme. There was a **79%** increase in knowledge from pre to post training

“Patients who had previously not participated in Bowel Screening have now completed this”

“I did my first bowel test with one of my guys and it was so easy to do”

“I have been able to speak confidently about the screening process and it was well received knowing it’s just one day sample now!”



- Knowledge to deliver information to people with a learning disability, **an average increase of 85%**
- Knowledge of information resources, **an average increase of 127%**

“I now feel more confident when discussing good bowel health / screening with people with a learning disability and their support network”

“The accessible information available has enabled me to increase clients understanding of importance of screening and what it involves”

Wider impact. . .



“[The] course has helped me to pass on information to colleagues and individuals that we support”

First nine months, 166 responses to follow up survey:

> **2621** = The number of additional people who have been told about the bowel screening programme as a result of the training. This includes **388 people with learning disabilities** as well as 775 colleagues that support people with a learning disability

> **36** = The average number of people each attendee told about screening in the first three months

Key learnings

9 in 10 people will
survive if diagnosed
at the earliest stage



- The new bowel screening test a great opportunity to increase equal access to screening
- Make sure you feel confident talking about bowel health - everything from symptoms awareness, to risk factors and screening
- Be proactive and involve people with learning disabilities
- Don't underestimate the difference that can be made with person centred support and user led, accessible information



Thank you!

bowelcanceruk.org.uk  @bowelcanceruk  /bowelcanceruk

Claire.Finlayson@bowelcanceruk.org.uk