

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



This report is about Bowel Cancer UK's training for learning disability healthcare professionals – a twelve month project supported by the Scottish Government's Screening Inequalities Fund.

Read it if you are involved or interested in bowel cancer screening, public health, health promotion, supporting informed choice, reducing screening inequalities, supporting adults with learning disabilities.

It will tell you how we delivered our bowel cancer education to over 300 participants and the impact of our work in tackling screening inequalities.

Introduction

Bowel cancer is the third most common cancer in Scotland and the second biggest cancer killer, with more than 1,600 people dying from the disease each year. However, this shouldn't be the case as bowel cancer is treatable and curable if diagnosed early, with an estimated 9 in 10 people surviving bowel cancer if diagnosed at the earliest stage.

To drive forward Bowel Cancer UK's goal of championing early diagnosis and support the Scottish Government's commitment to reducing cancer screening inequalities, we set up a tailored training programme to educate healthcare professionals about the disease and bowel cancer screening.

Supporting the needs of adults with learning disabilities

People with learning disabilities have the right to good bowel health and access to the same range of health services as everybody else. We know that bowel screening is one of the best ways to detect cancer early, but it is poorly accessed and underused by people with learning disabilities compared to the general population. To help overcome the barriers, our training programme specifically focused on giving

participants the knowledge and practical resources to provide the right, personalised support.

The role of healthcare professionals

Health and social care professionals are essential to ensuring people with learning disabilities have greater choices and the opportunity to access screening services. With this in mind, we designed our training to bring together a range of healthcare professionals supporting adults with learning disabilities, including NHS staff, Health and Social Care Partnership teams, and voluntary sector care organisations.

What we did

From March 2018 to January 2019, we provided **22** full day training sessions across **11** health board areas in Scotland to **304** attendees. We reached a range of healthcare professionals, including:

- **52 local authority care and support staff**
- **78 community nurses**
- **137 third sector care and support staff**

The training sessions covered the facts about bowel cancer - symptoms, risk factors, screening. To support informed choice we also

focused on accessible communication and examples of tailored support.

Health board areas

We delivered our training in 11 out of 14 health board areas in Scotland: Ayrshire and Arran, Borders, Dumfries and Galloway, Fife, Forth Valley, Grampian, Greater Glasgow and Clyde, Lanarkshire, Lothian, Orkney and Tayside.

Impact

We proactively worked with our participants to measure impact and look at how our training programme enabled professionals at the forefront healthcare to promote good bowel health and screening.

Our evaluation model has captured a range of outcomes, from increased knowledge and confidence to awareness activities and examples of person-centred support. Increasing knowledge and confidence Throughout the twelve month project participants reported significant increases in their understanding of bowel cancer – the symptoms to look out, stages and risk factors.

“Course was relevant to practice and beneficial in laying a solid foundation in tackling the issues around bowel cancer. It offers a springboard to help practitioners tackle this subject with patients and improving chances of early diagnosis of problems.”

Participants particularly benefited from learning about bowel screening, with many noting their surprise at the ease of the simpler, more accurate faecal immunochemical test (FIT).

Building awareness of bowel screening, participants reported a **77%** increase in knowledge from pre to post training.

Building confidence, **100%** of attendees told us that they felt confident explaining screening after their training.

“I now feel more confident when discussing good bowel health / screening with people with a learning disability and their support network.”
“I made a group aware of the difference in

detecting bowel cancer early and the importance of the screening test. I also made them aware that the new FIT test was much simpler and quicker than the old test.”

“My confidence in talking to others increased greatly from attending this course and who knows... it may save a life.”

Sharing awareness and education with patients, service users and colleagues

Our project has supported the crucial role of frontline healthcare professionals in supporting good bowel health and screening awareness. Participants successfully used their learning to spread awareness of bowel cancer amongst patients, service users, colleagues and even their own friends and family.

3,340 = the number of additional people who have been told about the bowel screening programme as a result of the training (in the first three months). This includes 566 people with learning disabilities and 938 colleagues that support people with a learning disability.

22= the average number of people each attendee told about bowel screening in the first three months¹.

“The Bowel Cancer UK training is brilliant and equips you with the right resources and tools to help spread the word far and ensure screening is accessible.”

“I supported an individual who was having irregular bowel movements. After discussion about bowel health they decided to see their GP and were prescribed medication.”

“I had private discussion with a family member whose daughter is supported at the project. We talked over the benefits of adapting her diet to improve her bowel health.”

“Bowel cancer is treatable if caught in its early stages so it is crucial that people with learning disabilities participate in bowel screening. The Bowel Cancer UK training is brilliant and equips you with the right resources and tools to help spread the word far and ensure screening is accessible.”



Overcoming the barriers to screening

We have received many examples of participants working alongside people with learning disabilities, their families and carers to promote informed bowel health choices and participation in bowel screening.

Examples of supporting informed choice included having open discussions with patients and service users about screening, as well as providing step-by-step demonstrations of the test. This encouraged the uptake of screening among people with learning disabilities who had previously avoided the test.

“I explained how the test has now changed and went over how simple it was to do now.”

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

“Two patients who had not previously agreed to a bowel screening have now completed this.”

“Successfully persuaded a service user to complete her screening. This person has never

before agreed to do this. She has several of the signs and has a poor diet so this was a big moment! Her reluctance and anxiety seemed based on the idea that the screening was like having a smear test, so I think she was pleasantly surprised and extremely proud of herself!”

Informed choice through accessible information
Importantly, the programme has been a successful platform for disseminating, raising awareness and making use of accessible information resources.

To aid communication, participants particularly valued the easy read information and demonstration test kits issued at the training. When asked what worked well, we received examples such as:

“The information and supporting documents supplied on the day have been an invaluable tool that I use regularly when having a conversation about good bowel health.”



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

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

“Having the easy read resource to show people a step by step guide on how to complete the test and explain the importance of this.”

Key learnings

Above all, healthcare professionals want to provide the best possible care to help improve good bowel health and participation in screening. This is evident in the popular demand for the training. They want to improve their knowledge and feel confident providing information and support tailored to the needs of people with learning disabilities.

Understanding the advantages of the new bowel screening test in Scotland (the faecal immunochemical test) has encouraged the healthcare professionals that we trained to

actively promote bowel screening – the test is easier to use, more reliable, more acceptable and therefore easier to promote.

Accessible information is key to supporting personalised informed choice and must be proactively shared with both people with learning disabilities and the carers and health professionals who support them.

Bowel Cancer’s UK education for healthcare professionals

Building on Bowel Cancer UK’s role as provider of education, the training programme provided a range of expert information, increasing awareness and championing early diagnosis. In our broader role as facilitator and bringing together a range of health care professionals, we received positive feedback about creating interactive and relaxed learning events.

Training activities were important in helping participants to better understand the information presented and stimulated thinking and discussion. They also facilitated the enjoyment of the training day and interaction

between participants and opportunity to share experiences. Participants were positive about all aspect of the training, but a key challenge was freeing up staff time to attend the training for a full day (10am-4pm).

Tips for other organisations looking to provide similar training

Make sure your training covers the key facts about bowel cancer and the screening programme – from symptoms and risk factor awareness to practical demonstrations of the bowel screening test.

Build local networks by inviting healthcare professionals from a range of backgrounds. Think about different learning styles, deliver your training with a range interactive activities and time for discussions.

Use the accessible information pack 'Bowel health and screening - supporting people with learning disabilities to take care of their bowel health'. Produced in partnership with NHS Health Scotland, packs can be ordered from: nhs.healthscotland-publications@nhs.net
Contact the bowel screening centre to request a supply of sample test kits (for demonstration only). Scottish Bowel Screening Centre: 0800 0121 833 / bowelscreening.tayside@nhs.net.

Grant key points:

Funding strand: Scottish Government Screening Inequalities Fund, 2018/19. Population Health Improvement Directorate, Health Protection, screening@gov.scot.

Bowel Cancer UK is extremely grateful to Scottish Government, and particularly Sarah Manson and team for their support. The funding from the Screening Inequalities Fund enabled us to have a dedicated training project, championing screening and early diagnosis across Scotland.

The training project provides a relatively low cost, transferable model, which builds upon the significant resources and skills of healthcare professionals in our community.

Conclusion

It is essential to support personalised informed choice and targeted interventions to increase participation in screening amongst adults with learning disabilities, especially as it represents one the best ways to detect bowel cancer early.

In the twelve-month grant period, our training programme went from strength to strength. Evaluations consistently show improved awareness of bowel cancer and screening, as well as proactive actions and the use of accessible information to support bowel health and uptake of bowel screening.

The project's biggest impact is the many awareness activities and tailored support that participants have subsequently provided to help ensure people with learning disabilities have access to health promotion and the opportunity to take part in screening.

Moving forward, it is important to consider the organisations best placed to invest in and deliver ongoing training and education – including NHS Health Boards, local authority or Health and Social care Partnerships as well as the third sector and Scottish Government. We call on these organisations to prioritise how they can facilitate learning and continue to tackle health inequalities in people with learning disabilities.

Visit: bowelcanceruk.org.uk

Email: training@bowelcanceruk.org.uk

 [/bowelcanceruk](https://www.facebook.com/bowelcanceruk)

 [@bowelcanceruk](https://twitter.com/bowelcanceruk)