Uptake of bowel screening among people with a learning disability is so low that one trust undertook a project to ascertain, and address, the reasons for it.

**Learning disabilities: improved bowel screening**

**In this article...**
- Why screening for bowel cancer is important
- Barrier to screening for bowel cancer
- Interventions to improve screening uptake

**Keywords:** Bowel cancer/Learning disabilities/Screening/Uptake

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**Authors** Mandy Bowler is clinical business manager, South Tyneside NHS Foundation Trust and Peter Nash is safe care lead at Learning Disability Service, South Tyneside NHS Foundation Trust.

**Abstract** Bowler M, Nash P (2015) Learning disabilities: improved bowel screening. Nursing Times; 111: 49/50, 14-16. Bowel cancer is the second most common cause of cancer death in the UK but it can be successfully treated if detected at an early stage. In 2006 the NHS Bowel Cancer Screening Programme was introduced to everyone aged 60–74 years in England. This article describes how South Tyneside NHS Foundation Trust community Learning Disability Service addressed the bowel screening needs of those people with a learning disability in Gateshead and South Tyneside. A project was developed to improve and increase the uptake of bowel screening for this population group.

People with learning disabilities have a shorter life expectancy than the general population (Emerson et al, 2012). A number of national reports – such as Michael (2008) and Mencap (2007) – have highlighted that adults with learning disabilities often experience poor levels of care and barriers to accessing healthcare services. Heslop et al (2013) also reported on the quality and effectiveness of health and social care given to people with learning disabilities, which has been shown to be deficient in a number of ways. As well as these differences, it is also claimed that both health and social care professionals regularly show a lack of understanding and adherence to the Mental Capacity Act 2005, especially when assessing capacity and implementing best-interest decisions (Mughal, 2014).

Patterns of health needs among adults with a learning disability are different to those of the general population (Emerson et al, 2012), and national screening programmes that target local population health, such as bowel screening, are often not designed to fully include this demographic group.

The lifetime risk of developing bowel cancer in the UK is 1 in 14 for men and 1 in 19 for women (Office of National Statistics, 2013). Although the National Bowel Screening Programme offers bowel screening every two years to men and women in England aged 60–74 years – including those with a learning disability – the uptake of it in England is poor (Box 1).

The late diagnosis of bowel disease is becoming increasingly common but if detected at an early stage, more than eight out of 10 cases of bowel cancer can be successfully treated (Office of National Statistics, 2013).

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**5 key points**

1. People with learning disabilities have a lower life expectancy than the general population
2. Bowel cancer can be cured if detected at an early stage
3. In England, all men and women aged 60–74 years are eligible for a national bowel cancer screening programme
4. Uptake of bowel cancer screening is low among people with learning disabilities
5. Different approaches may be needed to communicate the importance of the screening process, and what it involves, to people with learning disabilities
Although many studies have been carried out on the roll-out of bowel cancer screening for the general population, there has been little research into such screening in people with learning disabilities. Available data shows that incidence and mortality of bowel cancer for people with learning disabilities is lower than for the general population (12–18% versus 26%) (Emerson et al, 2012).

Developing the project
Across our two local areas of South Tyneside and Gateshead there are 1,921 adults with learning disabilities who are known to GPs. Of those, 16% (n = 311) are between the ages of 60 and 74 years, thereby qualifying for the NHS’s national bowel screening programme.

Of those who are eligible, 23% (n = 72) had initially discussed the subject of bowel screening with a member of the Community Learning Disability Team (CLDT). Fewer than half (47%) of those eligible service users who had the discussion had a bowel screening test. This is lower than the national average for mainstream population, which is 60% (Turner et al, 2013), so the CLDT carried out an intensive 12-week project to:

- Consider its current data;
- Implement ways to improve access and the uptake to bowel screening;
- Increase the number of people with learning disabilities engaging in the bowel screening programme;
- Increase current uptake of the screening test by at least 10% in the first 12 weeks.

The initial project commenced in January 2015 through to March 2015.

A nurse coordinator was appointed to lead on the project, and collect and collate the data. The number of people known to the CLDT who fell within the age range was established using the Health Action Plan databases in each GP practice. The data confirmed there were 311 people with a learning disability who were eligible for bowel screening, and that 72 had already discussed bowel screening with their community nurse. In total, 34 had already undergone bowel screening, which left a group population of 239 to focus on during the 12-week project.

Initial contacts were made with learning disability user groups, cancer screening leads, the wider Community Learning Disability multidisciplinary Team, and carers and families across the localities to explore their views and consider any reasons why those people with a learning disability may not undergo bowel cancer screening. Some common themes emerged through these preparation stages:

- Screening letters were not user friendly;
- People felt embarrassed, often failing to understand what was required to have the test;
- Issues with mental capacity were identified;
- There were no clear links between the cancer screening hubs and general practices or CLDT to identify people who had a learning disability;
- There was no clear pathway between GPs and CLDT when those with a learning disability did not respond to letters sent out about the national screening programme.

For the project to be successful, actions were necessary to address the identified themes.

Screening letters
Using the guidance from the Department of Health on reasonable adjustments for people with learning disabilities (Turner and Robinson, 2011), we developed “easy-read” letters, designed by our learning disability speech and language team.

Embarrassment and confusion
We identified that, as well as the person with a learning disability and their carer being embarrassed because of the subject matter, our own staff were also often embarrassed. Staff did not always know how to explain to the patient what they needed to do to submit their faecal sample and how to submit this as part of the screening process. As a result, a training pack was developed, which included screening information and leaflets.

Community teams were given a three-hour training session that increased their confidence and enabled them to better support the person with a learning disability and their carer in the community and thereby reduce embarrassment.

Mental capacity
We were aware that some people did not have the mental capacity to consent to screening. Those who were unable to consent, or lacked the capacity to decide whether they wanted to consent after being assessed using the mental capacity assessment framework process (Box 1), were subject to a best-interest decision. Best-interest decisions were based on the opinion that all people wanted to be screened. The decision was made with the person with a learning disability and their relevant representative to gain consent to use their stool sample for screening purposes.

The CLDT carried out 117 mental capacity assessments and 39 people with a learning disability were found to have capacity to make their own decision about screening; 78 were found to not have capacity. The other people in the project were either not subject to the mental capacity assessment as their ability to consent was not under review; an assessment was carried out by residential staff and samples collected and sent in for screening or carers/family members collected the specimens.

Identifying those with a learning disability and non-responders
One of the concerns identified at the outset of the project was the difficulties the screening service had in identifying those people with a learning disability. Since there were no flagging systems to identify someone with a learning disability, no reasonable adjustments could be made at the initial contact stage and a standard national screening letter is sent and followed up at six weeks if there is no response. If there is no response to the second letter at 13 weeks the national screening service writes to the GP.

By working together we were able to put in place a pathway between the screening service, the GP and CLDTs so that GPs use the 13-week non-responder letter to cross-check the patient details with the learning disability database. The pathway is outlined in Figure 1.

Project results
At the end of the 12-week project, of the 239 people with a learning disability who were eligible to be included, 36 declined to participate and six were unable to do so due to ill health. In total, bowel screening was discussed with 193 (81%) people, of whom 117 (61%) undertook bowel screening. The four remaining people were hospitalised; two
died, one was transferred out of area and one remained in a poor condition.

Of the 117 who undertook screening, 99 (85%) required no further action. However, 18 (15%) did require a follow-up colonoscopy due to the presence of occult blood. It was arranged that these individuals would have the support of the CLDT to help understand this process.

Figure 1. BOWEL SCREENING PATHWAY FOR PEOPLE WITH A LEARNING DISABILITY

Gateshead and South Tyneside Community Learning Disability Team and GP Practices

Person Identified by ePNL as requiring a bowel screening, invite letter and Bowel Screening Kit sent out by Bowel Screening Hub

Reminder letter sent by hub if no record of non-participation of completing test after four weeks

At 13 weeks a letter sent to GP from Bowel Screening Hub stating person did not participate in Bowel Screening Test

Person Contacted by CLDN within 30 days of referral receipt; arrange visit to discuss bowel screening

CLD Nurse assess capacity

Person has capacity and agrees to test CLDN orders Bowel Screening Kit

Person Lacks capacity in best interest to have Bowel Screening Test and agrees to test CLDN order Bowel Screening Kit supports carer/family/Nurse person with bowel screening. It was arranged that these individuals would have the support of the CLDT to help understand this process.

The project results demonstrate that the number of people with a learning disability (known to us and eligible for bowel cancer screening) who went on to be screened increased from 47% to 61% and exceeded our target increase of 10%.

**Conclusion**

Although the project was very successful in increasing the uptake of screening, we are aware that as 23% of those eligible for screening had already had a discussion about screening prior to the commencement of the targeted project, which would have an effect on our figures by reducing the overall total to 49%.

As a result, we have revisited those original people to review their decision to take part in screening.

The project has helped us consider the wider support that may be required for people with a learning disability who become eligible for inclusion in any of the current cancer screening programmes, not just that for bowel cancer. It has ensured that all staff working in learning disability services have a raised awareness of their role and responsibilities in helping individuals to understand cancer screening programmes and the choices they have.

The CLDT are recommending that we now consider how to adapt the same principles to increase screening for other cancers, for example by agreeing to an annual roll-out to continue improved access for screening.

Our approach now is to:
- Offer ongoing training and support to staff;
- Be proactive in identifying those people with a learning disability falling within age range for specific cancer-related screening each year;
- Target individual and carers/families with advice and support;
- Continue to record screening uptake. **NT**

**References**


*Adapted from Emerson et al Learning Disability Observatory*