



NHS GM Bowel Cancer Screening Programme

Case Study

Executive summary

The Learning Disabilities Mortality Review (LeDeR) is a national NHS England programme that reviews the deaths of people with a learning disability and autistic people to identify improvements in care.

The initiative found people with one or more learning disabilities experience significantly poorer health outcomes and a shorter life expectancy than the general population (LeDeR, 2022). The median age of death for people with a mild learning disability is 62, which is 21–24 years younger than those without a learning disability. Many of the contributing comorbidities are preventable if health services are equitable and accessible.

Bowel cancer is a significant concern. In 2022, it accounted for 15.8% of cancer deaths reported to LeDeR, compared to 10% in the general UK population. The median age of death from bowel cancer is 60 for people with a learning disability, compared to 75 in the general population, and the proportion of deaths has increased.

Whilst the NHS Bowel Cancer Screening Programme currently offers screening every two years to people aged 50–74, the LeDeR report (2022) recommended closer monitoring of bowel cancer symptoms and adjustments to screening for people with a learning disability.

In response, a Greater Manchester partnership expanded a pilot approach to improve support for people with a learning disability to understand bowel screening invitations and make informed choices.

What did we do?

Following a successful pilot in the Bury locality, the approach was expanded across Greater Manchester. Community Learning Disability Teams (CLDT) and Primary Care leads worked together to develop a pathway that identified people with a learning disability at the pre-invitation stage of the bowel cancer screening process. This ensured individuals were offered tailored support to understand their screening invitation and make informed choices, including access to specialist help where needed.

The project was delivered in partnership with:

- Representatives from CLDT and locality teams
- The Greater Manchester Screening and Immunisation Team
- The Regional Hub
- The Senior Clinical Lead for Health Inequalities for Greater Manchester

Regional Bowel Cancer Screening (BCSP) Hub, the Cancer Screening, leads across:

- The three BCSP screening centres in GM
- Learning Disability Primary Care Assistant Practitioners
- Community Learning Disability Teams

How did we do it?

Cancer Screening Improvement Leads worked with GP practices across Greater Manchester to support the implementation of the pathway.

Practices were contacted to ensure data sharing agreements were in place, with issues escalated to the NHS Primary Care team where required.

Training was delivered to Learning Disability Primary Care Assistant Practitioners (LD PCAP) and CLDT across Greater Manchester. This ensured staff were confident in identifying eligible individuals, making referrals, and providing appropriate support to help people understand their bowel cancer screening invitation and complete the test where they chose to do so.



What did we find?

Between November 2023 and March 2024, 103 referrals were received across Greater Manchester.

Of these, 58 people completed their Faecal Immunochemical Test (FIT), giving an uptake rate of

56%

This is higher than the average uptake in the non-learning disability population and reflects the impact of tailored support.

Engagement with screening was encouraging. **28 of 33 people who had previously completed screening without support did so again.** 30 people received their bowel cancer screening kit for the first time due to changes in the age range of the BCSP, with 20 completing their FIT. **Two positive FIT results were identified:** one person attended colonoscopy and had polyps removed, while another opted out following a best interest discussion.

Stephen's story:



Stephen Owen, 64, from Whitefield, Bury, completed his screening with the help of the Learning Disability Flagging Project, which helps people with learning disabilities take part in the national BCSP. Now he's hoping that his story will encourage other people who live in Greater Manchester to do the same.

"Always do the bowel screening sample and send it off. If you don't understand, ask for information about the test. Easy read information is available, and you can read this with your support worker."

Stephen

The pathway also reached people who had not previously engaged with screening. **This included one individual aged 72 who completed screening for the first time after being invited since 2011.** LD PCAPs in Bury, Heywood, Middleton and Rochdale, and Oldham played a key role in supporting referrals and engagement.

Key challenges & lessons learned

1. Improving identification and access

35% of individuals on the NW Bowel Screening list were not initially known to local services and did not receive additional support. The pathway was strengthened so the Cancer Screening Improvement Lead (CSIL) now proactively contacts those not known to services, improving equitable access.

2. Strengthening data sharing and consistency

Early data sharing limitations meant some practices and localities were not included, and support varied. Increased engagement with GP practices and the introduction of LD PCAPs have improved consistency, coverage and referral rates across the programme.

3. Collaborative working and impact

Strong partnership working between the Pennine Bowel Cancer Screening Programme and the CLDT underpinned delivery. Participants supported by the CLDT were more likely to complete the screening kit, demonstrating that reasonable adjustments and targeted support significantly increase participation in bowel screening.



Next steps

All 10 localities in Greater Manchester have now signed up to the pilot, with agreed delivery plans in place and a formal evaluation currently being produced.

We were nominated for an award at the GM Cancer Conference in June 2024 and received a highly commended. We were also nominated for an award at the 2026 GM Conference with a follow up video created showing the journey of a lady with LD to colonoscopy as an addition to the flagging project.

The model has already been successfully replicated within the NHS Breast Screening Programme. The next phase will focus on extending this approach within bowel screening to other under-served groups, including people with severe mental illness, physical disabilities, and sight or hearing loss, to further reduce inequalities and improve access.

[Endoscopy Journey](#)

[Bowel Cancer Screening Centre: Northern Care Alliance](#)

[Bowel cancer screening - NHS](#)

[Bowel cancer screening: easy guide - GOV.UK](#)

If you have any questions about this story of change please email gmhscp.adminpopulationhealth@nhs.net



Are you aged 50-74?

Received a bowel screening test in the post?

If you're between 50 and 74 years old, you'll get a screening test in the post every two years.

Take the test – it could save your life.



For more information, scan the QR code or visit [bowelcanceruk.org.uk/screening](https://www.bowelcanceruk.org.uk/screening)