

NHS Quality Checkers

Bowel Cancer Screening

North East North Cumbria Regional

Report May 2023

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Completed with support from:



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Completion of combined report for North East and North Cumbria

The North East and Cumbria Learning Disability Network commissioned the completion of bowel cancer screening Quality Checks. This report combines the individual reports completed on each service giving general comment and recommendations.

The quality checker teams who supported the Bowel cancer screening quality checks were: Skills for People, Your Voice Counts and People First Independent Advocacy, Cumbria.





Quality checks were completed at:




- North East, Yorkshire and Humber Bowel Cancer Screening Hub (visit to support understanding of the screening process)
- North of Tyne Bowel Cancer Screening Programme
- South of Tyne Bowel Cancer Screening Programme
- North Tees Bowel Cancer Screening Programme
- Cumbria Bowel Cancer Screening Programme


For each of the bowel screening centre the quality check included checks of areas that are used to deliver bowel screening; outpatients, endoscopy and radiology.




This is completed using service self-assessment questionnaires for each area, a quality checker team visiting the service and talking to staff, contacting patients and ask them what they think of the service and writing a service report including recommendations.

Easy read executive summary

 	<p>A Health Quality Check is a check on a service. It looks at how assessable a service is for people with a learning disability. It uses a set of standards.</p> <p>Standard 1. How does the service always involve people with a learning disability in their care?</p> <p>Standard 2. How is the care, treatment and support planned to meet the needs of each person with a learning disability?</p> <p>Standard 3. How does the service give good care and make the person with a learning disability feel safe?</p> <p>Standard 4. How well are the staff trained and know how to do their job? How well does the service continually improve?</p>
	<p>This report is about quality checks on bowel cancer screening services. The report highlights key findings and recommendations from 4 screening centres.</p>
	<p>The quality check is done by a small team including people with a learning disability.</p> <p>The teams who helped were:</p> <ul style="list-style-type: none"> Skills for People Your Voice Counts People First Independent Advocacy

	<p>Quality checks were completed at:</p> <ul style="list-style-type: none"> • North of Tyne Bowel Cancer Screening • South of Tyne Bowel Cancer Screening • North Tees Bowel Cancer Screening • Cumbria Bowel Cancer Screening
	<p>NHS Quality Checkers assess a service by:</p> <ul style="list-style-type: none"> • Sending a list of questions to the service • Visiting the service and talking to staff • Contacting patients and ask them what they think of the service • Writing a report including recommendations
	<p>Recommendations</p> <p>The quality checkers say what could be better. These are called recommendations. The recommendations are shown against a standard.</p> <p>Standard 1: How could the service be better at involving people with a learning disability in their care at all times?</p> <p>Recommendation 1: All screening centres should include the voices of people with a learning disability, families and carers, in service improvement.</p>

	<p>Recommendation 2: Consider an annual audit of patients with a learning disability who were referred to the bowel screening centre.</p>
	<p>Standard 2. How is the care, treatment and support planned to meet the needs of each person with a learning disability?</p> <p>Recommendation 3: Ensure people with a learning disability and autistic people are flagged.</p> <p>Recommendation 4 Information on reasonable adjustments must be shared to support the care of the individual.</p> <p>Recommendation 5: Ensure the physical environment has been fully considered to enable people with disabilities to access screening.</p> <p>Recommendation 6: Easy read and accessible resources must be available.</p> <p>Recommendation 7: Create communications folders available to support patients understanding of information.</p>

 <p>Mental Capacity Act</p>	<p>Standard 3: How could the service give better care and make the person with a learning disability feel safer?</p> <p>Recommendation 8: Ensure all staff understand and can follow the principles of the Mental Capacity Act.</p>
 <p>Training Room</p>	<p>Standard 4: How well are the staff trained and know how to do their job? How well does the service continually improve?</p> <p>Recommendation 9: All staff to attend learning disability and autism mandatory training.</p> <p>Recommendation 10: Offer Makaton training to more staff to aid communication with patients.</p>
 <p>Report</p>	<p>This report will be shared with people who work in bowel cancer screening to help them improve bowel screening for people with a learning disability.</p>

Introduction

NHS Quality Checkers Toolkits

The NHS has historically worked with the community voluntary sector to create quality checker toolkits for use in health and social care.

This is because people with a learning disability are more likely to have poor physical health than other people and less likely to use services such as screening. [Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022 - NDRS \(digital.nhs.uk\)](#)

It is important services improve the way they work with people with a learning disability to support them in looking after their long-term health.

The North East and Cumbria Learning Disability Network in partnership with Screening programmes and Skills for People developed two new quality checker toolkits to support the breast screening and bowel cancer screening programmes. These resources have been used to quality check screening services in the North East and North Cumbria.

The work to co-design and complete the quality checks started in 2020, due to the complications of covid this project took longer than expected with all visits completed by March 2023.

Bowel Cancer Screening

Bowel cancer screening aims to reduce deaths from bowel cancer by detect pre cancer bowel growths and bowel cancer at an early stage (in people with no symptoms).

About 1 in 15 men (7%) and 1 in 18 women (6%) in the UK will develop bowel cancer during their lifetime. It is the fourth most common cancer in the UK, and the second leading cause of cancer deaths, with over 16,000 people dying from it each year. [Bowel cancer statistics | Cancer Research UK](#)

According to the [CIPOLD](#) report in 2013: “The greatest difficulties for people with learning disabilities appeared to be with access to bowel cancer screening. Many did not respond to the invitation to participate, possibly because they did not understand the importance or implications of the screening, and possibly because they found the process difficult to follow. CIPOLD found little support provided to people with learning disabilities to enable them to engage with the bowel screening programme; there was no evidence that people had received accessible information about the screening programme, and it appeared that no reasonable adjustments had been made to support their participation. Where people were

supported by carers, there was evidence of some confusion on the part of carers as to what the process should be. For example, some carers believed that stool samples could not be collected from incontinence pads and so did not return a sample for testing; others reported that there was a lack of advice about how to get a sample from a person who could not collect their own and/or who found changes to their routine, or interference with privacy, distressing.”

Since the 2013 CIPOLD report bowel cancer screening services have made a number of changes. In the North East and Cumbria the bowel screening hubs run a flagging programme to identify people with a learning disability and offer support to understand and complete screening in partnership with the Community Learning Disability Teams (CLDTs). The National programme with support from the North East and Cumbria Learning Disability Network produced [easy read materials](#) including a facts booklet, invitation and results letters. Books beyond words also updated their materials <https://booksbeyondwords.co.uk/resources-dl>.

The National programme also changed the test used for collecting the initial sample which helped increase uptake.

Locally we have produced the [social care providers guidance and resource pack](#). And recently the Network started delivering [Be Screening Aware](#) a co-produced peer education programme.

Bowel Screening Pathway

The Bowel screening pathway uses a number of different teams, these interact with each other along a specified pathway.

The bowel screening hub starts the screening process inviting individuals to take part in screening, testing completed kits and manage a telephone helpline.

If an individual receives a positive test result (they require further tests) they are passed to the bowel screening centre and the specialist screening practitioner (SSP). The centre then liaises with a number of specialist departments locally to provide further tests, this includes; outpatients, endoscopy and radiology.

Further information on the pathway is available at: [Bowel cancer screening: programme overview - GOV.UK \(www.gov.uk\)](#)

Health Quality Checker Standards

NHS Quality Checkers assess services against a set of standards based on The Good Health for All standards created by Skills for People and Sunderland People First and Supported by the North East and Cumbria Learning Disability Network.

These standards are similar to the NHS Improvement standards, used by Trusts to self-assess their service overall. These complement the standards Quality Checkers use to assess the service from their viewpoint.

Standards used for Quality Checks

Standard 1. How does the service always involve people with a learning disability in their care?

Standard 2. How is the care, treatment and support planned to meet the needs of each person with a learning disability?

Standard 3. How does the service give good care and make the person with a learning disability feel safe?

Standard 4. How well are the staff trained and know how to do their job? How well does the service continually improve?

NHS Quality Checkers assess a service by:

- Send a self-assessment questionnaire to the service to complete and return.
- Visit the service and talk to the staff.
- Contact patients and ask them what they think of the service.
- Write a report about the evidence collected and recommendations.

Results of bowel cancer screening quality checks

Bowel Cancer Screening Hub Quality Checker Report - March 2020

The North East and Cumbria is served by 2 bowel cancer screening hubs. For this project only the North East, Yorkshire and Humber Bowel Cancer Screening Programme Hub was visited.

The Quality Checker team did not have a specific Quality Check List for this visit but wanted to find out about the Hub and the part it plays in supporting people with a learning disability to participate in screening.

About the Hub

The Hub is one of 5 across England. With a population of around 8.4 million people, it supports 9 screening centres.

The Hub manages:

- Invitations through in-house mailing process
- Telephone enquiries via national helpline (call-centre function)
- Processing of FIT test kits (laboratory process)
- Issue of results (in-house mailing process)
- Arrangement of appointments with Screening Centres (call-centre function)

Examples of good practice:

Bowel screening flagging for people with a learning disability

The flagging system improves the opportunity for people with a learning disability to make informed choices about bowel screening by providing specialist help and support.

GP's flag people with a learning disability on their system and sharing the information with the Hub. The Hub then contact the Local Community Learning Disability team (CLDT) to let them know that the person is about to be invited for bowel screening. CLDT can ensure the person receives the right help and support to make choices about taking part.

Support

The system used by the Hub does not automatically indicate if a person has a learning disability but can identify potential vulnerable people. If 2 kits are sent back "spoilt" this triggers an assistance alert on the system, the GP will be alerted by the call centre. The GP can contact the individual to arrange for support to be put in place.

Improvements in services:

The Hub is looking at ways to adapt kits for blind people and people with limited mobility.

Soon, a QR code will be visible on the FIT kit box. By using a smart phone, the code will be scanned, this will link to a video on how to use the kit.

At present, the software used by the Hub is a “one size fits all”. The system sends out 750,000 invitations from the Hub each year but can not send tailored letters to each individual when they are invited. The system does not flag up if someone has a learning disability and automatically send out easy read info. They hope to change this in the future.

Recommendations from Hub visit:

The Hub work hard with the CLDTs to provide support for people invited to complete screening. Further work with health and social care is needed to ensure full support through the pathway.

Ensure all GP practices are fully on board with flagging and are continually looking to improve their records. Most GP practices are onboard but there are still some who are not.

More awareness raising e.g. peer support training ‘[Be Cancer Aware](#)’ and ‘[Be Screening Aware](#)’ to ensure people with a learning disability increase their knowledge.

Awareness training should be offered to health care professionals in other settings such as care homes to ensure they understand the importance of screening and how they can support individuals to make informed decisions.

https://neclnetwork.co.uk/wp-content/uploads/2022/05/LDC_pack_2022.pdf

The Hub is continually looking at ways to improve the service, not just for people with a learning disability but for all users.

Bowel Cancer Screening Centres Combined Report

Introduction

Bowel Screening Centres manage the pathway for a participant following a positive test result. This part of the report brings together feedback from the four screening centres. The report highlights key findings from the self-assessment questionnaire, visit, staff and patient feedback and recommendations.

Key Findings

Key findings have been themed.

Below is a list of themes identified through the Quality Checks, under each theme are a selection of examples from individual reports. These are mapped against the standards.

Standard 1. How does the service always involve people with a learning disability in their care?

Easy read materials

- Easy read letters can be sent to patients if the service is aware of need.
- Easy read information is available to staff, not all staff know how to access.

Staff

- Quality checkers observed welcoming and attentive staff.
- Staff use a variety of communication methods to talk to individuals and check understanding.
- Staff access the Learning Disability Liaison Nurses for advice and support.

Working to support the individual

- Staff involve families and carers in care planning for a person with learning disability.
- Letters ask patients to contact the department if they need extra support.
- The appointment letter encourages the person to bring a supporter.
- Pre-visits can be arranged.
- Outpatients - If a person identifies as having a learning disability staff ask the person or carer if they can make any reasonable adjustments.
- If individuals are identified as having a learning disability, a health and care (hospital) passport is given to patients at their first appointment. This can be completed by the individual and their carers and brought to their next appointment.
- If a patient is afraid or anxious the department can provide quiet areas, offer early or late appointments, and liaise with the learning disability liaison nurse.

- If needed, a best interests meeting can be arranged for the patient.

Flagging

- Outpatients are not always informed if someone has a learning disability. If the information is not flagged, the first appointment may be when staff find out.
- Track care will alert staff if a patient attends the Outpatient Department for an appointment and the individual has a learning disability.

Physical environment

- Building fully accessible for wheelchair users with automatic doors and lifts.
- Quieter rooms available away from the main waiting area for patients.
- Area had a low reception desk which could be accessed by wheelchair users. However, at time of our visit the low desk was cluttered and not clear for use.
- The seats were all joined together in three's and only some of the end seats had an arm rest. We saw no raised seating for people with mobility issues. Lack of arm rests on seating and high seats can make it difficult for people to stand up/sit down safely.

Standard 2. How is the care, treatment and support planned to meet the needs of each person with a learning disability?

Physical environment

- Easy to access and clearly signposted.
- Hospital and car parking facilities are easy to access.
- The waiting area in Endoscopy has large reception desk, with an accessible low area.
- As you enter the Main Entrance there is a large colour coded and numbered map of the hospital. Quality Checkers found the map to be quite clear and easy to follow.
- There was a large accessible toilet which was fully equipped, clean and with good lighting.

Reasonable adjustments

- The patients have access to quiet waiting areas, changing facilities and toilets.
- There is no designated quiet room, however the Specialist Screening Practitioners (SSP) will always try and accommodate.
- SSP provide initial pre assessment appointments face to face, telephone and online. They can meet patients in different local venues and have used GP surgeries, libraries, and other places to make it easier to see people.
- SSP can allow more time for pre-assessment and the procedure.
- Interpreters can be used, but only if the staff are aware it is required.
- Hearing loops are available.
- Staff will use visual aids, pictures, hand gestures and large print to communicate with patients. They try to avoid using jargon.

- Music is played in the background which helps to make people feel more relaxed.
- The patient can bring an item of comfort, such as favourite Newcastle top or pillow.
- If the individual has a learning disability that is not shown on Bowel Cancer Screening system, staff will update this after the pre-assessment.
- There are Easy read guides to Colonoscopy and CTC. Staff can also use a Storyboard to help get information across.

Flagging

- Learning Disability flags should be added to the Bowel Cancer Screening Service (BCSS) system.
- The SSP can flag people who attend and they suspect have a learning disability by adding additional notes to the patient record. Additional needs notes can outline what support may be needed for that patient when attending screening appointments.
- Staff do not always know if patients with learning disabilities are flagged on the system, staff rely on GP's and other Referrers for this information. As staff do not always know if a patient has a Learning Disability, they cannot provide the necessary easy read information or reasonable adjustments a patient may require.

Care and support

- Staff confirm with the patient and family/carer that information given regarding the visit has been understood. This is recorded in the patient's notes.
- The Department always allows someone to accompany patients with a learning disability.

Standard 3. How does the service give good care and make the person with a learning disability feel safe?

Reasonable adjustments

- The SSP will bring easy read information if the person requires.
- The consultation rooms can be used as a quiet space when they are available. The doctor can be requested to come to the quiet room to see a patient. This avoids the patient having to move from room to room if they are anxious or afraid.
- Patients can have their appointments staggered and they can come back as many times as is needed.
- Staff can meet patients on arrival at the hospital and escort them to the department.
- Mobility equipment is provided for patients
- Interpreter/family members allowed in the room and on the department.

- We did not observe any easy read information displayed in the waiting area or on any of the other information boards.

Staff training / awareness

- SSPs - are trained and aware of the law about capacity to consent and contact the relevant department within the Trust for advice if required. If ever capacity is in question, the team would ensure a four point capacity test is able to be completed.
- SSPs - ensure they listen to and note a patient's concerns regarding their procedure they are trained and able to reassure patients about all parts of the screening process.

Consent and assessment of understanding

- The Screening Service - utilises robust consent policies to ensure that patients are appropriately assessed and have consented prior to any screening procedures.
- All patients are seen by a SSP to assess their suitability for Colonoscopy. This may be done with a carer or relative of the patient present. If further assessment or clinical intervention is needed at this stage, the patient can be booked in for assessment by a Screening Endoscopist.
- SSP - provide patients with all the necessary information required, in a variety of formats, in order to allow patients to make an informed decision about further participation.
- SSP - Patients are allowed time to consider their options if they do not wish to commit to a diagnostic procedure at the time of their assessment, they are always provided with contact details should they wish to speak to anyone about their choices once they have left their assessment appointment.
- If an individual permanently lacks the mental capacity to consent to screening, a best interest decision may be made on their behalf. A Best Interest Decision Recording Tool (MCA2) form would be completed to establish if taking part in screening is in the participant's best interest.
- Most staff said that they understand the Mental Capacity Act and follow the guidelines set out in the Act. Quality Checkers felt that the Mental Capacity Act wasn't always fully understood or was the responsibility of other staff.
- All staff have access to a Mental Capacity Advisor and a Safeguarding Lead.
- Staff always involve families and carers if the patient requests.
- Accurate and comprehensive records are kept and relevant information is recorded in patient's notes.

**Standard 4. How well are the staff trained and know how to do their job?
How well does the service continually improve? This standard refers directly
to staff training.**

Consent and assessment of understanding

- The Trust policy for obtaining consent is used to assess ability to give informed consent. Staff do a yearly DOPS on obtaining consent and have completed consent training to be on the Trust's register.
- Have access to a Mental Capacity Advisor, Safeguarding team, Dementia team or Learning Disability team, contactable via email or telephone.
- Most staff who answered the self assessment questionnaire said they did not feel confident in applying the Mental Capacity Act to people with learning disabilities but would seek advice.
- Staff follow Trust policies and procedures covering health and safety, consent, confidentiality, and information sharing.

Training programmes

- SSP undergo mandatory learning disability training every 3 years. Additional training on aspects such as communication available via Education Department.
- All Volunteers receive disability awareness/equality training.
- From December, Learning Disability and Autism Mandatory training will be added to everyone's training. It will include all trust staff including security, porters, admin etc.
- All staff receive Equality and Diversity training, Safeguarding and Mental Capacity training.

Patient experience

- Feedback is sought informally in appointments and using 'Family and Friends' cards available at the desk in the waiting area. These use limited words but are not in easy read format.
- The Bowel Screening Service sends out patient satisfaction questionnaires thirty days after a test. This is not easy read.
- All patient information produced is checked by a Patient Panel before being sent out.
- Feedback is discussed in team meetings to reflect on practice and make improvements.
- Staff were unsure if the number of people with a learning disability who attend the department was reviewed, but felt it was something worth considering.

Recommendations

The recommendations below identify things quality checkers feel services could be better at. These are collated from all 4 screening centre quality checks. These are mapped against the standards of care.

The recommendations are based on all the information gathered, when different screening services view the recommendations they may identify some recommendations that they already comply with.

Standard 1: How could the service be better at involving people with a learning disability in their care at all times?

Recommendation 1:

All screening centres should actively include the voices of people with a learning disability, families and carers, in service improvement.

This could be face to face through forum meetings, focus groups or working with existing learning disability groups or organisations.

Consideration needs to be given to methods of gathering feedback to ensure they are accessible to people with a learning disability, for example, friends and family test, post procedure questionnaires, complements and complaints processes.

Services should consider the value of including people with a learning disability in promotion of bowel screening in the community.

Patient panels within trusts that review patient information should include people with a learning disability.

Recommendation 2:

Consider an annual audit of patients with a learning disability who were referred to the bowel screening centre.

Use learning and feedback to identify areas of improvement for the service and staff continual professional development.

Standard 2. How is the care, treatment and support planned to meet the needs of each person with a learning disability?

Recommendation 3:

Ensure people with a learning disability and autistic people are flagged.

Any learning disability and autism flag should be visible on all systems along the patient journey from the Bowel Cancer Screening System to internal hospital systems.

Flags should include the reasonable adjustments a person requires and not just recognition of diagnosis.

Reasonable adjustments should be flagged using the Reasonable Adjustments Digital Flag snowmed codes.



Reasonable
Adjustment Updated !

Recommendation 4

Information on reasonable adjustments must be shared to support the care of the individual.

Departments need to have a process in place to share information on the reasonable adjustments an individual needs with other departments. This links to recommendation 3.

Recommendation 5:

Ensure the physical environment has been fully considered to enable people with disabilities to access screening.

Consider:

- Accessible reception desks
- Quiet waiting area for individuals who struggle in a noisy, busy environment
- Signage and maps that are easy to understand
- Seating includes higher seats with 2 arm rests
- Information displayed in departments is accessible and includes who to contact if additional support or information is required
- Notice boards stating which Doctors and Nurses are on duty to include photographs
- Hearing loops

Recommendation 6:

Easy read and accessible resources are available.

This will support compliance with the Accessibility Information Standard and should include: appointment letters, Bowel preparation leaflets, consent forms, results letters and feedback questionnaires.

Ensure all staff are aware of where and how to access easy read information.

Effective training must be in place to enable staff to feel confident in asking about learning disability and reasonable adjustments.

Recommendation 7:

Create communications folders available for specialist screening practitioners to support understanding of information.

Communication folders can include:

- Photos of process
- Story boards
- Makaton cards
- Links to people in trust who can support if needed
- Information for carers

Folders should be available at all appointments to ensure alternative format materials can be offered to any patients attending appointments.

Folders could be paper or electronic based.

Standard 3: How could the service give better care and make the person with a learning disability feel safer?

Recommendation 8:

Ensure all staff understand and can follow the principles of the Mental Capacity Act.

Staff MUST know who to contact for support with questions regarding mental capacity, consent and best interest decisions.

**Standard 4: How well are the staff trained and know how to do their job?
How well does the service continually improve?**

Recommendation 9:

Support all staff to attend learning disability and autism mandatory training.

The Health and Care Act 2022 introduced a requirement that regulated service providers must ensure their staff receive learning disability and autism training appropriate to their role.

Recommendation 10:

Consider offering Makaton training to more staff to aid communication with patients.

Conclusion

Health Quality Checks are a valuable tool to enable services in identifying how they can improve to support the needs of people with a learning disability. Through focusing on improving services for people with a learning disability, services will also become more accessible for many other groups of people who find using health and social care challenging. This may be physical barriers created by the environment, barriers due to services not accommodating the needs of individuals through reasonable adjustments or challenges from staff training and understanding.

The 10 recommendations shared offer opportunity for bowel screening centres to reflect and improve on the services they provide. It must also be highlighted that during the Health Quality Checks there were many examples of excellent practice and some centres will note they are already achieving many of the recommendations.

A number of the recommendations will also link to other local and national projects and these may be less in the control of centres.

Recommendation 3: Ensure people with a learning disability and autistic people are flagged.

Recommendation 4: Information on reasonable adjustments must be shared to support the care of the individual.

- [National Reasonable Adjustments Digital Flag](#)

Recommendation 9: Support all staff to attend learning disability and autism mandatory training.

- [National Learning Disability and Autism Mandatory Training](#)

While other recommendations centres may look to work collaboratively to achieve, or work with learning disability partners.

Recommendation 7: Create communications folders available for specialist screening practitioners to support understanding of information.

The North East and Cumbria Learning Disability Network would like to thank the Health Quality Checker teams for their ongoing support in this project and work to improve bowel cancer screening services for all.