

NHS Quality Checkers

Breast Screening

North East and 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 breast screening and bowel cancer screening Quality Checks. This report combines the individual reports completed on each breast screening service giving general comment and recommendations.




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




Quality checks were completed at:

- Newcastle Breast Screening Centre
- Gateshead Breast Screening Centre
- Cumbria Infirmary Breast Screening Centre
- North Tees Breast Screening Centre

This was completed using a 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 breast 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 from:</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"> • Newcastle Breast Screening Centre • Gateshead Breast Screening Centre • Cumbria Breast Screening Centre • North Tees Breast Screening Centre
	<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 services should include the voices of people with a learning disability, families and carers in service improvement.</p>

	<p>Recommendation 2: Complete annual audit of people with a learning disability who have accessed breast screening.</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 a robust system is in place to identify and flag people with a learning disability including the reasonable adjustments they require to access services.</p> <p>Recommendation 4: Ensure accessible information is available for every step of the screening process.</p> <p>Recommendation 5: Ensure the physical environment has been fully considered to enable people with disabilities to access screening.</p>
	<p>Standard 3: How could the service give better care and make the person with a learning disability feel safer?</p> <p>Recommendation 6: Link with local community voluntary organisations who support people with a learning disability to increase awareness and understanding of breast screening.</p> <p>Recommendation 7: Ensure the links to additional services that can support people with a learning disability are known by all staff.</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 8: Support all staff to attend learning disability and autism mandatory training.</p>
	<p>This report will be shared with people who work in breast screening to help them improve breast 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.

Breast Cancer and breast screening

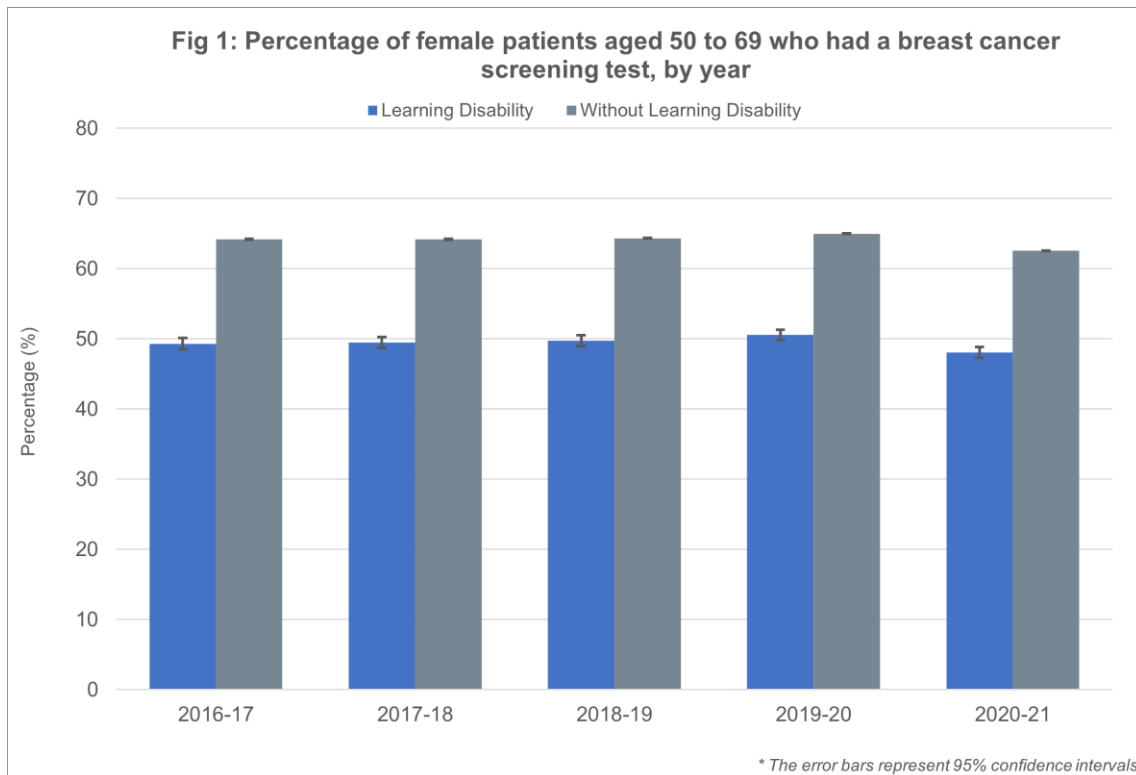
Breast cancer is the most common cancer in the UK. There are around 55,000 new patients diagnosed every year.

Treatment for breast cancer is most effective when it is found and diagnosed early. The NHS Breast Screening Programme aims to detect breast cancer at a very early stage.

[Breast cancer | Cancer Research UK](#) provides information on breast cancer including survival rates.

Women with learning disabilities have the right to good breast health and access to the same range of health services as everybody else. We know that breast cancer screening is one of the best ways to detect breast cancer early, but it is poorly accessed and underused by women with a learning disability compared to the general population.

The [Health and Care of People with Learning Disabilities Experimental Statistics 2020](#) tell us a significantly smaller proportion of patients with a learning disability had a breast cancer screening test in the years 2016-17 to 2020-21 compared to patients without a learning disability. The percentage point difference between the two cohorts has remained steady at 14.6 on average.



The National programme with support from the North East and Cumbria Learning Disability Network produced [easy read materials](#) including a facts booklet and invitation letters. Books beyond words have also updated their materials <https://booksbeyondwords.co.uk/resources-dl>.

The National team have also produced guidance such as [Population Screening: supporting people with a learning disability](#) and [Breast screening reducing inequalities](#).

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.

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.

Breast Screening Centres Combined Report

Introduction

Breast Screening Centres manage the breast screening pathway for a participant from point of initial invitation, completion of a mammogram and sharing of results.

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?

Information sharing and flagging

When the service is made aware that a woman has learning disabilities, staff can allow a longer appointment time, but this is dependent on receiving this information from the GP.

An Easy read booklet about breast screening can be sent to a patient with a learning disability, along with her invitation to screening. This is also available in the waiting area.

The service has access to an interpreting service when required.

The service works closely with the Specialist Learning Disability Nurse and Community Learning Disability Team if the women require further support and assistance to access the screening service.

Staff would inform the GP if person had refused the screening offer. The person can always come back at another time.

Physical environment

The service offer appointments at static sites where there are no steps for easier access to ladies in wheelchairs or those who have mobility problems.

For one site it was noted: Poor signage and subdued lighting in corridor that is used as waiting area by another service, making it difficult to walk together and/or if visually impaired.

There are currently no hearing loops in any of the imaging rooms.

Communication

Staff are aware of the need to use simple uncomplicated language and to speak clearly and slowly ensuring the woman can hear adequately when explaining the procedure.

Privacy is maintained by carrying out the screening interviews in private rooms, the screening test is usually carried out on a one-to-one basis, although with ladies with learning disabilities this may not be the case if the woman wants to have her supporter with her.

No Easy read information on display at site.

Feedback questionnaire, complaints process or results letter are not currently available in easy read.

Some auditing has been done but not clear if it is done yearly. Also it is not clear whether the auditing has been used to help improve the service.

Feedback is not currently collected from individuals and their carers about the service. There is currently no easy read customer satisfaction questionnaire or accessible information to provide compliments, complaints or general feedback.

Consent

The Breast Screening Service use implied consent, so as long as the woman cooperates willingly with the examination she is assumed to be consenting.

To ensure the woman has capacity to consent to the screening the service encourage supporters to accompany the woman to the pre-screening interview.

Consent to the procedure only becomes an issue if the woman is on their own and unable to answer questions. If the woman refuses verbally or physically staff will immediately stop screening.

There is a facility within the National Breast Screening IT System where staff can make notes about any issues or problems during an examination. Staff will note in this area if consent is withdrawn at any point.

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

Information sharing and flagging

When the service is made aware by GP/client or family the woman has a learning disability, the woman's breast screening record is flagged as a special appointment - reason selected as (L) which is listed as learning difficulties from the drop down box on NBSS (National Breast Screening Programme).

When the appointments are processed, a special appointment report is generated which highlights these ladies. The booking officer books a double slot and inserts an 'Easy guide to breast screening' leaflet in with her standard invitation. (An Easy read invitation is also available on the NBSS website and is currently under review)

GP practices are given 6 weeks notice to provide information about any of their patients with a learning disability, who will be invited for screening.

If a woman with a learning disability, attends without their prior knowledge, staff will tailor the care to suit her needs and record this on the NBSS system for future appointments.

Support

Women with a learning disability are notified in their invitation that they can bring a supporter with them. This is encouraged by staff.

If a woman and/or her supporter want to arrange a pre- visit to the unit, staff are happy to offer an individualised visit.

If the individual decides not to go ahead with screening, staff inform the individual and supporter they can call the unit to arrange an appointment if circumstances change and they will be routinely called in 3 years' time, up to the age of 71 years.

Staff advise any clients who are unsuitable for mammography to be breast aware and contact their GP if there are any problems.

Easy read

The easy read invitation is currently under review. The easy read invitation involves manual intervention from staff to populate certain areas. The Trust/Department is in the process of currently updating the Breast Services website to include easy read information. They are looking to include the link to this website in with the correspondence issued to every client.

The service has access to a wide range of easy read information and a video walkthrough of the screening process, these are available on the NHS website.

Reasonable adjustments

Staff emphasised they see everyone as an individual.

Staff try not to keep people waiting and try to fit appointment times around patient needs. Waiting can increase anxiety.

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

Physical environment

The unit was recently redecorated and the main waiting area rearranged to make it more accessible. There are 3 waiting areas which allows for privacy and quiet spaces if needed.

There are dedicated changing rooms. Help with changing can be offered

No defined quiet area that is separate from other waiting rooms.

Reasonable adjustments / support

Staff have a very flexible approach to their patients which is both respectful and encouraging. They will always chat and check in with the patient during their procedure.

The unit has volunteers once/week who can also provide support.

If a woman is frightened/anxious, staff would take whatever time was needed to make her feel ok. This is done in private and with sensitivity.

If a woman with learning disabilities was receiving abuse from another patient, staff would immediately step in and take the abuser to another area.

The service has easy read information available and will give this out at the appointment and easy read letters and invites are sent out to all women with a learning disability providing the service is made aware of this from the persons GP.

Privacy and safety

Staff at all screening locations ensure privacy at all times by taking the client to a private room and will not discuss personal information in an open forum or in the changing cubicle.

Women who have attended and had a partial screening are audited and this information can be available to establish the number of women with a known disability that attended and had partial screening.

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.

Training

At present there is no input from women with a learning disability into regular staff training.

All staff complete mandatory learning disability training.

The team have received input from people with learning disabilities or autism who explained what it was like from their perspective, discussing what helped and what did not. This was through staff participating in the Oliver McGowan Mandatory Training on Learning Disability & Autism Part 1.

All staff attend the Trust mandatory training programme that includes Safeguarding and the Mental Capacity Act, this is done on an annual basis.

Within Adult Safeguarding mandatory training there is specific learning disability module. The module covers reasons behind inequality of health care experienced by people with learning disabilities and communication issues and tips to aid communication.

All staff complete mandatory Equality and Diversity training. Additional training on aspects such as communication is also available.

Staff support / information

Details about how to apply the MCA are on the Trust's website and is accessible to all staff.

The Trust has robust policies, procedures, and risk assessments in place, and these are monitored and reviewed on a regular basis.

Staff have access to safeguarding team in the trust for advice, contact details are on the trust intranet.

The service has access to a named person who fulfils the role of a Learning Disability Liaison Nurse for people with a learning disability.

Safe Care sessions take place every other month and this may include bringing groups/individuals in to discuss supporting adults with learning disabilities.

Recommendations

The recommendations below identify things quality checkers feel services could do better. 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 services should actively include the voices of people with a learning disability, families and carers in service improvement.

Consider holding a focus group for women with a learning disability and their supporters to attend. This would help to provide feedback as to what the service is doing well and what they could do better.

When reviewing patient facing information as a screening centre or a trust, such as; customer satisfaction questionnaires or accessible information to provide compliments, complaints or general feedback, ask the opinions of people with a learning disability.

Recommendation 2:

Complete annual audit of people with a learning disability who have accessed breast screening.

Use the results of audits to further improve the breast screening services.

Consider inclusion of:

- Uptake rates against postcode
- Numbers who have, completed screening, partial completion, refusal, consent withdrawn and did not attempted.

Standard 2: How could the service be better at planning the care, treatment, and support to meet the needs of each person with a learning disability?

Recommendation 3:

Ensure a robust system is in place to identify and flag people with a learning disability including the reasonable adjustments they require to access services.

Consider additional ways to ensure people are flagged so screening is not only reliant on GP practices sharing information via the prior notification list.

Consider working with Trust IT systems to share information on people flagged as learning disabled and requiring reasonable adjustments

Consider sharing information on individuals identified by mammographers as learning disabled or needing reasonable adjustments back with the GP for confirmation and validation.

Recommendation 4:

Ensure accessible information is available for every step of the screening process.

This should include:

- Initial invitation and facts booklet
- Information displayed at screening venues
- Poster to display what reasonable adjustments are and how to request
- Signs and symptoms information leaflets and posters
- Information to enable feedback, comments, complements and criticisms
- Results letters
- information if further tests are required
- Information for women not able to complete breast screening

Recommendation 5:

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

Consider:

- Clear signage to identify route to the unit.
- Effective lighting in corridors.
- Avoid blocking corridors with equipment.
- Signs or use of colour coded zones to indicate the different areas.
- Identify quiet area for anxious patients.
- Make waiting areas less clinical.
- Install hearing loops.

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

Recommendation 6:

Link with local community voluntary organisations who support people with a learning disability to increase awareness and understanding of breast screening.

Consider working alongside the Peer Support Trainers who deliver '[Be Cancer Aware](#)' and '[Be Screening Aware](#)' training.

Recommendation 7:

Ensure the links to additional services that can support people with a learning disability are known by all staff.

This should include:

- Acute liaison nurse for trusts covered
- Community learning disability team
- Trust safeguarding lead, MCA lead
- Community voluntary organisations who provide advocacy

Standard 4: How could the service make sure all its staff are trained, know how to do their job well and are always looking to improve?

Recommendation 8:

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.

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 8 recommendations shared offer opportunity for breast 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 a robust system is in place to identify and flag people with a learning disability including the reasonable adjustments they require to access services.

- [National Reasonable Adjustments Digital Flag](#)

Recommendation 8: Support all staff to attend learning disability and autism mandatory training..

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

Breast Screening Services now have contacts with the Health Quality Checker teams and could reinvite them to visit their service to see improvements made following the Health Quality Check report and recommendations.

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.