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A multi-method evaluation of the effectiveness of the North and Central and East London Breast Screening Service enhancement project in improving uptake and engagement among women with learning disabilities

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Abstract

Background

The Breast Screening Service enhancement project was implemented in central, east, and north London following the COVID-19 pandemic, which had decreased uptake in breast screening appointments, particularly among those with barriers to access. This evaluation aimed to provide detailed insights into the process and impact of the project on the experience and uptake by patients with learning disabilities, informing future programmes to improve breast screening services.

Methods

The evaluation focused on the geographical areas covered by the North London Breast Screening Service and the Central and East London Breast Screening Service. The evaluation framework was co-developed with the Royal Free London NHS Foundation Trust, the North London Breast Screening Service, and the Central and East London Breast Screening Service. The approach was based on realist evaluation principles and Normalisation Process Theory. The evaluation involved mixed data collection methods, including practitioner (N1 = 9, N2 = 4), stakeholder (N = 6), and learning disability client (N = 5) surveys, interviews with practitioners (N = 10) to evaluate practitioners' and stakeholders' applied and patients' lived experience, and aggregated service data to assess uptake.

Results

The breast screening enhancement project made significant progress in increasing uptake. Initial challenges included lack of data and inadequate engagement systems, which were addressed through dedicated community engagement. Providing appropriate health information, site visits, rounded appointment times, and unblocked phone numbers reduced patient anxiety and improved attendance. Also, increased health literacy enhanced engagement with other health services.

Conclusions

Targeting low-uptake areas and improving collaboration with general practitioners and community-based learning disability teams led to better information sharing. This approach proved effective and was recommended for integration into standard health services.

Background

Context

In England, approximately 1.3 million people live with a learning disability (LD), and tend to experience significant health inequalities, with poorer physical and mental health compared to people without an LD (1), including dying from preventable and avoidable causes (2, 3). A confidential inquiry into the premature deaths of people with learning disabilities (PWLD) report (2) reviewed 247 deaths of PWLD over two years and found that 20% of PWLD had passed away due to cancer and 29% of deaths happened due to significant difficulty or delay in diagnosis of

the health issue. A contributing factor to several deaths was a lack of reasonable adjustments for PWLD to attend their appointments and investigations.

Breast cancer causes approximately 11,200 female and 85 male deaths annually in the UK; it is the fourth most common cause of cancer death and a leading cause of mortality in women under 50 (4). Breast cancer includes neoplasms of the ducts, lobules, and connective tissue of the breast. With approximately 59,000 new cases annually in the UK (4), breast cancer remains one of the most common types of cancer in women in the UK (5, 6) and globally (7, 8). Although mortality from breast cancer has gradually declined in the West, the increasing incidence among women has become a growing concern and poses a significant burden on the healthcare system (9, 10, 11, 12). Potentially modifiable risk factors for breast cancer among both PWLD (13) and women without LD (14, 15, 16) include a high-fat diet, low levels of physical exercise, obesity (particularly among postmenopausal women), and being nulliparous.

Cancer screening helps to reduce incidence and mortality (17). In the UK, the NHS breast screening programme invites women aged 50–71 for triennial mammograms (5, 18, 19, 20), with the AgeX trial expanding screening to those aged 47–49 and 71–73 (18). Screening aims to detect early-stage disease (e.g. pre-invasive conditions such as ductal carcinoma in situ) to enable rapid assessment and prompt treatment, which improves patient outcomes in terms of mortality and morbidity (5, 21) and is estimated to prevent around 1,700 deaths annually (22). In England, screening identifies cancer in approximately 9 out of every 1,000 women screened (23).

Local, regional, and national challenges in breast screening uptake and coverage

Despite availability, disparities in screening uptake persist. Studies within UK (24, 25, 26, 27) as well as international contexts (28) reported that factors such as ethnicity and deprivation reduce participation.

An independent review by NHS England (22) showed a decline in breast screening uptake for women aged 45 years and over, with only 2.89 million women being invited for screenings, representing a 2.4% decrease from the previous year. The screening uptake from routine invitations also decreased (70.5% in 2017/2018 in contrast to 71.1% in 2016/2017). The review highlighted regional differences, with London having the lowest uptake (63.3%) and East Midlands the highest (73.6%). Breast screening coverage data (i.e. the proportion of eligible women aged 53–70 who attended screening in the previous three years) showed similar trends, with 69.3% in London and 78.4% in East Midlands, and highlighted geographical disparities across England, with seven local authorities (LAs) reporting over 80% coverage and 35 LAs below 70%. The report (22) also emphasised challenges such as low uptake among women receiving routine invitations, inconvenient screening locations, limited resources for the upkeep of mobile screening units to address geographical barriers, and limited uptake through self-referrals, especially for women over 70. A review by the Scottish NHS (29) identified similar challenges, but with additional focus on cultural and emotional barriers, such as scepticism about the preventive value of screening, cultural taboos and discomfort with exposing breasts, and the impersonal nature of screenings.

Within the geographical context of this evaluation – that is, central, east, and north London – Eilbert et al. (30) noted the significant factors explaining low breast screening coverage in Tower Hamlets, London. Deprivation accounted for approximately 13% of the variation at Primary Care Trust level, while ethnicity contributed to 28% of variation. The authors also highlighted the potential impact of population turnover on low screening coverage. Likewise, NHS North Central London in Haringey (31) faced similar issues. In 2009, breast screening uptake was 55%, below the 75% national target. Factors included lack of knowledge, cultural beliefs, anxiety, and deprivation.

Younger women, those with severe mental health issues, and those facing social mobility challenges also had lower uptake. Inconvenient appointment times and difficulty getting time off work were additional barriers.

While these local, regional, and national challenges highlight overarching themes such as deprivation and ethnicity as barriers to screening uptake and coverage, the disparities in screening uptake due to LD have been understudied (32). However, previous studies drew attention to the link between LD and deprivation and found that people with intellectual disabilities were more likely to live in areas of high deprivation (33, 34) and to live in poverty (1), presenting compounding barriers to health equity.

The COVID-19 pandemic further disrupted services. Routine screening was paused during early 2020, leading to a significant backlog (35, 36, 37). This was further compounded by services operating at a reduced capacity due to infection control measures, as well as patient reluctance to attend screening for fear of exposure to infection (35). The Breast Cancer Now charity (37) estimates around 1.2 million fewer women in England were screened between March 2020 and May 2021, compared to pre-pandemic levels. A review by Gathani, Dodwell, and Horgan (38) found that the COVID-19 pandemic impacted referral numbers significantly; screening stopped during the peak of the pandemic and then returned to normal levels, leading to a backlog in treatment. To address this, the London Breast Screening Recovery Programme was launched in June 2020 to implement innovative solutions, including projects targeting health inequalities.

Barriers to breast screening uptake and coverage among LD women

With advancements in healthcare, women with LD are living longer and are becoming eligible to participate in the breast screening programme (13). The UK government has produced documents highlighting guidance on good practice for those involved in the care of people with LD (39, 40, 41), which includes the importance of equal access to all general and preventative health services, as well as information to aid accessibility and informed choices. Despite this guidance (39, 40, 41) and the recognition of the need for reasonable adjustments for PWLD, it is frequently reported that PWLD have a lower uptake of preventative screening compared to the remaining population (13, 42, 43). Data (44) over a period of five years from 2016–2021 shows that PWLD were consistently less likely to attend their breast screening appointment compared to people without LD; there was on average a steady gap of 14.6 percentage points between the two cohorts.

This low uptake is significant given the presence of risk factors for breast cancer in women with LD, such as obesity, low levels of exercise, poor diet, and nulliparity (13). Previous studies in UK (13, 32, 45, 46) and international contexts (47, 48) alike identified a range of barriers contributing to low screening uptake and coverage among LD women, such as: 1) LD women's lack of understanding of breast cancer and breast cancer screening, 2) fear, anxiety, and embarrassment associated with mammograms, 3) lack of access to breast cancer screening, 4) lack of (health)care or family support, and 5) systemic barriers.

Studies (13, 32, 47) noted that LD women had limited understanding both of what breast cancer is and of the breast cancer screening process. Poor literacy skills contributed to the lack of understanding of breast cancer screening information (3, 13), consequently highlighting the importance of accessible and tailored educational and promotional materials and ongoing and repetitive information provision using different mediums such as visual aids, easy-read materials, and discussions with LD women (3, 32, 47). It was also argued (32) that access to breast screening information and materials helps to enhance LD women's autonomy and informed decision-making, consequently contributing to their overall well-being.

Negative emotions associated with mammographs were also commonly reported, including fear of the procedure and anxiety (3, 13, 47), as well as embarrassment arising from needing to remove their clothes for the examination (32). Previous studies (3, 32, 46) argued that pre-appointment visits enabling familiarisation with mammography staff, equipment, and the environment, coupled with accessible information provided on these visits, can help to reduce anxiety and fear and encourage women with LD to attend screening appointments. Sykes, McGeechan, and Giles (3) noted that pre-screening visits also enable the cancer-screening staff to implement reasonable adjustments for LD women's screening appointments – for example, to ensure that the healthcare practitioner was female. Moreover, Truesdale-Kennedy, Taggart, and McIlfatrick (32) emphasised that offering extended appointments can also improve LD women's screening experience.

The lack of access to breast cancer screening depended on LD women's circumstances and care support (13, 47). For example, physical disabilities (alongside learning disabilities) exacerbate barriers (13) and reasonable adjustments need to be put in place. Lack of transport options (13) or lack of professional or family care support during appointments (47) also prevented LD women from attending screening.

Studies (3, 32, 47, 48) show that support from mammograph staff, carers, and family, coupled with clear, accessible communication, can reduce LD women's anxiety and improved their screening experiences and participation. Overall, care coordination facilitated LD women's breast screening uptake, which extended to care coordination between healthcare providers/mammography staff, carers and family (47), and LD nursing teams (13). Moreover, the involvement of LD teams helped to produce accessible materials for LD women and increase healthcare providers' awareness of the needs of LD patients (13). Utilising community champions as peer mentors further facilitated access to breast screening (49). Recommendations for service improvements (3, 48) also emphasised the importance of healthcare practitioners' understanding of LD women's needs in order to implement reasonable adjustments for screening appointments.

Willis, Kennedy, and Kilbride (13) drew attention to the systemic barriers in health services and noted that LD women in the UK are often not registered with GP services, therefore not receiving invitations for routine screening appointments. Moreover, breast cancer screening units might not be aware of the patients being learning disabled, hence not providing accessible information (13). Recent data (49) shows that only approximately a quarter of PWLD are represented on the GP disability registers in the UK, highlighting issues around identifying PWLD clients and consequently implementing reasonable adjustments for their care.

Similarly, those who move into new areas are more likely to miss screening appointments (13); therefore, LAs with a higher population turnover (of both PWLD and general population) report lower screening rates (30).

The LD breast screening service enhancement project delivered across central, east, and north London aimed to address these frequently reported barriers and improve screening uptake among LD women.

Project overview

This service enhancement evaluation explored the challenges faced by clinical service providers and by women with LD accessing breast screening. It also looked at potential solutions provided by the LD breast screening service enhancement project to improve referral pathways and the uptake of breast screening.

This rapid evaluation examined the impact of a targeted breast screening service enhancement project aimed at improving access and the quality of the screening experience for women with LD across central, east, and north

London. Implemented in the post-COVID-19 context, the project was developed in response to significant declines in screening uptake among equity-deserving groups. This enhancement project was designed to enhance service delivery, focusing on key aspects of how women with LD access and experience breast screening, in order to generate evidence and identify effective approaches. The LD Breast Cancer Screening enhancement project evaluated multiple outcomes, including the number of women with diagnosed LD reached, appointment scheduling and attendance, cancers detected, and the anticipated impact on future screening uptake. In addition, it examined patient experiences, overall service quality, accessibility and awareness of information, the effectiveness of partnerships, the extent of co-production and co-design, and the experiences of healthcare professionals involved in service delivery.

Methods

Methodology

The evaluation approach used a mixture of methods for data collection, and it brought together evaluative findings from routinely collected service data, primary data collected through online surveys (completed by healthcare practitioners, stakeholders, and LD patients), and one-to-one semi-structured interviews with healthcare providers and stakeholders. The study received research ethics approval in December 2023 from the University of East London Research Ethics Committee (No. ETH2223-0298).

This evaluation focused on the geographical areas covered by the North London Breast Screening Service (NLBSS) and Central and East London Breast Screening Service (CELBSS), which includes 13 boroughs and districts: Barnet, Camden, Haringey, Islington, Enfield, City and Hackney, Tower Hamlets, Newham, Waltham Forest, Brent, Harrow, Watford and Three Rivers, and Hertsmere.

The evaluation framework was co-designed with the Royal Free London NHS Foundation Trust, and NLBSS and CELBSS. It was reviewed regularly by the evaluation and commissioning team. The evaluation was informed by implementation science principles to measure the effectiveness of the implementation of a new intervention (50) – specifically, the Normalisation Process Theory (51, 52), a conceptual framework for explaining what people do to implement a new practice.

The evaluation approach was also influenced by Pawson and Tilley's (53) realist evaluation principles, which apply evaluation theory to investigate the question: what works for whom in what circumstances and in what respects, and how? This approach stresses the need to evaluate programmes within their context, and to assess what mechanisms and processes are acting to produce which outcomes.

The aim of this evaluation was to gather evidence on breast screening uptake, barriers, and disparities in order to inform strategies for improving access to and equity in breast cancer screening programmes. The evaluation aimed to provide detailed insights into the process and impact of this project, informing breast screening services in central, east, and north London, as well as other regional and national services.

Quantitative data collection

We systematically collected service data from various sources, including the Royal Free London NHS Foundation Trust, and the NLBSS and CELBSS. This comprehensive dataset encompassed two primary areas: 1) screening uptake; and 2) outreach, promotional, and awareness-raising initiatives, which included social media engagement, events, and stakeholder collaboration.

The screening uptake data was provided at three distinct time intervals: historical data from April 2018 to March 2023, and data pertaining to the initial two quarters of the Breast Cancer Screening service enhancement, from April 2023 to March 2024.

The data pertaining to outreach, promotional, and awareness-raising activities was disseminated on a quarterly basis, providing valuable insights into the community's reach and engagement with events, media coverage, and stakeholder engagements coordinated by the health promotion team.

In addition, we conducted multi-method primary data collection. The fieldwork was conducted between December 2023 and March 2024, and encompassed the collection of online surveys and virtual, semi-structured interviews.

Online surveys and self-assessment forms

The primary data collection involved online surveys and self-assessment tools completed by healthcare practitioners, LD patients, and stakeholders. These surveys were hosted on Qualtrics for ease of access. They involved both quantitative and qualitative questions.

Practitioner Self-Assessment Forms 1 and 2 were collected from members of breast cancer screening teams at two different points in time (N1 = 9, N2 = 4). Information from these forms aimed to provide an understanding of practitioners' views on the service enhancement over time, and to identify barriers and facilitators of implementation and embedding. Each form consisted of eight scale questions and one open-ended question, focusing on implementation science principles. They were distributed through the commissioning organisation.

The Collaborate Survey, a standard NHS tool (54), was completed by LD patients (N = 5) to capture their perceived involvement in recent breast cancer screening appointments. Administered by social care workers during appointments, the survey assessed patients' control over their care during screening.

The Stakeholder Survey aimed to explore the perceived impact and value of the Breast Cancer Screening service enhancement on local stakeholders, and levels of co-production in its design. Stakeholders (N = 6), including primary care, community LD teams, and LA teams, were invited to complete the survey through the commissioning organisation.

Qualitative data collection: interviews

Semi-structured one-to-one interviews were conducted with healthcare practitioners (N = 11) to explore their experiences in implementing and integrating the Breast Cancer Screening Service enhancement project. Guided by the Normalisation Process Theory (51, 52), these interviews focused on the implementation science aspects of the project to identify effective strategies and areas for improvement. The objective was to inform breast cancer screening services in north, central, and east London and beyond.

Ten interviews were conducted with 11 participants. Participants 10 and 11 took part in a joint interview. The interview participants encompassed diverse roles, including frontline staff such as mammographers and nurses, back-office staff, strategic leads, and LD team members.

The interviews were conducted via Microsoft Teams with participants' consent, and they were recorded. Each interview lasted between 30 and 60 minutes and followed a semi-structured format comprising ten questions. The

conversations were transcribed using the Microsoft Teams transcription function, and the transcripts were checked for accuracy by the research team.

Sampling strategy and recruitment

The research team recruited participants using a convenience sampling strategy, with the commissioning organisation overseeing the recruitment process. Surveys were distributed via email by the commissioning organisation, targeting healthcare practitioners and stakeholders. For the Collaborate Survey, LD teams were contacted, and social care workers assisted in completing the survey during social care appointments.

Interviewed participants were also recruited through the commissioning organisation. While convenience sampling was primarily used, interviews followed a theoretical sampling approach to ensure comprehensive knowledge and representation across different healthcare roles. The research team identified various roles to be included in the sample, and the commissioning organisation contacted staff members in each role. Interested participants were then connected with the researchers to schedule interview appointments.

Data analysis

Exploratory data analysis was conducted on the routinely collected service data. The primary data was coded using the Normalisation Process Theory evaluation framework (52), along with the key learning categories highlighted by the commissioners. Subsequently, the data underwent thematic analysis (55) to identify patterns and derive meaning related to the implementation of the service enhancement and its impact on patients, communities, and stakeholders.

Results

Insights on screening uptake

At its inception at the end of March 2023, the LD Breast Cancer Screening enhancement project had engaged 7 LD women and 4 carers. By September 2023, it had engaged with 186 women in project booking and run 14 LD events that engaged with 291 women. By March 2024, the team had engaged with 317 women in project booking; 41 of these attended appointments, with 3 women going to assessment and 1 positive diagnosis. The team had run around 24 LD events, which engaged with 619 women, and 25 general events, which engaged with 737 women.

Learning Disability Service uptake is depicted in Fig. 1 for NLBSS and Fig. 2 for CELBSS. The vertical dashed lines show the COVID-19 pandemic period, marked by lockdowns.

General service uptake was similar across NLBSS (mean = 58.8%) and CELBSS (mean = 49.5%) and followed similar trajectories, with moderate decreases in uptake over the pandemic period, before showing an uptick through early 2023. Learning Disability Service uptake was considerably higher in NLBSS boroughs (mean = 69.7%) than in CELBSS ones (mean = 46.9%). Both areas showed decreases over the pandemic period, before showing upticks through early 2023; however, these changes were steeper for NLBSS boroughs.

Source: Primary data – service uptake

Source: Primary data – service uptake

Survey and interview insights

The practitioner and stakeholder survey and one-to-one practitioner interviews produced a range of insights into the impact of the service enhancements. The enhancements included providing easy-to-read letters and personalised support to help LD women understand and attend their appointments. Identifying these women and ensuring that they received the necessary accommodations, such as longer appointments and additional support, was crucial, although some women might not perceive themselves as needing extra assistance.

The breast screening project made significant progress in achieving its goals. Initial challenges included a lack of data in order to identify targeted patients, and inadequate systems for engaging patients in their healthcare. These issues were successfully addressed, making the service more inclusive and ensuring that all patients received quality care. A dedicated team focused on relationship building, booking, outreach, and monitoring proved effective, and it was recommended that this approach be integrated into standard services and extended across other NHS areas to improve access for individuals with LD. Four stakeholders (66%) reported that the programme met expectations, one (17%) reported that it exceeded expectations, and one (17%) reported that it fell below expectations. Four (66%) reported that their voices were heard a great deal or a lot, one (17%) reported that their voice was heard a little, and one (17%) was unsure. Five (83%) reported that stakeholders' opinions on the LD project was that it was extremely or very valuable, and one (17%) did not provide a response.

All patients reported that they strongly agreed that practitioners helped them understand their health issues, listened to their concerns around their health issues, and helped them make plans regarding their health issues based on these concerns.

The interview and survey insights highlighted the key outcomes of the service enhancement (see Table 1) and weaknesses and potential improvement opportunities (see Table 2).

Table 1
Outcomes of the service enhancement

Theme	Summary of findings
Access	Focused promotion improved access to screening services for people with LD. The provision of NHS transport reduced anxiety and mobility-related barriers, resulting in improved attendance at screening appointments.
Empowerment	The intervention increased participants' comfort and confidence in attending screening appointments. Positive experiences also encouraged engagement with other healthcare services, supporting wider health-seeking behaviours.
Efficiency	Targeted outreach, aligned with screening cycle stages, and the use of pre-appointment invitations ensured that relevant information reached eligible individuals at the appropriate time, improving the efficiency of service delivery.

Source: Primary data – stakeholder, practitioner, and collaborator surveys

Table 2
Weaknesses and potential improvements for the service enhancement by theme

Theme	Summary of findings
Health literacy	Participants emphasised the need for clear, plain-language information on cancer prevention, screening, and treatment. Community health workers were identified as important sources of support. Recommendations included incorporating health education into special school curricula, supporting transition to adulthood, and providing ongoing public health education for people with LD.
Targeted engagement	Effective engagement required regular collaboration with local LD services, proactive follow-up of missed screening appointments, and the co-production of resources with local communities. Participants also highlighted the value of involving women with LD as screening champions to promote awareness and participation.
Accessible and tailored information	Improving service accessibility required easy-to-read materials, accessible booking systems, and information tailored to the needs of people with LD. Participants reported that greater understanding of screening processes could support informed decision-making, increase breast awareness, and reduce confusion surrounding appointments.
Patient and public involvement	Participants recommended involving women with LD from different boroughs in service design and evaluation. Encouraging women who had attended screening to share their experiences and hosting workshops with patients and support staff were identified as important strategies for strengthening service development and engagement.
Capacity and administration	Service delivery was constrained by challenges in identifying appropriate LD leads and by slow data collection processes, limiting opportunities for timely engagement and service improvement.

Source: Primary data – stakeholder and practitioner surveys

The interview insights highlighted four key areas within the service enhancement that helped to achieve better screening uptake among LD women. In the following sections some of the quotations are paraphrased and are not presented as verbatim by the research participants (represented in italics without quotation marks), while others are direct quotations (i.e. italics with quotation marks).

Increased accessibility of appointments

The team enhanced services for women with LD by providing easy-read letters and ensuring that support staff guided them through appointments. Feedback from LD women indicated that unconventional appointment times caused anxiety. To reduce anxiety and make the process more comfortable, appointment times were standardised to more familiar intervals.

[Feedback from LD clients] highlighted that appointments were scheduled for very specific times, such as 10:47 or 11:53; that was giving them a little bit of an anxiety. So, we worked with the service to change them to 5 or 10 minutes from the hour instead of these specific times, which just reduces anxiety.

However, opinions differed as to whether there should be more accessible ways to arrange appointments, as the service already had an ‘inclusive and accessible’ approach in place:

Basically, we run a special clinic targeted for people with special needs, be it language, wheelchair users, disabilities … It’s sometimes used in its fullness, and it’s sometimes underused. We’re trying to really cover up those gaps and see that we reach throughout – to everybody … who goes to the GP because they’ll be informed and quite acutely needing care, and [they] will also be insured.

Concerns were expressed about technical difficulties with the appointment system at the start of the service enhancement:

[The service was struggling] with 'smart clinics', which is essentially an algorithm that book[s] women into time slots based on their probability of attendance. But that algorithm wasn't working well, which meant that … 20 women [were booked] in the same slot and all of them are turning up.

LD women's access to breast cancer screening was also facilitated by the implementation of a new pre-visit (i.e. pre-screening appointment) initiative.

An additional adjustment that we have created for them beyond the standard ones … was at the service level when we do pre-visits. So, let's say someone who doesn't know what this is all about, doesn't understand it. We offered pre-visits to the women who had missed an appointment, and we offer that to people who might not have missed an appointment either. They just need to request it.

The pre-visit appointments enabled LD women to familiarise themselves with the screening site, the staff, and the process, and they served as opportunistic screening appointments for those feeling comfortable enough to go through the process at that time.

"They came and they got to see their screening site, the facility, the machine, get to know the team a little bit, the mammographers … Initially, we were just doing the pre-visit, but we realised that if they have missed an appointment, if they've come here, if they're feeling comfortable enough, we just screen them, because they are due anyway."

These visits are coordinated with LD teams and support workers to help clients feel comfortable and offer flexibility to accommodate their needs. While some clients may still withdraw consent on the screening day, pre-visit arrangements have generally been successful in encouraging attendance and participation.

That's really helped because it gave the LD teams and the clients the flexibility to actually come [to] see the centre, and if they're feeling up to it, they do get screened … They can bring the[ir] carer or [a] friend along; they can request a time of the day that works better for them.

The overarching impact of pre-visits also extended to improved health literacy and comfort in engaging with health services among LD women, highlighting a ripple effect in positive health impacts.

"One of the LD clients was very nervous and never engaged with any healthcare staff, ever … She came to one of our pre-visits … She got screened because she felt comfortable enough, and then since then she has engaged with the LD team and social care to get her eye checkup, to get her blood pressure [taken]. So, she has basically engaged with health services for herself much more ever since the breast cancer screening appointment, because that was a pleasant one."

Post-COVID-19 transportation support provisions also helped LD clients to access their appointments. Practitioners highlighted the systemic improvements in providing transport – for example, working closely with LD teams to minimise physical barriers (and arrange support for LD women) or healthcare and community organisations offering such support:

Now, with hospitals or communities offering transport services, they're back to be[ing] able [to access screening appointments]. So, we're kind of coming out of it and being able to reach out to more people now than we did, let's say, two years back.

Increased outreach and engagement

The results above highlight how the project addressed broader factors influencing patient attendance, such as transportation issues, pre-visit arrangements, or appointment time adjustments. Personalised follow-up with patients helped to identify and mitigate these barriers, leading to improved attendance and engagement. The service used feedback forms, both physical booklets and online tools with QR codes to gather patient insights, enabling continuous service enhancement. This feedback helped in understanding patient needs and refining the screening approach.

Healthcare practitioners argued that LD patients were able to access and engage with the service because reasonable adjustments were made to accommodate those patients' needs:

A significant portion of the implementation was influenced by feedback from screening staff. For instance, discussions with nurses and mammographers have highlighted the need for reasonable adjustments. As a result, LD patients now receive twice the duration of a regular appointment (16 minutes instead of 8).

Mammographers highlighted that within the specialist clinics' structure the longer appointments enabled them time to build trust with LD women and progress the screening. The trust-building process was essential to ensure that LD women returned if the full screening could not be completed and/or needed a follow-up appointment.

They [special clinics] are useful because they allow us to build bridges, to build trust … For example, if somebody comes and we are able to acquire two images, that's a win situation because we are not gonna write them off immediately off our books because it's not [a] full [screening]. They cannot have a report based on those two images. So, what we tend to do is we can book them for another time slot of that nature, knowing that we just have another two more to do [to] complete their process.

Working closely with LD community teams and delivering information for them led to better engagement from LD women.

We've had some meetings and presentations with the support workers and [LD] teams in different communities. I think that's helped a lot by speaking to them ... to have seen the improvement … [They] engage and want to bring their clients in for an appointment.

Engagement with LD teams also facilitated engagement with LD clients. This allowed the service enhancement project delivery team to explain reasonable adjustments at outreach events and encourage women to attend screening.

We, at a learning disability event, sort of explain about the reasonable adjustments that are available ... They didn't really have any knowledge of it before and maybe hadn't always come to their breast screening, but all of them so far have actually been really, really keen to engage with us.

Moreover, the service enhancement engaged LD community champions who played a significant role in encouraging other LD women to attend screening appointments. The delivery team highlighted how community champions, who had a positive screening experience, took on a peer advocacy role:

We did find that from the first person that got screened, the second person that came … heard the feedback from the first client, which was positive, that 'it wasn't so bad; it was quite quick'. And that she's happy that she had it

done, so that encouraged the second person.

Regarding the project's sustainability, strategic leads emphasised the importance of continuing outreach and educational activities for LD teams and community champions. They highlighted the need for ongoing engagement and suggested embedding LD teams into national screening programmes. This approach would involve training trainers within the community and screening services to ensure continued engagement with LD patients.

"So that would be what I would like to see for the LD project: that we get the funding to have these LD teams embedded within our national screening programmes and this LD engagement continues as part of that work. It is very much about training the trainers out there, as well, within the community as well as within our screening service to make sure this engagement continues."

Staff training

Comprehensive training played a pivotal role in enhancing the coherence of the breast screening service enhancement. The workforce training for the LD Breast Cancer Screening service, delivered by an LD lead at the Royal Free NHS Trust, was attended by approximately 150 staff members from the NLBSS and CELBSS. These inclusive LD training sessions were provided to all screening staff, ensuring a shared understanding of LD criteria and the significance of accurate patient flagging. This approach aimed to address any reluctance or uncertainty among staff, creating a supportive environment conducive to effective engagement with LD patients. Building connections with LD teams proved instrumental in raising awareness about the importance of screening among primary care providers.

Participants reported that the training sessions were informative and useful:

She had a couple of training sessions, and we also had training sessions about what constituted an LD woman, including how to mark them up and ensure we had the correct flags.

Inclusive LD training was provided to the entire screening staff.

Better data management

A system was created in which the LD team shared client data with the screening team, who then assessed and returned screening status updates. Establishing data-sharing agreements was complex, taking six months and support from the Cancer Alliance to involve information governance leads across boroughs. The booking process was hindered by outdated, manual systems that depended on updates from women, GPs, and LD groups – often resulting in incomplete records. The absence of reliable data on women with mild to moderate LD further complicated implementation.

Most participants felt that there should be better data management, data accuracy, and data sharing in place:

We already had women flagged as LD on our systems for my two services. This applies to all services in London, but from my statistics, we already have them flagged. The accuracy of that data was questionable in the beginning. There were no audits done, and there was no cleansing of data or anything else.

The LD project requires external data from GPs and other services, which has not always been readily available when needed. Consequently, we were heavily reliant on information from various sources, including the woman herself, the GPs' data, and LD groups. This was essential to ensure that the data was as accurate and complete as possible.

We weren't confident initially, but I'm more confident now about the data. We're continuously working on it. We've got a lot of data cleansing going on in north London breast screening, and [in] central and east London. My two services involve contacting LD women. If we have DNA samples, we ensure that we're appropriately handling them, marking them correctly, and avoiding mislabelling LD women who aren't LD women or women who genuinely need to be marked as LD.

The delivery team highlighted that accurate data is essential for implementing reasonable adjustments, sending out the right types of invitations, and overall for ensuring that the services respond to individuals' needs.

The LD flagging process provides a different type of invitation to these women. I believe it's often about ensuring that we've provided the appropriate invitations to these women. We've encountered cases where LD is marked, [and] the woman is actually LD but she also has physical disabilities. So, it's about capturing both aspects. She may need an extended appointment, not just for the LD aspect, but also for the physical disability aspect, as she might be difficult to position. It's about making sure we have the time to address these issues.

Despite these difficulties, the team made progress in identifying LD women and engaging them with the breast cancer screening service. Our evaluation identified key ingredients in this process. At a whole-system level, the importance of continued mutual data sharing with LD teams, primary care networks, and GPs, and collaboration with each borough's information governance leads were emphasised by participants. At a service level, having a dedicated role within the service helps to maintain these collaborative relationships and facilitate any future work on data accuracy and, consequently, ensure that LD women are identified and receive the right support to attend breast cancer screening appointments.

So I think having a dedicated resource within the breast screening service, like my team, is very crucial for this kind of work to carry on because the[n] we actually have the expertise and capacity to lead on it, versus the service [doing it] alone when they are focusing on running the service and doing the screening.

Discussion

This study demonstrated that targeted engagement with LD teams significantly enhanced comprehension of the challenges faced by women with LD in accessing breast screening services. Although screening is offered from ages 50–71, our findings show that LD women would benefit from receiving accessible, tailored information at younger ages to strengthen health literacy (32). Consequently, increased health literacy reduced patient anxiety, improved attendance at appointments, and fostered greater engagement with other healthcare services (32, 47).

A multifaceted strategy for disseminating health information to individuals with LD demonstrated efficacy. This approach, which aligned with previous recommendations for improving LD women's breast cancer screening uptake, encompassed outreach initiatives by healthcare providers, the preparation and sharing of easy-read materials (3, 32, 47), the prioritisation of trusted relationships for information dissemination, and the use of community champions to support peer advocacy (48). Considering that the lack of health literacy and understanding of breast cancer and screening are primary barriers of breast cancer screening uptake (3, 47), these pre-appointment strategies helped improve LD women's understanding of the screening process, fostered self-advocacy, and facilitated more informed discussions during screening appointments (32).

Relational practices, such as assigning a designated contact within the LD team and enhancing communication with GPs, families, and community LD services, contributed to enhanced accessibility and continuity of care.

Collaborating with LD teams in addressing logistical barriers, including transportation requirements, further augmented screening uptake among LD patients. While previous studies emphasised the importance of care coordination (47, 48) and working with LD teams (13), the LD Breast Cancer Screening enhancement project facilitated a multifaceted, collaborative working relationship with LD teams extending to community outreach, mutual education, and data sharing. This approach allowed progress to be made in LD teams' and LD women's understanding of breast cancer and the importance of screening, as well as increased the breast cancer screening teams' understanding of LD women's needs. It also facilitated a whole-system change, whereby data is shared across services in helping to identify LD patients.

A substantial challenge encountered during implementation was the accessibility, accuracy, and sharing of patient data. The project was in response to previously identified problems – namely, that a high proportion of PWLD are not represented in GP LD registers (13, 49) and the recommendations of improving data accuracy within health services (1). The mutual data sharing with LD teams, primary care networks, and GPs, and collaborations with LA information governance leads, facilitated the data-cleansing process. Moreover, this workstream benefitted from parallel work carried out by the NLBSS, CELBSS, and Royal Free London NHS Foundation Trust to implement data-sharing agreements across public and voluntary sector health and care services to improve data accuracy, therefore laying a foundation for the relationships used in this project.

Pre-visit opportunities at screening clinics have also been identified as an effective intervention. Our findings align with previous studies (3, 32) and show that these sessions enable patients to become familiar with the clinical environment and equipment and reduce LD women's anxiety regarding their breast screening appointment. Moreover, pre-visits functioned as opportunistic screening appointments, and enhanced LD women's comfort with health services, consequently increasing their confidence to seek out further healthcare appointments for other health problems.

The implementation of simplified appointment scheduling reduced anxiety. Moreover, special clinics with longer appointment times, allowed screening staff to build trust with LD women and progress the screening. The trust built through these appointments helped to achieve positive screening experiences for LD women, which then facilitated repeated engagement with the service. Overall, these reasonable adjustments, implemented by the screening service enhancement that responded to LD women's needs, limited barriers to access and engagement (3, 32, 46).

Staff lack of knowledge and lack of training have been reported as key barriers for LD women's screening access (3, 13, 48). The service enhancement project delivery team identified the need for staff training within NLBSS and CELBSS. The training helped to improve service providers' understanding of LD women's needs and aimed to facilitate the identification of LD women when not indicated in the system. While no empirical evidence was collected on staff competencies, the researcher team observations suggested that variability in confidence and preparedness among screening staff may have affected their ability to support patients with LD.

Although there have been positive outcomes, there is a concern that progress in community engagement and trust building may diminish over time if it is not consistently maintained, particularly given the three-year interval between routine screening invitations. Sustained investment, oversight, and staff engagement will be crucial to ensure long-term success.

In summary, the project resulted in enhanced patient experiences and increased breast screening uptake. The findings indicate that key implementation mechanisms, such as coherence, cognitive participation, collective

action, and reflexive monitoring, contributed to successful service improvements. Awareness-raising initiatives and reasonable accommodations tailored to specific needs have enhanced engagement among underserved populations. Pre-visit clinics and specialised sessions have supported both patient well-being and staff preparedness, fostering a more sustainable healthcare environment. Ongoing project monitoring meetings facilitated real-time problem-solving, contributing to a more responsive and patient-centred service. While challenges persist, particularly in data collection and workforce training, the evidence supports the adoption of a holistic, system-wide approach to achieving equitable access to breast screening services for individuals with LD.

Limitations

This study employed a multi-method approach guided by realist evaluation (53) and Normalisation Process Theory (51, 52) to comprehensively assess practitioner, stakeholder, and patient experiences, alongside screening uptake. However, several limitations warrant consideration. Inadequate data systems hindered timely and comprehensive data collection, and mechanisms for sustained stakeholder engagement were limited. Although community outreach and enhanced information dissemination partially mitigated these issues, systemic constraints remained. These limitations highlight the ongoing need for more robust infrastructure and inclusive communication strategies to support equitable access to breast screening services.

Conclusions

This evaluation underscores the paramount significance of integrating inclusive practices throughout the entirety of service design and delivery to augment breast screening uptake among marginalised populations, particularly women with LD. At the strategic level, the incorporation of the health promotion team model into the commissioning and delivery of all screening services across the central, north, and east London NHS regions can substantially enhance accessibility and engagement.

At the practice level, it is crucial to ensure that young women with LD receive early and accessible health literacy resources related to breast cancer. By engaging and educating key adults, particularly those in LD support teams, about the unique challenges faced by these women, service responsiveness can be further enhanced. Additionally, breast screening staff should be allocated dedicated time and receive targeted training to effectively support women with LD during their appointments.

At the operational level, sustained collaboration with LD teams and continued investment in the LD community champions model will contribute to the provision of patient-centred care. Practical measures, such as unblocking outbound phone numbers and providing pre-visit opportunities and extended appointments to patients with LD, can effectively reduce missed appointments and enhance the overall patient experience.

In conclusion, robust and strategic partnerships and collaborations continue to be paramount. LD teams and GP practices should routinely report on their health literacy initiatives to dispel concerns and misconceptions surrounding screening. Providers must proactively communicate that NHS screening services are accessible to all individuals. The involvement of external stakeholders who provide support to vulnerable populations in the co-design of future services will be instrumental. Research conducted in this area demonstrates a clear and positive correlation between LD team engagement and enhanced screening attendance among their clients (13), underscoring the significance of cross-sector collaboration in promoting health equity.

Abbreviations

CELBSS
Central and East London Breast Screening Service
LA
local authority
LD
learning disability
NLBSS
North London Breast Screening Service
PWLD
people with learning disabilities

Declarations

Ethics approval and consent to participate

All participants provided informed written consent prior to participation in this evaluation. Ethics approval was granted by the University of East London Research Ethics Committee (Ref no. ETH2223-0298).

Consent for publication

Not applicable

Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due to the potential inclusion of personally identifying information, but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

DS was the Principal Investigator and contributed to the evaluation planning, framework development, methodology and research tools development, data collection, data analysis, interpretation of findings, writing, editing, and finalising the manuscript. NM contributed to the evaluation planning, framework development, methodology and research tools development, data collection, data analysis, interpretation of findings, writing, and editing the manuscript. OK contributed to the evaluation planning, framework development, research tools development, data collection, data analysis, interpretation of findings, and drafting the manuscript. TK contributed to the literature review and review of the manuscript. EO-A contributed to research tools development, data collection, data analysis, and interpretation of findings. LGM contributed to data collection, data analysis, and

interpretation of findings. MT contributed to the evaluation planning, framework development, and review of the manuscript. CM contributed to the evaluation planning, framework development, and review of the manuscript.

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Figures

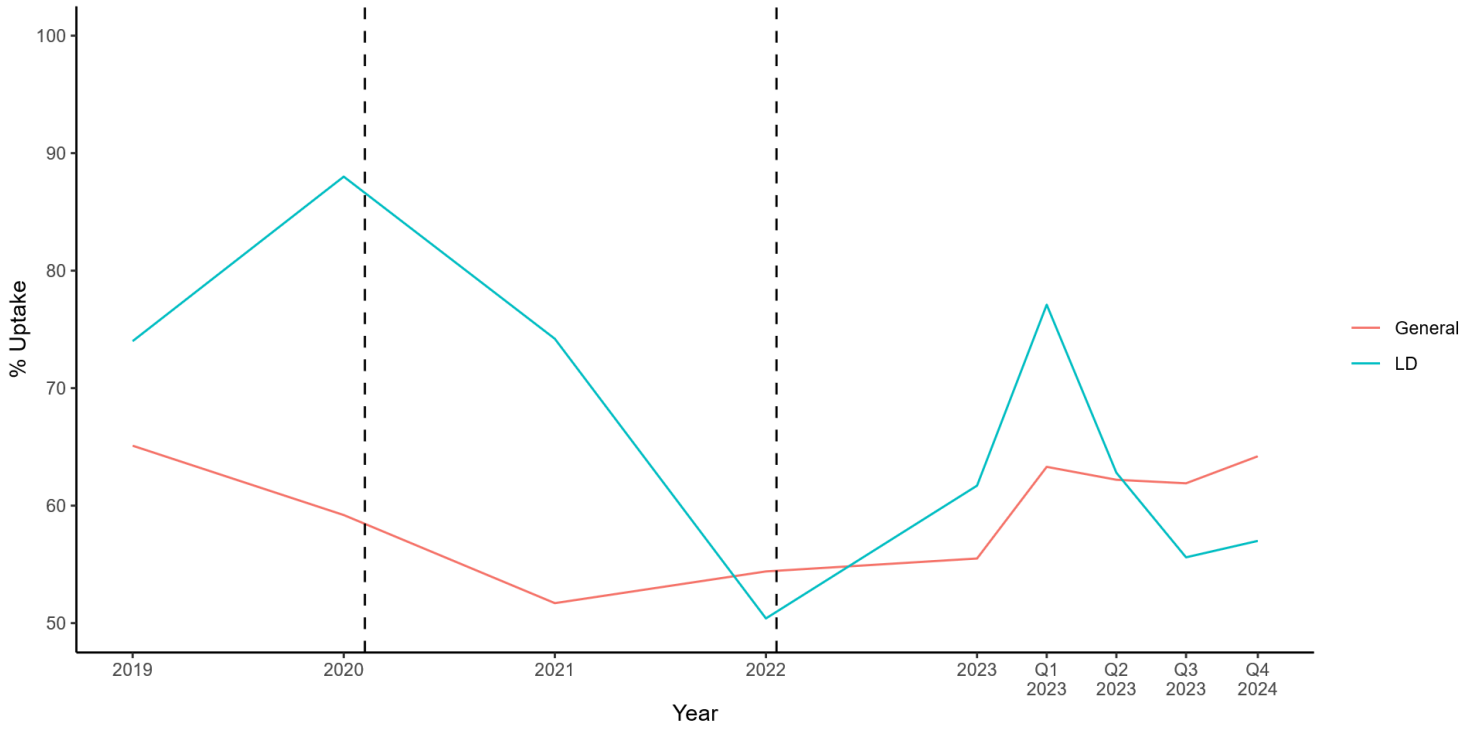


Figure 1

Learning Disability Service uptake in north London (NLBSS)

Source: Primary data – service uptake

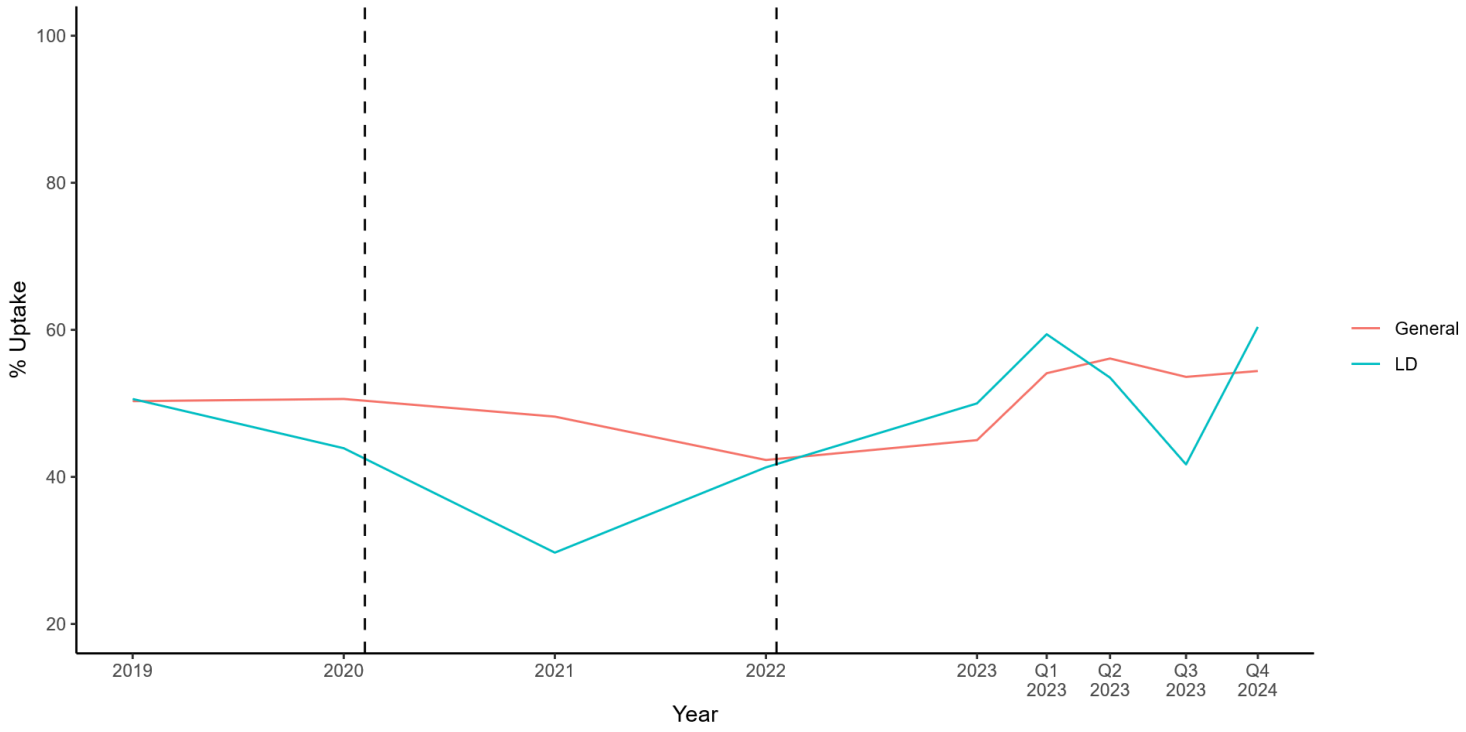


Figure 2

Learning Disability Service uptake in central and east London (CELBSS)

Source: Primary data – service uptake