THE INSTITUTE FOR CONNECTED COMMUNITIES

Breast Screening Enhancement Evaluation Report

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RESEARCHTHATMATTERS

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1. Executive summary

1.1 Background

Breast cancer is the most common cancer in women in the UK. The statistics highlight the widespread impact of the disease and the need to increase awareness so that everyone affected knows how we can support them and how they can help drive change. Eight out of ten cases are diagnosed in women aged 50 and over, with one-quarter in women aged 75 and over. Over 10,000 women under 50 are diagnosed each year, with about 7,600 in their 40s and 2,300 aged 39 or younger. Breast cancer in men is rare, with only 370 new cases annually, compared to around 55,000 in women. The number of women diagnosed is expected to increase by 13,000 each year, reaching 68,000 annually in the next decade. Almost 85% of women survive breast cancer for five years or more, and survival rates have doubled over the past 40 years due to better treatments, earlier detection, and faster diagnosis. Currently, about 600,000 people in the UK are living after a breast cancer diagnosis, and this number is expected to rise to 1.2 million by 2030. Despite these advancements, the emotional and physical effects of the disease can be long-lasting.

1.2 Key findings

The breast screening projects aimed at increasing uptake following the pandemic made significant progress in achieving their goals. Initial challenges included a lack of data 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 learning disabilities (LD) or language barriers.

Targeting LD teams with information increased their understanding of the challenges faced by this client group. Providing appropriate information to adults with LD about breast screening and general health and wellbeing from a young age was crucial. Increased health literacy was found to reduce patient anxiety and improve appointment attendance. Furthermore, the study revealed that greater health literacy led to enhanced engagement with other healthcare services.

A multi-level approach to sharing health literacy information with LD patients proved effective. This included outreach by health services, prioritizing information sharing within trusted relationships, and using community champions for peer advocacy. These pre-appointment efforts promoted self-advocacy and information sharing during screening appointments. The development of relational practices, such as appointing a named person from the LD team and improving transparency with GPs, families, and community LD teams, made the service more accessible. Additionally, addressing transportation needs for LD women to attend screening appointments significantly increased service uptake.

A further key ingredient was pre-visits to the screening clinics to familiarize patients with the space and equipment, simplified appointment times to reduce anxiety in LD patients, and regular project monitoring meetings to identify problems and find solutions in real time.

One of the main challenges was the availability, accuracy, and sharing of data on vulnerable patients. Efforts were made to review and clean patient datasets, which was less successful for those with language barriers.[1,2] Ethnicity and 'race' were often not recorded – often due to patients declining provision of information – and translation services lacked detailed reporting, complicating future planning. The language app – used across both projects – helped with patient identification. This approach was supported by tailored information leaflets designed to address common questions for targeted communities. However, training for LD screening staff was insufficient to build the necessary confidence and competencies. A buddy system and multi-method training approaches were effective in supporting staff with new technologies.

Despite the positive outcomes, there is concern that the progress in engagement and trust building could be lost if not maintained consistently over time, especially as LD women are invited back for screenings every three years. Continuous effort and resources will be necessary to sustain the project's success.

To summarize, the evidence suggests that the LD project successfully increased patient screening uptake and improved patients' experience of the screening process. Similarly, the language project achieved its stated goal in improving patient experience through the adoption of the translation app.

1.3 Recommendations

Strategic level

Incorporate the HP team model into the design and commissioning of all screening services across Central and Northeast NHS. This will better support service uptake among marginalized groups.

Practice level

Ensure that young women with disabilities have early access to health literacy information on breast cancer to enhance their health and wellbeing awareness.

Engage, inform, and educate significant adults, including LD teams, about the challenges, importance, and solutions for clients' breast screening appointments.

Allocate dedicated time and provide specialized training for breast screening frontline staff to effectively engage and support women with LD during their appointments.

Operational level

Maintain continuous engagement with LD teams and sustain the LD Community Champions model to ensure ongoing patient-centred service. Build capacity to deliver the level of community engagement demonstrated in the projects.

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[1] The Health Promotion Team invested significant efforts into cleaning and updating all records shared across the 12 boroughs through revised data sharing agreements to ensure that the correct datasets are in place.

[2] The Breast Cancer Screening Service have used Language Line, a virtual translation service that facilitates three-way communication with those whose first language is not English over the phone. This service has been used alongside the language enhancement for clients with extensive translation support needs.

Unblock phone numbers for outbound calls to make it clear who is calling, and to allow patients to respond to missed calls, reducing the rate of missed appointments (DNAs). Ensure this becomes a standard feature, and consider scaling it across services.

Collect accurate data on patients requiring language support, including ethnicity, to predict future demand. GP practices should review and update patient records to ensure the best patient experience, which might include appropriate language support.

Offer extended appointments to patients with language barriers, if their needs are known before the appointment.

Partnerships and collaborations

LD teams and GP practices should report on health literacy education among their clients/patients to help reduce fear and stigma related to screening appointments.

Healthcare and social care providers should inform non-indigenous patients that NHS screening services are free, addressing concerns from those who might decline appointments due to their country of origin's healthcare payment systems.

Involve external stakeholders who support vulnerable patients in the future co-design of services.

There is a clear link between the engagement of LD teams and increased attendance of their clients at screening appointments.

2. Introduction

Every year, around 11,500 women and 85 men die from breast cancer in the UK. That is nearly 1,000 deaths each month, 31 each day, or one every 45 minutes. Breast cancer is the fourth most common cause of cancer death in the UK, and a leading cause of death in women under 50. Breast cancer includes neoplasms of the ducts, lobules, and connective tissue of the breast. With approximately 55,900 new cases annually in the UK, breast cancer accounts for 15% of all new cancer cases, and it is the second most common cause of cancer death among females in the UK (Cancer Research UK, 2024). Breast cancer remains one of the most common types of cancer in females in the UK and globally (UK NSC, 2019; PHE, 2021; Shin et al., 2020; Coles et al., 2022). Although mortality from breast cancer has gradually declined in the West, the increasing incidence of breast cancer among women has become a growing concern and places a significant burden on the healthcare system (King et al., 2003; Tryggvadottir et al., 2006; Evans et al., 2008; Pacelli et al., 2014). Potentially modifiable risk factors for breast cancer include excessive alcohol intake, high-fat diet, low physical exercise, obesity, particularly among postmenopausal women, and being nulliparous (Tjonneland et al., 2007; Key et al., 2003; McPherson et al., 2006; Blackburn et al., 2003).

The adoption of cancer screening has been shown to have the potential to reduce cancer incidence and mortality globally (Torre et al., 2016). In the UK, the national NHS breast screening programme routinely invites women aged 50–70 every three years for a mammogram (NICE, 2022; PHE, 2021; Marmot et al., 2012; NHS Digital, 2022a). The AgeX trial is piloting the extension of the programme for one additional screening to adults between the ages of 47 and 49 years, and 71 and 73 years (NICE, 2022). The purpose of the screening programme is to find early signs of breast cancer (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 (PHE, 2021; Massat et al., 2016). It is estimated that breast screening services probably prevent about 1,700 deaths per year (Richards, 2019).

Despite the availability of cancer screening services in the UK, disparities in cancer screening uptake have been reported among some individuals and groups, which may increase health inequalities. Numerous studies have demonstrated that disparities in breast cancer screening are impacted by several factors, including race/ethnicity, and socio-economic status (Bhola et al., 2015; Maheswaran et al., 2006; Szczepura et al., 2008; Tangka et al., 2017; NHS Guidance, 2024). For instance, race/ethnicity have been shown to influence stage of breast cancer presentation and mortality rates, with studies suggesting lower screening uptake in ethnic minority groups, particularly South Asian women, who are often diagnosed at a more progressive stage (Woof et al., 2020; Szczepura et al., 2008). Furthermore, breast screening uptake is reduced in areas of social deprivation (Bhola et al., 2015; Maheswaran et al., 2006). However, the disparities in screening uptake due to learning disabilities (Truesdale-Kennedy, 2011) and language barriers (Karliner et al., 2011; Todd et al., 2011; Jacobs et al., 2005; Sheppard et al., 2015) have been under-studied.

In England, approximately 1.3 million people live with a learning disability, and tend to experience significant health inequalities, with poorer physical and mental health compared to people without a learning disability (PHE Guidance, 2023). With advancements in healthcare, women with learning disabilities are living longer, and are becoming eligible to participate in the breast screening programme (Willis et al., 2008). The UK government have produced a number of documents highlighting guidance on good practice for those involved in the care of people with learning disability (Scottish Executive, 2000; Department of Health, 2001; NHS Cancer Screening Programme, 2006), which includes the importance of equal access to all general and preventative health services, as well as access to information to aid accessibility and informed choices. Despite this guidance, it is frequently reported that people with learning disability have lower uptake of preventative screening compared to the remaining population (Whittaker & McIntosh, 2000; Powrie, 2001). This low uptake is significant, given the presence of risk factors for developing breast cancer in women with learning disability – e.g. obesity, low level of exercise, poor diet, nulliparity (Willis et al., 2008). Low uptake in cancer screening can be due to challenges in accessing healthcare resources (e.g. screening), and in having symptoms and concerns understood or acted on (NHS England and NHS Improvement, 2020).

Language can impact individuals' ability to access medical resources, navigate the health system, and potentially the stage at which patients with cancer seek health care (Dubard & Gizlice, 2008; Karliner et al., 2012; Oliveira et al., 2011). People with learning disabilities can have varied communication requirements, for which reason reliance on literacy alone is insufficient, and reasonable adjustments in communication methods is needed in screening programmes – e.g. Makaton, visual recordings (Byrnes et al., 2019). Language as a barrier to breast screening is not limited to adults with learning disabilities, but also impacts adults who are deaf and require British Sign Language (Druel et al., 2018), and communities that are non-English speaking or have limited English proficiency (Cataneo et al., 2023; Balazy et al., 2019). To aid with NHS cancer screening, information is provided in various languages. However, despite the use of translations in screening programmes, breast screening healthcare professionals rated their ability to communicate verbally with South Asian woman as poor (Jain et al., 2012). These findings parallel data from Black and ethnic minority cancer patients in the UK, who reported difficulties in accessing healthcare services due to a lack of confidence in healthcare professionals, knowledge, and communication barriers (Pinder et al., 2016).

In 2020, during the first peak of the COVID-19 pandemic, most routine breast screening was paused for several weeks (Duffy et al., 2022; NHS Digital, 2022b; Breast Cancer Now, 2022). When routine cancer screening recommenced, there was a significant backlog of women waiting to be screened (Duffy et al., 2022). Service backlog was further compounded by services operating at reduced capacity due to infection control measures, as well as patient reluctance to attend screening for fear of exposure to infection (Duffy et al., 2022). The Breast Cancer Now (2022) charity estimates around 1.2 million fewer women in England had been screened between March 2020 and May 2021, compared to pre-pandemic levels. Supporting services to recover from this screening backlog, identifying, and treating undiagnosed women must be prioritized. In June 2020, the London Breast Screening Recovery Programme was established to enable collaborative working to develop and implement innovative novel solutions to resolve the service backlog (e.g. delivery of health inequalities project).

3. Aim

3.1 Definition of breast screening

Breast cancer screening checks healthy people for early signs of cancer in the breast tissues using a test called mammography, which takes X-rays of the breasts. Screening helps to find breast cancer early, when it is too small to see or feel. These small cancers are easier to treat than larger ones. Screening does not prevent breast cancer, but it aims to find it early. In England, about 9 out of every 1,000 women who get screened are found to have cancer (Cancer Research UK, 2023).

3.2 Challenges in breast screening

Recent studies have shown that breast screening in the UK faces several challenges, including low participation rates and issues with referral pathways. A review by Gathani, Dodwell, and Horgan (2022) 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. However, this backlog was addressed quickly.

On international, national, and local levels, there have been challenges in accessing mammography, especially among Black, Asian, and Minority Ethnic (BAME) groups and other migrant ethnic communities, as shown in studies by Jain et al. (2012), Jack et al. (2014), Gorman (2015), and Sharma, Patlas, and Yong-Hing (2023).

The underrepresentation of ethnic minority groups in breast screening might also be attributable (alongside the factors discussed previously) to inaccurate recording of ethnicity data in breast cancer screening services. Missing patient ethnicity data have been a widespread limitation in health services (Bignall and Phillips, 2022), due to systemic issues in data systems and patients not providing this information. The latter is caused by a multitude of underlying factors (Bignall and Phillips, 2022), for example, patients not understanding the purpose of providing details of their ethnicity or not finding the ethnic categories appropriate to describe themselves, and historic associations of ethnicity and race, and concerns over discrimination.

Breast screening and mammography are not routinely offered to men unless there is a significant diagnosis presenting a risk. This assessment is only available via referral from their GP to a symptomatic breast service.

3.3 Evidence review

This review explores the challenges faced by clinical service providers and female service users in breast screening. It also looks at potential solutions to improve referrals, referral pathways, and the uptake of breast screening.

3.4 Local challenges in breast screening uptake

Tower Hamlets NHS used community outreach and campaigns to increase breast screening among Bangladeshi women. High population turnover and deprivation affected screening rates, with a 4% variation between Primary Care Trusts (PCTs) and a 13% drop in deprived areas. Ethnicity also played a role, with a 28% variation showing that BAME women had lower screening rates, partly due to cultural beliefs, such as seeing cancer as a death sentence. The whole-systems approach improved uptake from 44.5% in 2005 to 63.4% in 2009.

Haringey Council 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, particularly among Caribbean, African, Cypriot, and Asian groups. 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.

Data show inequities in breast screening among ethnic groups. White British women had the highest attendance for both first and routine screenings, while Bangladeshi and Black African women had the lowest. Screening rates also varied by geographic region in London. The report suggests collaborating with community groups to improve uptake.

3.5 Challenges in breast screening uptake in England and Scotland

England

An independent review by NHS England in 2018 showed a decline in breast screening for women aged 49 and over, with only 2.89 million women completing screenings. The review highlighted regional differences, with London having the lowest uptake and the East Midlands the highest. Challenges included:

- Low uptake among women receiving routine invitations.
- Inconvenient screening locations.
- Limited uptake through self-referrals, especially for women over 70.

Scotland

A review by the Scottish NHS identified barriers to breast screening, including:

- Perception that screening has little preventive health value.
- Cultural taboos and discomfort with exposing breasts.
- Inconvenient screening locations and times.
- Lack of emotional support during appointments, especially in mobile screening units.
- Reactions to follow-up appointments and the impersonal nature of screenings.

Mobile screening units helped reduce geographical barriers, but uptake was still lower in deprived areas (59.5%) compared to less deprived areas (79.7%). Public locations for mobile units, such as supermarkets, also caused discomfort.

Ethnic inequities

Research shows disparities in breast screening uptake among different ethnic groups. White British women had the highest attendance rates for both first and routine screenings, while Bangladeshi and Black African women had the lowest. Uptake also varied significantly by region in London. Collaborating with community groups is suggested as a way to improve screening rates.

Both England and Scotland face challenges in breast screening uptake due to social, cultural, and logistical barriers. Addressing these issues through community collaboration and better support systems could help increase participation. Data from the UK and Scotland show similar issues with socio-economic challenges, access, and cultural and language barriers to breast screening.

3.6 International examples of breast screening challenges

Canada

A study by Sharma, Patlas, and Yong-Hing (2023) highlighted racial disparities in breast cancer screening uptake in Canada. Barriers such as fear, lack of knowledge, and cultural insensitivity were significant factors. Negative health experiences further discouraged women from participating in screenings. The authors suggested community-based breast screening programmes that provide culturally sensitive environments to address these disparities and increase participation.

Germany

In Germany, mammography screening attendance is about 50%, which is lower than the 70% seen in other European countries. Germany's approach includes opportunistic screening, where screenings are offered as part of other health services. This method aims to address language and cultural barriers, but it may contribute to the lower overall attendance rate (Katalinic et al., 2019).

United States of America

Research by Karliner et al. (2012) found that language barriers significantly impacted breast screening in San Francisco. Among 13,014 women with abnormal mammograms, 31% spoke a non-English language. Within 30 days of a follow-up appointment, 67% of English speakers had a follow-up exam, compared to only 50% of non-English speakers.

Canada (Disability)

A study by Guilcher et al. (2021) focused on breast screening in women with disabilities in Ontario. Out of 10,363 women, 4,660 had some level of disability. Screening rates were higher for women with moderate disabilities (71.4%) compared to those with no disabilities (62.0%) and severe disabilities (67.9%). However, women with severe disabilities and chronic conditions had lower overall screening rates.

3.7 Summary

International studies highlight common challenges in breast screening, including racial disparities, cultural insensitivity, language barriers, and the impact of disabilities. To improve screening uptake, it is recommended to implement community-based and culturally sensitive approaches.

4. Objectives

To develop evaluative evidence and insights in the following key areas:[3]

LD project:

- Number of women living with learning disabilities that were successfully reached
- Number of women living with learning disabilities that book an appointment
- Number of women that attend an appointment
- Estimated impact on future uptake
- Number of cancers detected
- Patient experience of attending screening
- Quality of services
- Access to awareness materials, and awareness of the service
- Quality of collaborations and partnerships
- Levels of co-production and co-design of service
- Healthcare practitioners’ experience of delivering the service enhancement.

Language project:

- Access to breast screening for the cohort of women who use the translation application
- Estimated impact on future uptake
- Number of women who use the translation application that complete their screening
- Number of women who use the translation application that report an improved screening experience
- Number of cancers detected amongst women who use the translation application
- Patient–professional relationships, including individually tailored information offered to patients

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[3] Service data were obtained from the Royal Free London NHS Foundation Trust and the North London and Central and East London Breast Screening Service to evaluate these objectives alongside primary data – see 5.1 Study design.

- Co-production and co-design of service
- Healthcare practitioners’ experience of delivering the service enhancement.

5. Methodology

The Institute for Connected Communities at the University of East London conducted an independent evaluation of two breast cancer screening service enhancement projects: "Improving screening participation for people with Learning Disabilities" (LD project) and "Improving language support during screening appointments" (Language project).

The aim was to gather evidence on breast screening uptake, barriers, and disparities, to inform strategies for improving access and equity in breast cancer screening programmes. The evaluation aimed to provide detailed insights into the process and impact of these projects, informing breast screening services in Central East and North London, as well as other regional and national services. Recommendations were made for areas of development, strategies, and future project extensions to maximize impact.

The desktop research lasted four working days and included a follow-up iteration later. Various search engines (e.g. Google, Google Scholar, UEL repository, Bing, BMJ Open, and Science Direct) were used. Keywords related to breast cancer screening, uptake, barriers, language, mammography, inequity, disparities, inequalities, apps, technology, and linguistics were focused on. Additional literature was obtained from BMJ Open and Science Direct in the second phase of research.

5.1 Study design

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

The evaluation framework was co-developed with the Royal Free London NHS Foundation Trust, and the North London and Central and East London Breast Screening Service, and it was reviewed regularly. The evaluation approach was strongly influenced by Pawson and Tilley’s (1997) realist evaluation principles, which apply evaluation theory to investigate the question of: 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 evaluation was also informed by implementation science principles to measure the effectiveness of the implementation of a new intervention (Mitchell and Chambers, 2017), specifically the Normalization Process Theory (NPT) (May and Finch, 2009), a conceptual framework for explaining what people do to implement a new practice.

The evaluation approach used a mixture of methods for data collection, and it brings 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.

5.2 Quantitative methods – Routinely collected service data.

We obtained routinely collected service data from various sources, including the Royal Free London NHS Foundation Trust and the North London and Central and East London Breast Screening Service. These data covered three main areas: 1) screening uptake; 2) outreach, promotional, and awareness-raising activities, which included social media, events, and stakeholder engagement; and 3) languages and expressions used in the translation app.

The screening uptake data were provided at three time points: historical data from April 2018 to March 2023, and data covering the first two quarters of the Breast Cancer Screening service enhancement from April 2023 to March 2024.

The data on outreach, promotional, and awareness-raising activities were supplied quarterly, giving insights into the community reach and engagement with events, media presence, and stakeholder engagements organized by the Health Promotion team.

Additionally, the language translation application data included details on the languages used and the most common expressions translated during screening appointments. These data were also provided quarterly.

5.3 Primary data

The fieldwork took place between December 2023 and March 2024, and included the collection of online surveys and virtual semi-structured interviews.

5.3.1 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 all hosted on Qualtrics for ease of access.

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). These forms aimed to understand practitioners' views on the service enhancement over time, and to identify barriers to 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 commissioner organization.

The Collaborate Survey, a standard NHS tool, 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 Learning Disabilities, and Local Authority teams, were invited to complete the survey through the commissioning organization.

5.3.2 Qualitative interviews

Semi-structured one-to-one interviews were conducted with healthcare practitioners to delve into their experiences with implementing and integrating the Breast Cancer Screening Service enhancement LD and Language projects. These interviews were guided by the Normalization Process Theory, and they focused on the implementation science aspects of the projects to understand what worked effectively, and which areas needed improvement. The aim was to inform Breast Cancer Screening services in North and Central-East London and beyond.

The interview participants represented various roles, including frontline staff such as mammographers and nurses, back-office staff, and strategic leads. Additionally, stakeholders from learning disability teams were included in the interviews.

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 with ten questions. The conversations were transcribed using the transcription function in Microsoft Teams.

5.4 Sampling strategy and recruitment

The evaluation recruited participants using a convenience sampling strategy, with the commissioning organization overseeing the recruitment process. Surveys were distributed via email by the commissioning organization, 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.

Interview participants were also recruited through the commissioning organization. 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 organization contacted staff members in each role. Interested participants were then connected with the researchers to schedule interview appointments.

5.5 Participants

The surveys were completed by a total of 24 participants. Table 5.1 summarises the participant numbers for each survey.

Table 5.1. Number of participants per survey

	Practitioner Survey 1	Practitioner Survey 2	Collaborate Survey	Stakeholder Survey
n	9	4	5	6

Ten interviews were conducted with 11 participants. Participants 10 and 11 took part in a joint interview. The roles of each interview participant are detailed in Table 5.2.

Table 5.2. Interview participants’ numbers and project roles.

No.	Role
1	Health Promotion Team Lead
2	Health Promotion Support Administrator Officer
3	Health Promotion Support Officer (Monitoring and Evaluation)
4	Lead Clinical Nurse Specialist and Health Promotion Team Manager
5	Service Programme Manager
6	Mammographer
7	Mammographer
8	Lead Mammographer
9	Nurse (Assessment & Events)
10	Stakeholder (Newham Learning Disabilities Team)
11	Stakeholder (Clinical Service Manager)

5.6 Data analysis

Exploratory data analysis was conducted on the routinely collected service data. The primary data were inductively coded using the NPT process evaluation normalization framework (Murray et al., 2010), along with the key learning categories highlighted by the commissioners. Subsequently, the data underwent thematic analysis (Aronson, 1995) to identify patterns and derive meaning related to the implementation of the service enhancement and its impact on patients, communities, and stakeholders.

This report provides a summary of the evaluation results, focusing on the key insights derived from the service enhancement:

- The context, including the background of the projects
- External factors, such as any related work that could interact
- 'Active ingredients', referring to key activities and outputs of the projects
- Implementation and measurement of activities and changes
- Lessons learned from the projects, particularly which aspects could be replicated elsewhere and the contextual factors necessary for success
- The impact of the projects
- Project outcomes and beneficiaries
- Considerations of cost-effectiveness and sustainability.

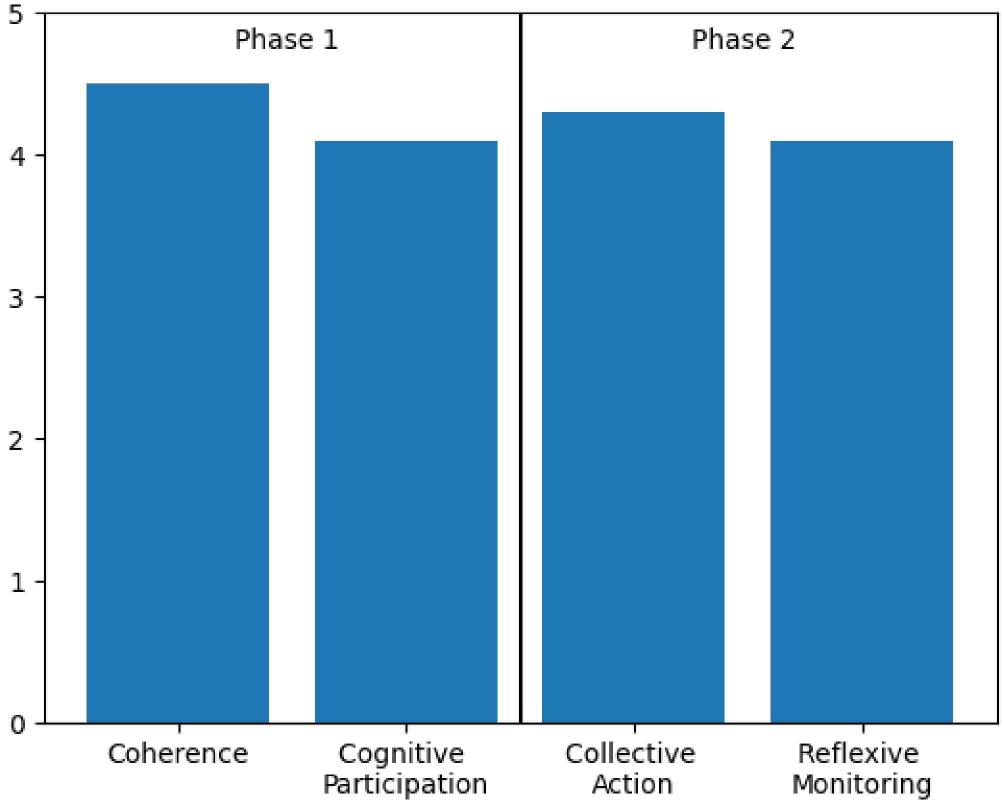
The study received research ethics approval in December 2023 from the University of East London Research Ethics Committee (No. ETH2223-0298).

6. Findings/outcomes

Six stakeholders responded to the survey. The stakeholder organizations were: BLDS, Enfield Learning Disability Service, Hackney Integrated Learning Disability (ELFT), North London/Central and East London Breast Screening Service, Newham Health Team for Adults with Learning Disabilities, Central London Community Healthcare NHS Trust. 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 their voices were heard a little, and one (17%) was unsure. Five (83%) reported that stakeholders' opinion on the language and learning disability projects was that they were extremely or very valuable; 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.

Figure 6.1. Practitioners' self-rated project engagement

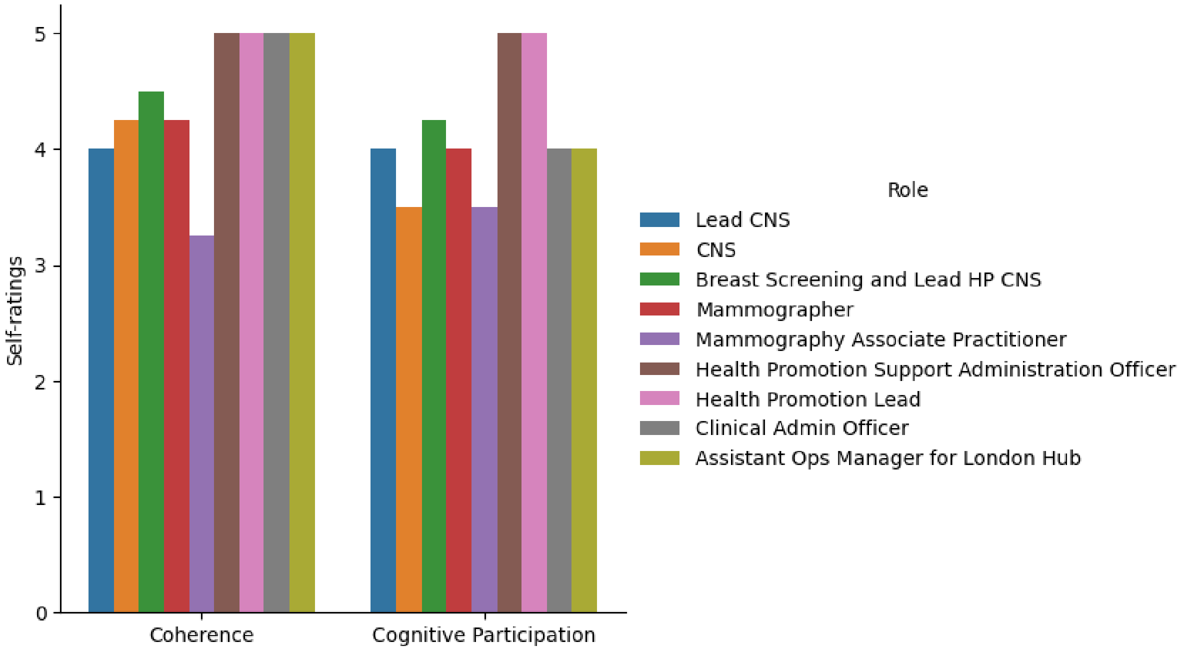


Source: Primary Data – Practitioner Surveys 1 and 2

Project engagement was measured across four indicators across two phases, with two indicators assessed at each stage. Project engagement varied across project roles;

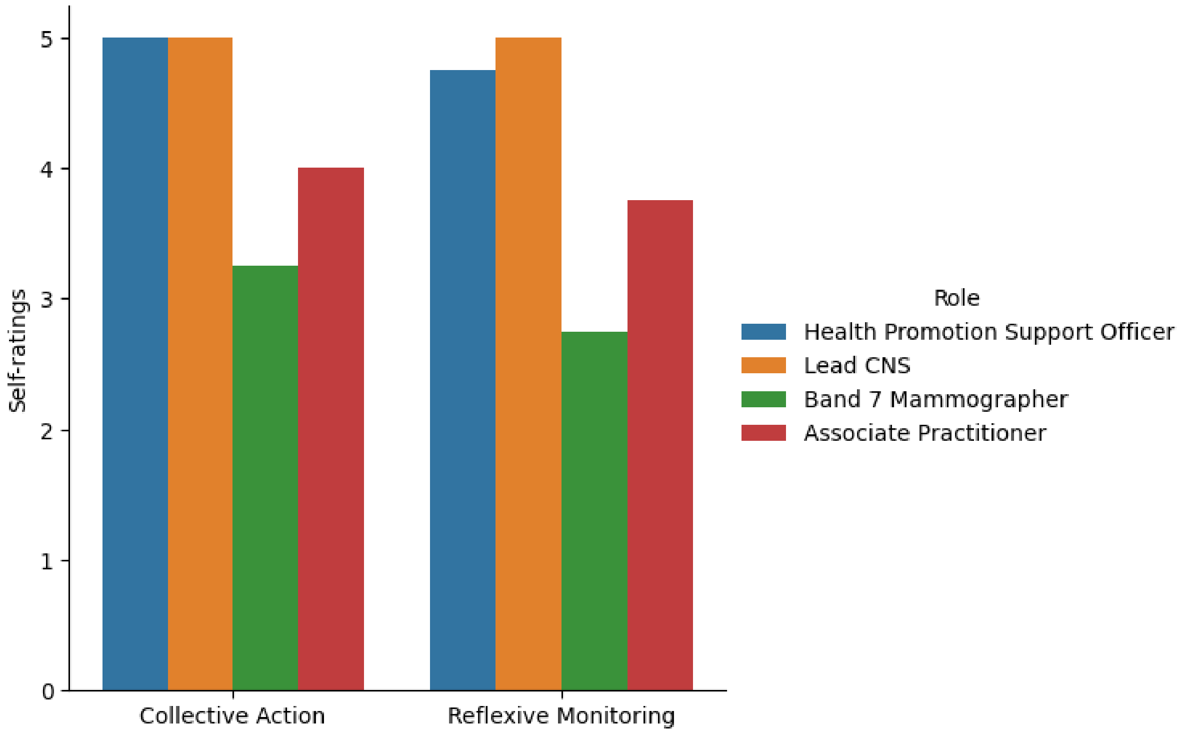
however, all showed moderate to high project engagement. Senior Project Leads (e.g. Lead CNS, Health Promotion Lead) and Health Promotion Support Officers showed consistently high project engagement. Mammographers and Associate Practitioners showed lower project engagement across all four indicators.

Figure 6.2. Role-wise self-rated project engagement – Phase 1



Source: Primary Data – Practitioner Survey 1

Figure 6.3. Role-wise self-rated project engagement – Phase 2



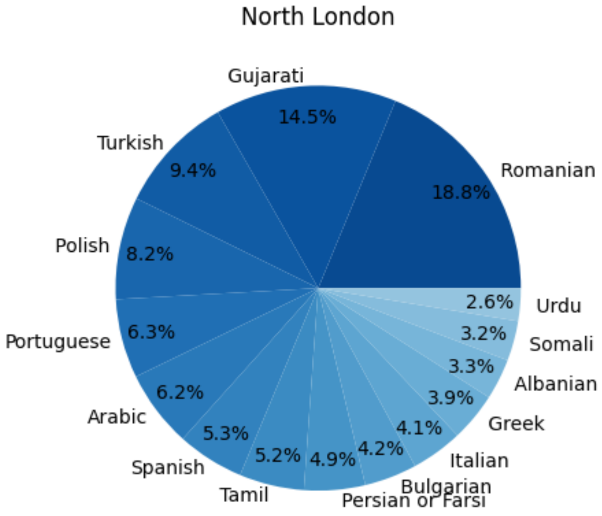
Source: Primary Data – Practitioner Survey 2

6.1 Language enhancement

The decommissioned Translation Interpreter Service, which ran from January 2019 to June 2023, assessed non-English speakers to be 305 individuals; 265 (87%) of these were fulfilled by the service. Specifically, fulfilment was high for Spanish (100%) and Portuguese (71%) speakers. However, fulfilment was low for Albanian speakers (25%).

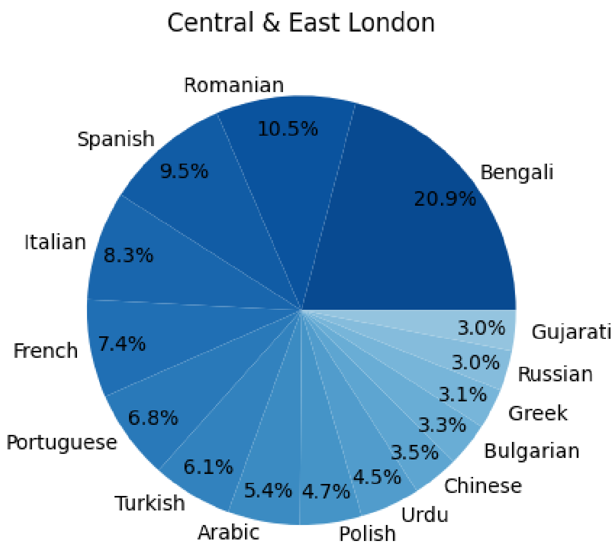
To provide baseline data about language representation across the screening areas, exploratory analysis of ONS data was conducted. The Language Service provided translation across a broad range of languages – particularly, Turkish, Arabic, Romanian, Chinese, Spanish, Ukrainian, Bulgarian, Portuguese, Bengali, Tamil, and Polish. This is aligned with the most common non-English spoken languages across the North London Breast Screening Service (NLBSS) (Figure 6.4) and the Central and East London Breast Screening Service (CELBSS) (Figure 6.5), suggesting that the language service appropriately addressed the local populations' language needs.

Figure 6.4. 15 most common non-English spoken languages in North London (NLBSS)



Source: ONS data

Figure 6.5. 15 most common non-English spoken languages in Central & East London (CELBSS)



Source: ONS data

Despite the decommissioning of the Translation Interpreter Service, the Breast Cancer Screening Service has used Language Line, a virtual translation service that facilitates three-way communication with those whose first language is not English over the phone. This service has been used alongside the language enhancement for clients with extensive translation support needs. The next section now examines how different countries approach breast screening, focusing on their methods, advancements, and the importance of early detection in saving lives and improving outcomes.

In Bolivia, public healthcare does not offer mammography or breast cancer screening, but people can access these services through private healthcare, if they can afford it. Cancer patients in Bolivia may face stigma and financial difficulties, similar to people with HIV. A cancer diagnosis can be financially devastating, and some patients may even be abandoned by their families. Breast cancer is the second most common cancer among Bolivian women after cervical cancer. There are three types of cancer care in Bolivia: social security, public care, and private care. The type often depends on a person's socio-economic status. However, the government's coverage of cancer treatment is irregular, due to political conflicts. While social security and workers' insurance cover some cancer treatments, the availability of medication can be limited, and many patients are diagnosed at advanced stages of the disease.

In Peru, breast cancer is the third leading cause of cancer-related deaths among women, and about half of cases are diagnosed at advanced stages. Factors contributing to late diagnosis include lack of awareness, misconceptions about breast cancer, socio-economic status, and education level. A study in Peru aimed to assess the feasibility of a nationwide breast cancer screening programme, and found significant barriers, such as lack of awareness, misconceptions about breast cancer risk factors, and fear of screening procedures. Economic limitations and geographical barriers also hindered access to screening services.

Albania's National Cancer Control Programme aims to reduce cancer incidence through early detection and improved patient care. Despite efforts to enhance public awareness and access to screening services, universal healthcare coverage is still not fully realized in Albania, with a significant proportion of the population uninsured and facing financial barriers to healthcare.

In Brazil, breast cancer screening services are provided for free through the public healthcare system, targeting women aged 50 to 69 years. Mammography screenings are recommended every two years for this age group. However, despite the availability of free screening services, challenges such as late diagnosis and limited access to healthcare persist.

Colombia offers breast cancer screening services for free through the public healthcare system, primarily targeting women aged 50 to 69 years. These services are part of national health initiatives aimed at early detection and effective treatment of breast cancer, although regional variations in availability may exist.

Similarly, Ecuador provides free breast cancer screening services for women aged 40 and older through the public health system. Regular mammograms are offered as part of the national strategy to promote early detection and treatment of breast cancer, with initiatives in place since 2019 to expand screening services for eligible women.

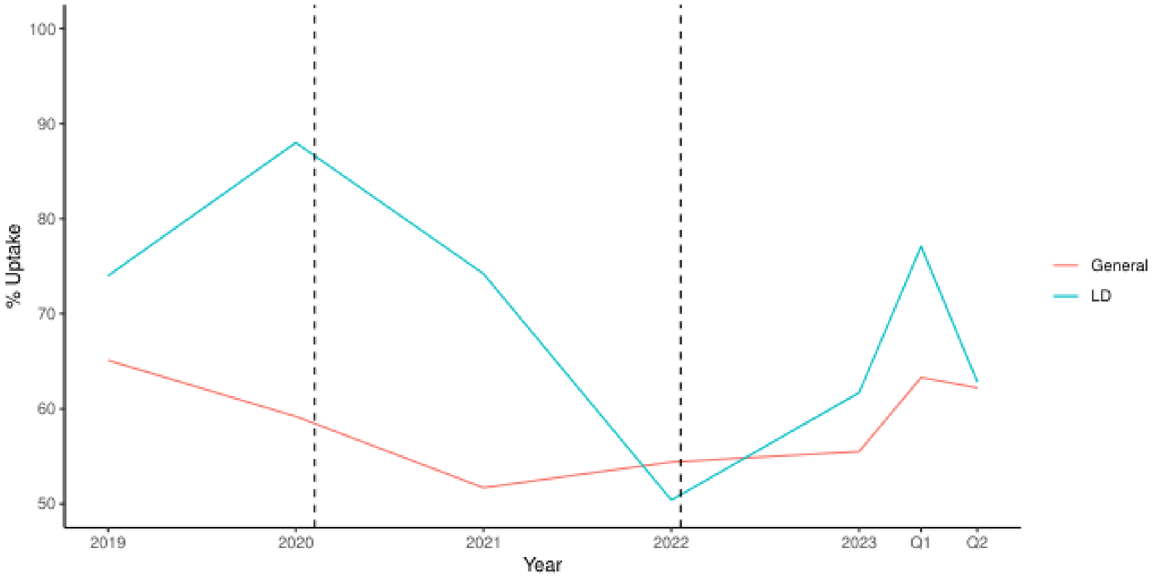
6.2 Disability service enhancement

Learning Disability Service outreach contacted 326 individuals; 41 of these attended appointments, with 3 to assessment and 1 positive diagnosis.

Learning Disability Service uptake is depicted in Figure 6.6 for NLBSS and Figure 6.7 for CELBSS. The vertical dashed lines show the pandemic period marked by lockdowns.

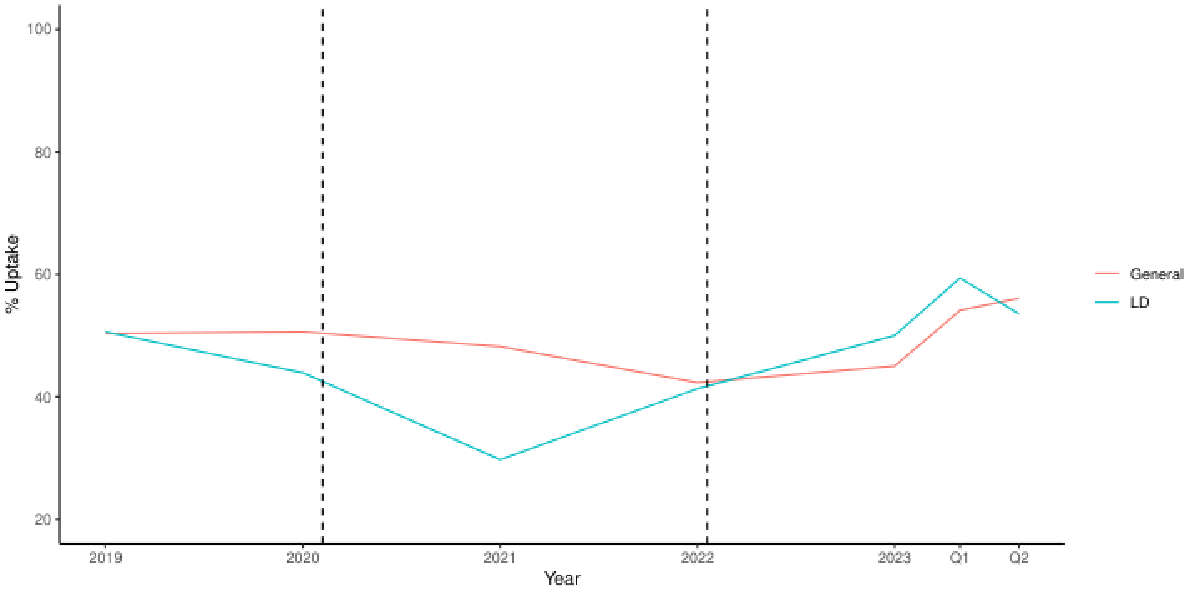
General Service uptake was similar across NLBSS (Mean = 58.8%) and CELBSS (Mean = 49.5%), and showed similar trajectories, with moderate decreases in uptake over the pandemic period, before showing an uptick through early 2023. Learning Disability Service uptake was considerably higher in NLBSS boroughs (Mean = 69.7%) than CELBSS (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.

Figure 6.6. Learning Disability Service uptake in North London (NLBSS)



Source: Primary Data – Service Uptake

Figure 6.7. Learning Disability Service uptake in Central & East London (CELBSS)



Source: Primary Data – Service Uptake

6.3 Breast screening: Getting ready

6.3.1 Coherence

The effort to improve breast screening services for women with learning disabilities and language barriers in London stemmed from recognizing the need for better service delivery. Initially prompted by guidance, it was clear that improvements were necessary, particularly in how the region addressed language and cognitive barriers in screening.

For women with learning disabilities, who are statistically less likely to engage with health services and have higher cancer-related mortality rates, enhancements included providing easy-to-read letters and personalized support to help them understand and attend their appointments. Identifying these women and ensuring they receive the necessary accommodations, such as longer appointments and additional support, was crucial, although some women might not perceive themselves as needing extra assistance.

Addressing language barriers was another major focus. Regulations require a three-point identification check (name, date of birth, and address) before screening, which posed significant challenges for non-English speakers. The reliance on a language line was often inefficient, with wait times varying widely and sometimes causing significant delays. This led to the exploration of more effective translation methods, such as AI-driven tools, to streamline the process and reduce the number of women turned away due to identification issues.

Additionally, the screening service faced operational challenges, such as overbooked time slots due to a malfunctioning algorithm, and the lack of translated resources on some websites, which further complicated access for non-English speaking women. The project also recognized that even with translated written information, literacy issues in some communities, such as the Somali community, made it essential to provide alternative means of communication.

The project highlighted the importance of coherent and coordinated efforts from the workforce, involving strategic planning and operational adjustments. Ensuring that all women, regardless of language or cognitive barriers, could be screened efficiently and accurately was the overarching goal. This required addressing both systemic issues and individual needs, emphasizing the necessity of a tailored approach to healthcare service delivery.

6.3.2 Cognitive participation

The initiative to enhance breast screening services for women with learning disabilities and language barriers in London required significant cognitive participation from the workforce. The administration hub, handling six services across London, played a crucial role in this effort, leveraging extensive experience in client engagement and understanding the challenges faced by these underserved groups.

The team recognized the need to improve services for women with learning disabilities by providing easy-to-read letters and ensuring support staff were available to guide them through appointments. For non-English speakers, the challenge of the mandatory three-point identification check often led to delays and complications. The team explored more efficient translation methods and addressed literacy issues in some communities to make the screening process smoother and more accessible.

The workforce's cognitive participation was essential in identifying these barriers and developing practical solutions. This involved understanding the clients' needs and implementing strategic and operational changes to accommodate them. The goal was to ensure that all women, regardless of language or cognitive barriers, could access breast screening services efficiently and effectively.

6.3.3 Collective action

The enhancement of breast screening services for women with learning disabilities and language barriers in London required significant collective action from the workforce. Patient records were updated directly by the screening staff without needing GP permission, which ensured that changes in names, addresses, or GP practices were promptly reflected in the system. This streamlined process helped maintain accurate records and reduced administrative delays.

The scheduling system, however, often resulted in multiple patients being booked into the same time slot, creating challenges in managing time efficiently in a fast-paced environment. Additionally, the existing dial-in translation service was not robust, leading to frequent difficulties in securing the correct language interpreter, which caused women to have to rebook appointments. This inefficiency was compounded by the fact that appointment reminders and information were often provided in English, making it difficult to track if non-English-speaking women rebooked their appointments.

The project also addressed broader factors affecting patient attendance, such as transportation issues or the need for adjustments in appointment times. Personalized follow-up with patients helped identify and mitigate these barriers, ensuring better attendance and engagement.

Feedback forms, both physical booklets and online tools with QR codes, were used to gather patient insights, allowing the team to continuously improve services. This feedback was crucial in understanding patient needs and refining the approach to screening.

The initiative aimed to make breast screening easily accessible to all women. Despite improvements, there remained challenges in fully implementing effective translation services and utilizing technology such as iPads for multilingual support at screening points. Engagement from GPs varied, affecting pre-appointment communication and coordination.

A significant gap in breast screening uptake among women with learning disabilities was identified, with consistently lower participation rates compared with the general population. Cancer was found to be a major cause of death for people with learning disabilities, highlighting the importance of improving screening access and support for this group.

Feedback from the screening team indicated that language barriers often prevented accurate identification and screening of women, emphasizing the need for reliable translation services to ensure patient safety and proper identification during the screening process. The collective action of the workforce was vital in addressing these multifaceted challenges, and in improving the accessibility and effectiveness of breast screening services for all women.

6.3.4 Reflexive monitoring

The enhancement of breast screening services for women with learning disabilities and language barriers in London involved significant reflexive monitoring by the workforce. This process included continuously evaluating and adjusting practices to better support these women.

One of the key issues identified was access to the screening locations. Many clients faced transportation challenges, with some being housebound or finding the available locations too far away or unfamiliar. There were also instances where family members did not agree to the screening, and the limited availability of appointment times, particularly in the afternoons, conflicted with clients' schedules and medication routines.

Additionally, language barriers significantly impacted the check-in process. In a diverse city such as London, many clients were not confident in English or did not speak it at all. The requirement to provide name, date of birth, and address at appointments was a substantial hurdle, as was the need for clear communication during the screening process. Clients who could not communicate effectively often had unpleasant experiences, which discouraged them from attending or rebooking appointments.

The workforce's reflexive monitoring involved gathering feedback from patients through booklets and online tools, which provided insights into these challenges. This ongoing evaluation allowed the team to identify and address issues such as transportation needs, appointment scheduling conflicts, and communication barriers. By implementing changes based on this feedback, the team aimed to make breast screening more accessible and comfortable for all women, regardless of their language abilities or physical limitations.

Through these efforts, the workforce continuously adapted their strategies to improve service delivery, ensuring that women with learning disabilities and language barriers received the necessary support to access breast screening services effectively.

6.4 External factors

6.4.1 Coherency

The enhancement of breast screening services for women with learning disabilities and language barriers in London revealed the critical need for workforce coherency, especially when dealing with external factors. Various challenges emerged related to booking appointments, accessing accurate data, and ensuring effective communication.

The booking process faced difficulties due to historical and manual data handling, which required updates based on information from women themselves, GPs, and learning disability groups. This reliance on external sources often led to incomplete or outdated records. For the LD project, the lack of comprehensive data on patients with mild to moderate learning disabilities further complicated the process.

Language barriers posed another significant issue. While a translation service was available, it was often inefficient, leading to lengthy appointment times and poor experiences for non-English-speaking women. The mobile units, with their small and enclosed spaces, were not well-suited for extended waits, resulting in dissatisfaction and reduced likelihood of women returning for future screenings.

Training for mammographers was necessary to address the inconsistencies in data from GP surgeries, and to improve their interaction with LD patients. The workforce also had to navigate challenges such as carers not being adequately prepared with patient details, which caused delays and added stress in busy waiting rooms. Additionally, carers sometimes interjected their own experiences, hindering the screening process.

The COVID-19 pandemic exacerbated these issues by reducing the number of patients attending screenings. Post-pandemic, there was a gradual increase in attendance, but this also included a backlog of individuals who had missed previous appointments. Managing this surge required careful demand and capacity planning, further stressing the system.

Overall, the workforce's coherency was essential in coordinating these external factors, and in ensuring that all women, regardless of their cognitive or language barriers, could access breast screening services effectively. The need for seamless integration of data, efficient booking systems, and effective communication strategies was paramount in achieving this goal.

6.4.2 Cognitive participation

The effort to enhance breast screening for women with learning disabilities and language barriers in London faced several external challenges, highlighting the need for significant workforce cognitive participation. One major issue was the lack of preparedness among carers, who often did not have essential patient details. This led to delays, as they had to contact offices for information during appointments, causing inefficiencies and frustration.

The impact of COVID-19 also persisted, affecting the number of women attending screenings. As more people began returning, including those who had missed appointments during the pandemic, the need for effective demand and capacity planning became crucial. The transition to a "Smart Booking" system, intended to optimize appointments, did not perform as expected, adding further strain to the process.

Carers often interjected their own experiences, which could hinder the screening process for women with learning disabilities. This interference sometimes required healthcare providers to manage the carers separately to streamline the process.

Language barriers required special attention. Although translation services were available, they were not always efficient, especially during back-to-back clinic appointments. In-depth conversations and assessments often necessitated human translators, complicating the scheduling and extending appointment times.

Additionally, inadequate data sharing and lack of audits complicated the rollout of interventions. Early stages of the project suffered from poor data quality, which required significant manual effort from the service delivery team to clean and update all records shared across the 12 boroughs through revised data sharing agreements to ensure that the correct datasets were in place. This was crucial for identifying and flagging women with learning disabilities to ensure that they received appropriate support.

6.5 Collective action

The improvement of breast screening services for women with learning disabilities and language barriers faced challenges due to the level of collective action from carers, occasional interpreter delays, and limited support with transport. Post-COVID, hospitals and communities began offering assistance with transportation, easing access to the service.

However, establishing effective data sharing agreements proved cumbersome. Information governance leads within boroughs were tasked with signing agreements, but not all were linked to LD teams, making engagement difficult. IT system updates were also time-consuming, requiring adherence to organizational guidelines.

Data sharing emerged as a crucial factor in identifying LD individuals needing support. Collaborative efforts involved entering into information-sharing agreements to cross-reference patient lists and identify those eligible for breast screening. This process helped identify individuals requiring reasonable adjustments for attendance.

Improvements were identified in pre-visit booking procedures, highlighting the need for better utilization of available support services. Overall, addressing these challenges required concerted efforts to ensure effective and accessible breast screening services for individuals with cognitive and linguistic barriers.

Overall, these external factors underscored the importance of workforce cognitive participation in identifying, addressing, and mitigating challenges to improve breast screening accessibility for these vulnerable groups.

6.6 Reflexive monitoring

Our research findings indicate that the workforce responsible for improving breast screening for women with learning disabilities and language barriers lacks effective monitoring of their progress and faces significant challenges from external factors. To sustain the success of this service, it is crucial for different professionals to work together closely. This joint effort ensures a shared strategy and better outcomes. One major challenge is booking appointments, especially for clients without strong support networks. Sometimes, family members or caregivers decline screening on behalf of the client. Even when pre-visit arrangements are made to familiarize them with the process, communication remains difficult, often limited to brief phone calls. In the case of the learning disabilities project, data analysis revealed a substantial gap in appointment attendance between individuals with learning disabilities and the general population, with a significant 14% difference since 2015. This disparity has persisted over time, indicating a longstanding issue that requires attention and intervention.

6.**7** Getting started: Active ingredients**.**

6.7.1 Coherency

Our research delved into how effectively the workforce collaborates to shape improvements in breast screening services for women facing learning disabilities and language barriers. We discovered several key factors at play. Firstly, providing comprehensive training on learning disabilities for all screening staff was crucial. Feedback from staff informed many adjustments, such as extending appointment times for LD patients to accommodate their needs, resulting in appointments being twice the length of regular ones. Engagement efforts with carers and stakeholders, through various channels such as events, newsletters, and forums, also played a pivotal role in service enhancement.

Regarding language barriers, training sessions were conducted for screening staff, acknowledging varying levels of IT literacy. A buddy system was established to support less tech-savvy staff, fostering practical learning experiences. Building connections with LD teams proved instrumental in raising awareness about the importance of screening among primary care providers. However, challenges persisted, such as initial screening difficulties due to language ambiguity, often resolved during subsequent stages, when translation services became available.

Additionally, the Health Promotion (HP) role emerged as multifaceted, involving resource procurement, event presentations, and personalized client interactions. The DNA project, focusing on Did Not Attend (DNA) cases, and also highlighted the importance of understanding client requirements, including those previously unnoticed, through ongoing communication. These findings underscore the complexity of workforce coherence in optimizing breast screening services for vulnerable populations, emphasizing the significance of continuous training, stakeholder engagement, and adaptive strategies to address evolving challenges.

6.7.2 Cognitive participation

Our research examined how the workforce actively contributes to shaping breast screening services for women with learning disabilities and language barriers. We identified several key practices that enhance patient experience and accessibility. Firstly, staff prioritize seeing every patient during appointments, even if they have limited English proficiency, by verifying essential information, such as name and address. Effective communication strategies, such as simplifying language and using visual aids, improve patient understanding and comfort, especially for those with language barriers.

Efforts to support LD patients include offering pre-visits to familiarize them with the screening process, providing easy-read inserts with appointment letters, and conducting video calls before assessments to explain procedures. Consistency in care is ensured by involving the same staff members throughout the patient's journey. Collaborative efforts among staff, including running specialist clinics and booking appointments, further enhance service provision.

Innovative approaches, such as unblocking caller IDs on dedicated phone lines and engaging community champions, contribute to increased patient engagement and awareness. The crucial role of the Health Promotion (HP) team is highlighted, necessitating continued support until the system becomes self-sufficient. Moreover, efforts to involve other caregivers in raising breast awareness among LD patients underscore a holistic approach to patient care.

Challenges remain, particularly regarding the efficiency of telephone translation services and staff readiness to utilize new technologies. However, ongoing training and resource provision help address these obstacles. The multifaceted nature of roles within the workforce, from preparing presentations to engaging with patients, underscores the diverse skill set required for effective service delivery. Overall, our findings highlight the importance of proactive engagement, tailored support, and continuous improvement in ensuring accessible and patient-centred breast screening services for vulnerable populations.

6.7.3 Collective action

Our research examined how the workforce collaborates to enhance breast screening services for women with learning disabilities and language barriers. Collective actions were observed to streamline the screening process and ensure patient participation. Special clinics appointments occasionally involve two mammographers working together to manage time constraints and acquire necessary images effectively. Patient cooperation is crucial, especially with LD patients, where quick, efficient procedures are preferred to capture their best moments.

Close collaboration with LD teams is key to facilitating screening for LD patients, involving data exchange, pre-visits, and dedicated support personnel throughout the screening journey. Regular communication through weekly meetings aids in planning and problem solving across departments. Maintenance of IT systems and strong relationships with Primary Care Networks (PCNs), LD teams, and GPs are vital for effective service delivery and patient engagement.

In the Language Project, efforts were made to provide translation services through iPads, ensuring accessibility for all patients. Universal letters containing LD information were sent to identified patients, aiming to improve understanding through pictorial aids. Open communication channels, including accessible phone numbers and liaising with patient support teams, facilitate booking and communication with clients, especially those residing in supported housing.

Overall, our findings underscore the importance of coordinated efforts within the workforce to address the unique needs of LD and language-barrier patients, emphasizing the significance of effective communication, collaborative initiatives, and ongoing support mechanisms to ensure equitable access to breast screening services.

6.7.4 Reflexive monitoring

Our research explored how the workforce monitors and evaluates the effectiveness of breast screening service enhancements for women with learning disabilities and language barriers. Reflexive monitoring involves constant review and adjustment of procedures to ensure optimal service delivery. In the LD project, administrative staff serve as a central hub for incoming calls, booking appointments, and tracking patient attendance. Instances of patients not attending appointments, termed DNA (Did Not Attend), trigger proactive outreach efforts by designated personnel.

For example, within the DNA project, staff identify individuals who have missed appointments in the past six months and engage them in breast awareness education. This proactive approach aims to emphasize the importance of breast screening and encourage rebooking. This outreach is integrated with the LD project, ensuring alignment with broader initiatives aimed at improving service accessibility for vulnerable populations.

However, challenges remain in identifying all patients who may benefit from these interventions, as some individuals may not readily disclose their needs, or may not be identified through existing screening processes. Nevertheless, ongoing efforts are made to refine monitoring processes and address gaps in service delivery, underscoring the commitment to continuous improvement in providing equitable breast screening services for all women, including those with learning disabilities and language barriers.

6.7.5 Service enhancement delivery

Table 6.1. Weaknesses and potential improvements for the service enhancement

Thematic area	Health literacy	Targeted engagement	Increasing accessible and tailored information	Patient and public involvement in the design of the service	Capacity & administration
	Offer understandable information about cancer prevention, screening, and treatment options. Use plain language materials.	Engage with local LD services regularly. Follow up actively if a woman with LD misses a screening. Collaborate with local communities to	Improve accessibility and understanding of healthcare services. Empower patients to participate in healthcare decisions.	Include women with LD from various boroughs in project development. Engage screened clients to share their experiences and encourage others.	It was challenging to identify the LD team leads for each borough and engage with them. Once they were identified, signing and gathering data took a very long time.

	Engage community health workers for effective communication. Education needed in special schools. Girls need education to transition into adulthood. Ensure continuity of public health education outside of school.	create targeted resources. Ensure resources are accessible to all groups. Involve women with LD as champions for breast screening. Use their positive experiences to encourage others.	Address lack of breast awareness and uncertainty about appointments. Weaknesses include online booking, non-easy-read appointment letters, and inadequate information materials.	Conduct workshops involving patients and support staff for feedback and input.	The iPads are not useful in a breast screening environment on vans … where the lists that are run in breast screening involve 1/multiple patient bookings every 8 minutes all day.

Source: Primary Data – Stakeholders' and Practitioner Surveys

6.7.6 Coherency

Our research looked into how the workforce ensures consistency in delivering breast screening enhancements tailored to women with learning disabilities and language barriers. A crucial aspect was the systematic identification and flagging of LD patients within the screening system, facilitating targeted engagement throughout their screening journey. However, initial data accuracy was questionable, lacking audits or data cleansing procedures. Efforts were made to address this through a pan-London approach presentation, emphasizing the importance of accurate flagging for effective service provision.

Staff training played a significant role in enhancing coherency in service delivery. Inclusive LD training sessions were provided to all screening staff, ensuring a shared understanding of LD criteria and the importance of accurate flagging. This comprehensive approach aimed to address any reluctance or uncertainty among staff, fostering a supportive environment conducive to effective engagement with LD patients.

Furthermore, the use of iPads was integrated into the screening process, providing a standardized tool for data collection and evaluation. Each screening unit received an iPad with clear instructions for use, enabling mammographers to efficiently capture and utilize patient data. Additionally, ongoing monitoring and evaluation activities were conducted to assess the effectiveness of these enhancements, and to identify areas for further improvement.

Overall, these findings highlight the importance of systematic approaches to data capture, staff training, and technology integration in ensuring coherency in delivering breast screening enhancements for women with LD and language barriers. By addressing these aspects, the workforce can enhance service accessibility and effectiveness, ultimately improving outcomes for vulnerable populations.

6.7.7 Cognitive participation

Our research delved into how the workforce actively participates in shaping breast screening service enhancements for women with learning disabilities and language barriers. One notable initiative involved the creation of a comprehensive crib sheet by a staff member to ensure thorough communication with clients, covering all necessary topics and obtaining consent at every step. This individual effort highlights the dedication of staff to improve patient experience, even beyond programme requirements.

Strategic decisions, particularly amidst the COVID-19 pandemic, were made collaboratively through improvement boards, with national guidance influencing changes in the invitational process for LD women. This collective effort aimed to streamline identification processes and ensure appropriate support for LD patients throughout their screening journey.

Additionally, efforts were made to better understand patient needs through service tours and questionnaires for patients and their caregivers. These initiatives aimed to gather insights that could inform service improvements, such as offering group tours before appointments to enhance patient comfort.

Incorporating additional roles for healthcare staff into job adverts reflects a proactive approach to aligning workforce capacity with the demands of new services. This formal recognition of cancer screening roles emphasizes the evolving nature of healthcare responsibilities and the need for ongoing training to support staff in adapting to these changes.

Furthermore, streamlining the booking process and providing early training on new technologies were identified as crucial steps in ensuring efficient service delivery. This proactive approach demonstrates the workforce's commitment to optimizing processes and embracing innovations to better serve women with LD and language barriers.

Overall, these findings underscore the workforce's cognitive engagement in identifying, implementing, and adapting breast screening enhancements to meet the unique needs of vulnerable populations, reflecting a commitment to continuous improvement and patient-centred care.

6.8 Collective action

Our research highlights the collective actions taken by the workforce to enhance breast screening services for women with learning disabilities and language barriers. These actions focus on teamwork, data management, technology integration, community outreach, pre-visit arrangements, and partnership management.

Teamwork in special clinics:

In special clinics, staff members work as a cohesive team, discussing roles and responsibilities to ensure efficient operation. This collaboration includes rotating tasks to give radiographers necessary breaks, reducing the risk of injury, and managing workload effectively. Longer appointments are scheduled, allowing the staff to work under less pressure, leading to a more balanced and positive work environment.

Data management system:

A system was developed where the LD team sends client data to the screening team, who then assess the screening status of these women and share the information back. Establishing data-sharing agreements was challenging, requiring six months of preparatory work and assistance from the Cancer Alliance to engage information governance leads across different boroughs.

iPads for translation:

Initially, there was concern among radiographic staff about using iPads for translation during short 6–8-minute appointments. However, through operational trials and process mapping, the team adapted to using iPads, which helped in translating information for non-English-speaking patients without significantly disrupting their workflow.

Community outreach:

The team actively participates in community events to book appointments and reach potential clients. They maintain regular communication with LD teams, who provide valuable insights into client needs, helping to arrange suitable appointment times. This engagement ensures clients are supported and more likely to attend their screenings.

Pre-visit arrangements:

Pre-visits are organized for clients to familiarize themselves with the screening site and equipment. These visits are coordinated with LD teams and support workers to help clients feel comfortable. While some clients may still withdraw consent on the screening day, pre-visit arrangements have generally been successful in encouraging attendance and participation.

Partnership management:

The team also focuses on managing partnerships by identifying potential collaborators and maintaining communication with organizations interested in supporting the breast screening programme. This proactive approach helps build a network of support, enhancing the overall effectiveness of the screening services.

6.9 Community engagement

Engagement with community teams is crucial. Staff members find it helpful to speak with LD teams, who know their clients well and can provide specific insights on how to contact and comfort them. Support workers from these teams play an essential role in coordinating appointments and ensuring that clients feel supported and are more likely to attend.

Pre-visits:

For clients who are hesitant to book appointments, pre-visit sessions are set up to help them get familiar with the site and the screening process. These sessions, supported by LD teams and support workers, are generally successful in making clients comfortable and increasing their participation in screenings.

Partnership management:

Building and managing partnerships is also a key focus. The team actively seeks out potential partners and maintains communication with organizations interested in supporting the screening programme. This approach helps create a supportive network, enhancing the programme's overall effectiveness.

In summary, the collective efforts of the workforce, including teamwork, data management, technology integration, community outreach, and partnership management, significantly enhance breast screening services for women with learning disabilities and language barriers. These actions ensure a more inclusive and effective healthcare service.

6.10 Reflexive monitoring

Enhanced checking system:

A critical improvement in the breast screening service was the implementation of a three-point checking system. This system ensures that the correct individuals receive the screening services they came for, enhancing accuracy and reliability. Without this thorough verification process, the screening could not proceed, underscoring its importance in service delivery.

Engagement and nervousness:

Despite frequent communication in their roles, some staff members expressed unexpected nervousness when engaging with clients. This highlights the need for ongoing support and training to help staff feel more confident and effective in their interactions, which is essential for providing a positive experience for all service users.

Simplified appointment times:

Feedback from women with learning disabilities indicated that unconventional appointment times, such as "2:13 p.m.", caused anxiety. In response, appointment times were standardized to more familiar intervals, such 2:00 p.m., 2:15 p.m., or 2:30 p.m. This change aimed to reduce anxiety and make the process more comfortable and predictable for these women.

Effective data sharing:

To better target screening services, data-sharing agreements were established, allowing the team to track where clients with learning disabilities were in their screening cycles. This enabled the planning of targeted events and interventions. The most recent agreement was finalized in 2024, marking a significant step in improving service coordination and effectiveness.

Use of iPads to overcome language barriers:

iPads equipped with translation tools such as Google Translate were introduced to assist women facing language barriers. Initially, setting up these devices required significant manual effort, including configuring each iPad and installing necessary apps. Over time, the process stabilized, although occasional maintenance, such as resetting devices to factory settings, was still needed. Regular data collection and feedback ensured that the iPads remained a valuable tool in facilitating communication and service delivery.

6.11 What changed?

Table 6.2. Outcomes of service

Thematic area	Access	Empowerment	Efficiency
	The language project facilitated easier communication for non-English-speaking clients during appointments. Learning disability-focused promotion improved accessibility for those with learning disabilities. Successful screening of previously unscreened clients was achieved. NHS transport alleviated client anxieties and mobility issues, making clinic attendance easier.	The LD project facilitated access to screening for clients with learning disabilities, boosting their comfort and confidence during appointments. This support had a ripple effect, encouraging engagement with other healthcare services and cancer screening programmes. Positive experiences at breast screening empowered clients to seek out additional healthcare services.	Google Translate improved clinic efficiency by providing quick access without delays. Unlike telephone translators, Google Translate did not cause scheduling disruptions. Short appointments benefited from the efficiency of Google Translate, minimizing delays. Targeting clients based on where they are in the screening cycle and inviting them for pre-visits has been successful for ensuring that information is given to the people who it is most relevant for.

Source: Primary Data – Stakeholder, Practitioner, and Collaborator Surveys

6.12 Coherency

Utilization of readily available resources:

The workforce identified challenges in accessing resources to support communication with women facing language barriers and learning disabilities. To address this, they focused on leveraging existing resources, leading to the implementation of projects centred on iPads. This approach aimed to establish immediate communication with women without causing delays or additional stress. By aligning resources with the goal of providing efficient and accessible screening services, the workforce ensured coherency in service delivery.

Identified need for further resources for LD patients:

A recognized need emerged for additional resources to support women with learning disabilities, particularly those requiring further tests beyond initial screening. To address this gap, plans were made to create easy-to-read resources specifically tailored for the second step of breast screening assessment. The intention is for these resources to be utilized nationally, highlighting the coherency in efforts to address the unique needs of women with learning disabilities across different regions.

Improved understanding for language patients:

While the original goal of language projects was primarily to aid in patient identification, the translation apps significantly enhanced patients' understanding of procedures. This was particularly beneficial for women with limited English literacy who lacked support from literate family members. The ability to understand and consent to procedures effectively empowered these patients, ensuring coherency between the information provided and patients' comprehension, regardless of language barriers.

Positive experiences driving engagement:

Positive feedback from women with learning disabilities who participated in pre-screening tours had a notable impact on subsequent engagement. The sharing of positive experiences created a coherent narrative that encouraged other women to access the service. This ripple effect underscored the importance of fostering supportive and reassuring environments to promote engagement and participation in breast screening services.

Broad geographic coverage:

The breast screening service covers 12 boroughs across North London, Central and East London. This broad geographic footprint ensures coherency in service provision across diverse communities. By extending services to multiple regions, the screening programme aims to promote equitable access to breast health resources, maintaining coherency in service delivery standards regardless of location.

6.12.1 Cognitive participation

Time allocation and special requirements:

Staff members noted that while the overall pace of the service remained fast, adjustments were made to allocate more time for patients with specific barriers, such as learning disabilities or language barriers. This conscious effort to slow down the process ensured that individuals with special requirements had sufficient time to navigate through appointments effectively. Although the fundamental nature of the service remained unchanged, this shift in time allocation was crucial in accommodating diverse patient needs.

Reduced anxiety and improved engagement for LD patients:

Pre-visit initiatives aimed at reducing anxiety among patients with learning disabilities yielded positive outcomes. As a result, these patients were not only more likely to engage with breast screening services but also demonstrated increased engagement with other healthcare services. Additionally, the provision of concrete resources for identifying key service members further facilitated their involvement in the screening process, fostering a sense of empowerment and agency.

Enhanced communication with language patients:

While the impact on screening uptake among language patients remained uncertain, the use of iPads equipped with translation tools significantly improved their screening experience. These tools enabled smoother communication, particularly in cases where complex discussions were necessary and Google Translate was insufficient. By providing access to telephone translation services for languages not available in Google Translate, the service ensured effective communication with all patients, regardless of language barriers.

Implementation of reasonable adjustments for LD patients:

Significant changes were implemented to accommodate the needs of patients with learning disabilities. These included the provision of longer appointment times, designation of a specific team member as a contact point for patients with learning disabilities, and implementation of rounded appointment times for special clinics. These reasonable adjustments aimed to enhance the overall experience for patients with learning disabilities, ensuring that they felt supported and understood throughout the screening process.

Overall, the workforce's reported cognitive participation in implementing these enhancements has led to tangible impacts, including reduced anxiety, improved engagement, and more effective communication, ultimately contributing to a more inclusive and accessible breast screening service for women with learning disabilities and language barriers.

6.12.2 Collective action

Streamlined booking process for LD patients:

The implementation of a new booking system has significantly improved the process for LD patients scheduling their second appointments. Previously, it could take a considerable amount of time to secure a follow-up appointment after the initial screening if additional images were needed. However, with the new system managed by the booking team, LD patients now experience shorter wait times, often securing their second appointments in the same month or the following month. This collective effort to streamline the booking process has resulted in more efficient and accessible care for LD patients.

Advocacy for national adoption of projects:

The workforce expressed a desire for both projects to be recognized and adopted at a national level. They take pride in the initiatives undertaken to enhance breast screening services for women with learning disabilities and language barriers, and they believe that these approaches should be shared and implemented across the country. Advocacy efforts include showcasing the projects to relevant stakeholders, such as the board, to highlight the positive impacts and encourage broader adoption, underscoring the collective commitment to improving service delivery standards.

Collaboration with LD community teams:

Efforts to engage with LD community teams have led to significant improvements in collaboration and service delivery. Previous reluctance from support workers to engage with screening services has been addressed through meetings and presentations, fostering better communication and understanding between teams. This increased collaboration has resulted in improved engagement from care homes and other community organizations, ultimately leading to more LD patients accessing screening appointments and receiving necessary support.

Pre-visit initiatives and accessibility enhancements:

The introduction of pre-visit opportunities has received positive feedback, allowing clients to familiarize themselves with the screening centre and procedures before their appointments. This initiative has boosted confidence among LD patients and made them more comfortable with the screening process. Additionally, accessibility enhancements, such as accommodating wheelchair users during screening, further demonstrate the collective effort to ensure inclusivity and accessibility for all patients, regardless of their individual needs.

Overall, the workforce's collective action in implementing these initiatives has led to tangible improvements in service delivery for women with learning disabilities and language barriers. From streamlining booking processes to advocating for national adoption and enhancing accessibility, these efforts highlight the collaborative commitment to providing equitable and effective breast screening services for all women.

6.12.3 Reflexive monitoring

Longer appointments facilitating trust and success:

The extension of appointment times has proven beneficial in capturing all four necessary images during breast screenings for women with learning disabilities and language barriers. While not guaranteed, longer appointments increase the likelihood of completing the required images, ensuring a more comprehensive assessment. Moreover, these extended sessions foster trust between patients and healthcare providers. Even if patients require follow-up appointments, the established trust makes scheduling and communication easier, contributing to a smoother and more effective screening process.

Challenges in outreach efforts:

Despite efforts to reach out to women for breast screening appointments, challenges persist, particularly in mobile or remote site environments. While outreach initiatives aim to encourage participation, logistical barriers sometimes hinder their effectiveness. However, ongoing monitoring of, and reflection on, these challenges are essential for adapting and improving outreach strategies in the future.

Sustainability and funding concerns:

There are concerns about the sustainability of certain initiatives, particularly those requiring ongoing resources and funding. While projects such as the use of iPads may continue as long as they remain functional, others, such as the LD project, depend on dedicated funding for personnel and resources. Securing continued funding is crucial for sustaining the positive impacts of these projects and ensuring their long-term effectiveness in improving breast screening services for women with learning disabilities.

Impact on screening experience for language patients:

While it remains uncertain if language projects have directly influenced screening uptake, they have significantly enhanced the screening experience for language patients. By providing alternative communication methods and easing time pressures, these projects have improved patient satisfaction and accessibility. Additionally, positive experiences with breast screening services have encouraged patients to engage with other healthcare services, demonstrating the broader impact of these initiatives on healthcare utilization and patient well-being.

Learning and awareness through phone bookings and additional services:

Booking appointments via phone has provided staff with valuable insights into the diverse needs and preferences of patients, contributing to continuous learning and improvement in service provision. Furthermore, the availability of alternative communication methods, such as iPads, has relieved time pressures and facilitated communication with patients. This has not only enhanced the screening experience; it has also encouraged patients to engage with other healthcare services. Additionally, events focused on learning disabilities have raised awareness of available accommodations, leading to increased engagement and positive feedback from patients, particularly within underserved communities such as the Somali community.

6.13 Conclusion

The reported findings suggest that a combination of coherency, cognitive participation, collective action, and reflexive monitoring has yielded positive outcomes in the Breast Screening Service enhancements aimed at women with learning disabilities and language barriers. Through awareness-raising activities tailored to specific communities, and the implementation of reasonable adjustments, there has been an increase in understanding and engagement among target groups. Special clinics and pre-visits have not only improved patient experience, but have also facilitated preventive measures for staff, contributing to a more sustainable working environment. Collaborative partnerships with LD teams and other services have sparked interest and led to better engagement with communities, resulting in improved screening uptake. While challenges remain in data collection and patient identification, efforts to address language barriers and tailor services to specific needs have shown promise. Overall, the findings indicate that a holistic approach, involving both systemic changes and targeted interventions, is essential for achieving equitable access to breast screening services for all individuals, regardless of their cognitive or linguistic backgrounds.

Breast Screening Outreach Approach for Women Living with Learning Disabilities

In early 2023, the Breast Screening Service initiated a focused outreach approach to improve accessibility for women with learning disabilities (LD). This ongoing effort, which covered areas served by the North London and Central East London Breast Screening Services (NLBSS and CELBSS), aimed to make health services more inclusive. To achieve this, they collaborated closely with Learning Disability teams and general practitioners (GPs).

Specialized training sessions for healthcare staff were organized, ensuring that they were equipped to support LD patients through the screening process. Pre-visit arrangements to clinics were tailored to accommodate LD individuals, making the experience less intimidating.

During LD week events in Waltham Forrest, Barnet, and Hackney, health fairs were held to directly engage potential patients and educate them about breast screening in a supportive environment. Visual aids and simplified materials were used to explain the process clearly.

Collaboration extended to training sessions and sharing resources with GPs, nurses, LD specialists, and carers. Easy-read pamphlets and educational materials were distributed to enhance their understanding of LD patients' needs.

Preliminary data from late 2023 showed a promising increase in screening uptake among LD individuals, indicating the positive impact of these efforts. This rise underscored the benefits of a comprehensive approach to addressing health disparities in breast screening services for LD individuals.

6.14 Training

Table 6.3. Training table for LD and language projects

Project	**Training type**	**Frequency and length**	**Staff completion**
Both – mandatory	MAST (Mandatory and Statutory Training)	Not known	Not known
Both – mandatory	Safeguarding training	Not known	Not known

LD	LD training delivered by Learning Disability leads at the Royal Free NHS Trust	One off, half a day	Approx. 150 staff members
Language	Video guide sent to all staff	As required	Not known
Language	Printed laminated user guides sent to screening sites	As required	Not known
Language	Buddy-up system	Not known	Not known

The workforce training for the LD project

The workforce training for the LD project focused on equipping staff with the necessary skills to engage effectively with patients with learning disabilities. The training, delivered by a Learning Disability lead at the Royal Free NHS Trust, was attended by approximately 150 staff members from the Central-East and North London Breast Screening Services. It covered topics such as making reasonable adjustments when interacting with LD patients. Participants in strategic roles highlighted the importance of this training in increasing staff awareness.

However, some participants mentioned gaps in their personal training experiences. One participant noted that they had not received specific training themselves, but they acknowledged that training for community champions and LD teams had been conducted by the health promotion team. Frontline staff members expressed a desire for additional training, even though they already received ongoing training in various areas related to mammography.

Another aspect of training involved the Health Promotion Team providing sessions to communities, LD teams, and community champions. This training aimed to raise awareness about breast cancer screening, inform about reasonable adjustments, and guide on how to support LD individuals in attending appointments.

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

The Language Project Workforce Training

The Language Project aimed to improve breast screening services for women facing language barriers. Unlike centralized training methods, Health Promotion Teams localized the training, while screening teams conducted it independently. Primarily, the training targeted mammographers.

Training materials included a video guide on using iPads and translation apps, along with printed user guides sent to all screening sites. A buddy-up system paired proficient staff with those needing assistance, facilitating practical learning.

Despite efforts, some staff faced occasional challenges, particularly with technology. Ongoing support, including regular feedback sessions, helped address these issues. Strategic leads emphasized the importance of continuous support for successful implementation.

7. Discussion

7.1 Number of women living with learning disabilities that were successfully reached.

Research findings indicate a notable increase in the successful engagement of women with learning disabilities (LD) in breast cancer screening services. The consensus among LD community teams and mammographers suggests a moderate improvement in LD patient participation, attributed to various support initiatives. These include targeted outreach events, collaboration with LD teams, and the provision of bespoke information and appointment options. Despite challenges in accurately identifying LD populations, efforts to involve support networks and adopt patient-centred approaches have shown promise. Noteworthy strategies include extended appointment times and tailored site arrangements to enhance accessibility. Success metrics, such as a 10% increase in service uptake, underscore the effectiveness of these enhancements, highlighting the importance of continued efforts to reach and support LD patients in breast cancer screening endeavours.

7.2 Number of women living with learning disabilities that book an appointment.

The breast screening enhancement evaluation revealed significant improvements in appointment attendance and patient engagement through targeted initiatives. A key highlight was the implementation of a DNA project, which effectively reached out to women who missed their original appointments. By unblocking telephone numbers and assigning a dedicated officer for DNA tracing, proactive communication was prioritized over standard reminder letters, resulting in increased contact rates. Immediate appointments during pre-visits, particularly scheduled during lunchtime, emerged as a successful strategy to enhance convenience and encourage future uptake. Moreover, fostering good communication between the LD team, patients, and clinic staff was identified as crucial for creating a more inclusive appointment environment. Rounded appointment times were also instrumental in reducing patient anxiety. These findings underscore the importance of tailored interventions, proactive communication, and patient-centred approaches in optimizing breast screening participation and promoting positive patient experiences.

7.2.1 Number of women that attend an appointment.

- ***Estimated impact on future uptake.***

The study indicates a potential positive impact on future uptake of breast screening services. Longer appointment times have facilitated the establishment of trusted relationships and contributed to reducing patient anxiety. The hope is that these factors will lead to a decrease in DNAs (Did Not Attend) at subsequent appointments. Efforts to build relationships with the LD team and engage with individuals around LD patients show promise in improving future uptake rates.

However, uncertainties remain regarding whether building positive relationships will directly translate into attendance at future appointments, particularly given the three-year gap between screenings. Pre-visit initiatives have proven valuable in building trust with the clinic and facilitating access to other NHS services, highlighting the importance of comprehensive patient support.

As the intervention becomes integrated into daily clinic practices, there is an opportunity for mainstreaming, ensuring sustained benefits beyond the study period. The involvement of the HP Team in outreach, bookings, and partnership management should be extended until LD patients are accurately flagged in the system, enabling better accommodation of their needs. These findings underscore the importance of ongoing efforts to enhance accessibility and support for LD patients in breast screening services.

7.2.2 Number of cancers detected

- ***Patient experience of attending screening***

Patient experience of attending screening was notably positive, as revealed by collaborative surveys. The implementation of extended appointments and the presence of two mammographers significantly contributed to fostering better relationships and enhancing the overall experience. The additional time provided opportunities for thorough explanations and personalized support throughout the screening procedure, highlighting the importance of patient-centred care in optimizing screening experiences.

- ***Quality of services***

The breast screening enhancement study revealed significant improvements in the quality of services. The workforce was developed to work in a more inclusive and patient-centred manner with patients with learning disabilities. However, mammographers reported feeling time pressures due to the potential increase in service uptake without corresponding increases in staffing levels. These findings underscore the need for continued workforce development and potential staffing adjustments to maintain high-quality, patient-centred care amidst growing demand.

- ***Access to awareness materials, and awareness of the service***

The study highlighted significant progress in increasing access to awareness materials and overall awareness of the breast screening service. Tailored materials, iteratively produced for community events and appointment invitations, were pivotal in this effort. Workforce training focused on effectively engaging with patients with learning disabilities, ensuring that staff were well-equipped to provide inclusive and supportive care.

The LD teams received comprehensive training on breast screening procedures, facilitated by the Health Promotion (HP) team, nurses, and mammographers. This training extended to LD champions, who play a crucial role in community outreach and education. The introduction of easy-read leaflets saw moderate success, indicating a positive impact but also suggesting room for further refinement and improvement. These initiatives collectively enhanced service awareness and accessibility, contributing to better engagement and participation from the LD patient community.

7.2.3 Quality of collaborations and partnerships

The study revealed significant improvements in the quality of collaborations and partnerships, despite the unchanged number of patients attending appointments. However, carers and family members sometimes posed barriers to successful appointment booking and clinical procedures due to their own biases or expectations about the screening process. Enhanced collaboration with community LD teams and GP clinics was noted, although engagement levels varied across boroughs. Areas with better engagement from Primary Care Networks (PCNs) and associated LD teams showed higher screening uptake among LD patients, underscoring the importance of active PCN and GP involvement.

Data sharing agreements initially presented challenges, causing time delays and hindering the establishment of effective partnerships. Eventually, a standard data sharing agreement was implemented, with all data requests being assessed by a designated committee. Communication improvements were also highlighted, with language being adapted to better reflect the service and patients. Despite these advancements, gaps in knowledge persisted, often due to reliance on service names rather than individual contacts. This indicates a need for continued efforts to enhance system-wide understanding and collaboration.

- ***Levels of co-production and co-design of service***

The breast screening enhancement study highlighted high levels of co-production and co-design in service development. The newly created Health Promotion (HP) Team was actively involved from the outset, fostering increased buy-in and a better mutual understanding of roles and responsibilities. This iterative approach allowed for ongoing improvements, such as incorporating community champions, refining the delivery style of outreach talks, and holding weekly and monthly operational meetings for collaborative problem-solving. The service improvements originated from the team itself, surpassing national guidance and demonstrating the value of inclusive and adaptive co-design processes in enhancing service delivery.

- ***Healthcare practitioners' experience of delivering the service enhancement.***

Access to breast screening for women using translation applications was significantly enhanced through the use of iPads, which increased the success rate of completing appointments. However, challenges arose regarding the under-reporting or recording of patient ethnicity and language, which hindered the provision of adequate communication support. To address this, tagged language on patient systems was identified as a potential solution to improve communication and ensure appropriate support for patients utilizing translation applications. These findings highlight the importance of technology in facilitating access to screening services for diverse populations, while also emphasizing the need for accurate recording and utilization of patient demographic information to provide effective communication support.

- ***Estimated impact on future uptake.***

Our study reveals promising insights into the potential impact on future uptake of breast screening services. By expanding our outreach efforts, we successfully reached marginalized communities that had previously been underserved. This proactive approach enabled us to engage individuals who had not accessed screening services before, potentially leading to increased participation rates. Moreover, staff members expressed optimism about their ability to communicate more effectively by using individuals' first languages, which could enhance accessibility and acceptance of screening services. This suggests a positive outlook for future uptake, as improved communication strategies and targeted outreach efforts have the potential to foster greater participation in breast screening services, particularly among marginalized communities. Overall, these findings underscore the importance of continuous improvement and innovation in breast screening programmes to ensure equitable access and promote better health outcomes for all.

- ***Number of women who use the translation application that complete their screening.***

Our study found that the use of iPads effectively increased the completion rate of pre-screening eligibility questions, particularly for women utilizing translation applications. The iPad facilitated the process of verifying identification information, enabling more efficient and accurate screening appointment scheduling. This technological intervention played a crucial role in streamlining the screening process for women relying on translation applications, ultimately improving their overall screening completion rates. These findings highlight the importance of leveraging technology to enhance accessibility and efficiency in breast screening services, particularly for diverse populations requiring language assistance.

- ***Number of women who use the translation application that report an improved screening experience.***

Our research indicates that women using translation applications reported an enhanced screening experience, as perceived by healthcare teams. The implementation of translation applications has led to notable improvements from the healthcare perspective, including reduced waiting times, fewer instances of appointment rescheduling, and the opportunity to build rapport and relationships during appointments. These findings suggest that integrating translation applications into breast screening services has not only improved access for non-English-speaking women but has also streamlined processes and enhanced the overall quality of care provided by healthcare teams.

- ***Number of cancers detected amongst women who use the translation application.***

In our study, both iPad and telephone translation services were utilized to assist women using translation applications during breast screening. However, we encountered time pressures associated with obtaining translation responses via phone, which posed challenges to the efficiency of the screening process. Despite these obstacles, our findings underscore the importance of accessible communication methods for all women undergoing breast screening, irrespective of language barriers. While further investigation is warranted to assess the specific impact on cancer detection rates, our study highlights the need for streamlined and effective translation services to ensure equitable access to breast screening and timely detection of cancer among diverse populations.

7.2.4 Patient–professional relationships, including individually tailored information offered to patients.

Our study explored patient–professional relationships and the provision of individually tailored information during breast screening appointments. Historically, patients faced challenges in accessing appropriate language support, resulting in time lost while waiting to connect with a workforce member proficient in their first language. Despite the introduction of iPads for translation assistance, staff still needed to discern the patient's language, including dialects, and assess their literacy level in their native language. The presence of illiteracy further emphasized the necessity of utilizing oral/vocal iPads for communication. These findings underscore the critical importance of addressing language barriers and providing tailored communication support to enhance patient–professional relationships and ensure equitable access to breast screening services.

7.2.5 High-level research findings: Breast screening enhancement study

The co-production and co-design of breast screening services revealed several insights regarding the use of iPads for translation assistance. Initially, training on iPad usage was inconsistent, with no formal training programme in place. To address this, a training video and a laminated guide were created and made available in each clinic. Additionally, a buddy system emerged organically, allowing staff to support each other in using the iPads.

However, the ongoing support and maintenance of the iPads were found to be inconsistent. Some devices required re-sending for repairs or replacements, and maintaining the iPads proved challenging. Monthly meetings were established to address these issues, providing a platform for continuous support and troubleshooting. These findings highlight the necessity of structured training programmes and robust support systems to ensure the effective implementation and sustainability of technological tools in healthcare services.

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Appendix 1: Weaknesses and potential improvements for service

Table X.1. Weaknesses and potential improvements for service

Theme	Health education	Targeted engagement	Increasing accessible and tailored information	Co-design of programme with clients
Comments	*Health Literacy Initiatives: Implement programmes to improve health literacy, offering understandable information about cancer prevention, screening, and treatment options. Use plain language materials and*	*Active involvement with all local authority LD services – regularly sharing information.* *Active follow up when a woman with LD does not attend, rather than assuming it is a choice not to attend a screening – alert GP, call the woman, ask to speak to her support*	*Making healthcare services more accessible and understandable, thereby empowering patients to actively participate in their healthcare decisions.*	*Include women with LD in all the various boroughs in developing your projects.*

	engage community health workers for effective communication.	*provider where applicable, raise a safeguarding where there are concerns that a woman is not being supported by a care provider to attend a screening etc.*		
	I think there needs to be education in special schools because once girls become women and are outside of education, whether living at home or in residential or supported living, they often miss those public health	*I think they should work with local communities to develop more resources about breast screening aimed specifically at groups less likely to attend (e.g. resources in different languages or for people experiencing homelessness).*	*Clients may not have had breast awareness or were not able to come to the appointments. They did not know what to expect at the appointments.*	*To involve clients who have been screened to talk to other clients about their experience of breast screening, so that they can encourage others to be screened.*
		Seek the involvement of women with LD in each area/borough, who are positive about Breast Screening, and use these women as 'champions' to speak to other women less convinced about the benefits.	*Weaknesses are always where appointments need to be booked online, where appointments sent by post are not in easy read, where there is no easy read information leaflet about the screening, where there are maps, not contact number etc.*	*Some workshops involving patients and their support staff.*

Source: Primary Data – Stakeholder Survey

Table X.2. Benefits of service

Theme	Access	Empowerment	Efficiency
Comments	*The language project makes screening more accessible for clients who don't speak English, as they are able to communicate with mammographers easily during their appointment.*	*The LD project has helped clients with learning disabilities to access screening and feel more comfortable and confident during their appointments. As a group known to be less likely to engage with screening, this has also had a knock-on effect. When the extra support and education*	*It also helps clinics to run more smoothly as Google Translate is quick to access and does not cause delays like waiting to connect with a telephone translator does. This is especially helpful as each appointment is very short and so even short delays can have a big impact on the schedule.*

	Increased Accessibility: Engaging in learning disability-focused breast screening promotion helps make healthcare services more accessible to individuals with learning disabilities. Clients who previously may not have been screened have been screened which has been a success. *NHS transport helped a lot due to clients' anxieties and mobility issues. It was easier to get to the clinic and not get lost if coming on your own*	*helps PWLD [people with learning disabilitities] to have a positive experience at breast screening, they then feel empowered to engage with other healthcare services and access other cancer screening programmes.*	

Source: Primary Data – Stakeholder and Collaborator Surveys

Appendix 2: Drivers and Barriers to accessing breasting service for patients living with disabilities

Table X.3.

Patient group	Drivers	Barriers
Physical disabilities (Edwards, Sakellariou, and Anstey, 2020)	• Increasing effectiveness of preventative care for people with learning disabilities • Improvements to accessibility, relevance and flexibleness of cancer screening services for breast cancer services.	• having major lower limb difficulties • being non-ambulatory • using mobility aids • living further from facilities that offer mammography • having a relative as the main caregiver, as opposed to a spouse/partner caregiver • the absence of research focusing on access to cancer services for men with disabilities
Women with learning disabilities (research by Skyes et al., 2022)	• potential solutions using easy-read documentation throughout the screening process • inviting women with learning difficulties to	

	attend cancer screening, ensuring that they know the symptoms of cancer • ensuring carers are informed and supportive of patient decisions. • offering reasonable adjustments throughout the cancer screening pathway, from invitation through to receiving the results.	
Women with learning disabilities (Connolly, 2013)	• evidence for strong interventions to reduce the barriers to access to cancer screening for people with learning disabilities is very weak • but the evidence about what barriers do exist is stronger.	• scarcity of information, • fear of medical intervention, • embarrassment.
Women with learning disabilities (Truesdale-Kennedy, 2010)	• predetermined visits, • individuals need assessments • improved communication about health needs.	• Lack of proper sources of awareness leading to screening pathways. • Fear and embarrassment were regarded as emotive reasons with disabilities to not take up breast screening services. • Strategies to support this user group can include pre-admission visits, individuals need assessments and improved communication about health needs.
Women from ethic minority groups (Jain et al., 2012)	• would be helpful to record a patient's language to improve clinical services • recorded languages when patients attended services for mammography	• Service providers did not all send out letters to service users. • referral units arrange interpreters in advance • South Asain women not consulted when alterations to services were being made.
Women from ethnic minority groups (Gorman and Stoker, 2015; Bansal et al., 2012)	• Evidence of cultural differences and variation in international breast screening services appear as a factor for the low uptake of Polish women. • 'Opportunistic mammography' widely available in Poland in public and community settings • Opportunistic screening has more pronounced access and visibility.	

Women from ethnic minorities (Woof et al., 2020; Bolarinwa and Holt, 2023)	• information sheets were made available in different languages	• Language barriers prevented breast screening uptake • very few interventions provide accessibility towards • recognizes issues with language for care seekers and breast screening uptake • For service providers; delivering a service without sharing ethnicity and linguistics resulted in difficulty of sharing accurate information. • Lack of shared language also acted as a deterrent for women in breast screening services.

Appendix 3: Enhancing Breast Screening Services for Target Groups

To increase breast screening uptake, especially among target groups, service enhancements are crucial. Here are key recommendations and insights based on recent studies and reviews.

General Recommendations:

- Media Campaigns: Promote awareness through various media channels.
- Flexible Appointment Times: Offer more convenient scheduling options.
- Clear Information: Provide simple, accessible information to demystify the screening process.
- User-Friendly Venues: Make screening locations more welcoming and accessible (NSD, 2022).

Ethnic Groups:

- Community Engagement: Build knowledge within communities through outreach and education.
- Telephone Counselling and Peer Support: Offer counselling and support through trusted community figures (Eilbert et al., 2009).
- Language Services: Ensure information and services are available in multiple languages to address language barriers (Jain et al., 2012).

Women with Intellectual Disabilities:

- Emotional and Informative Support: Provide tailored support and accessible information.
- Education Programmes: Implement structured education programmes for both women and healthcare professionals to address specific barriers (Truesdale-Kennedy, 2010).

- Accessible Resources: Use pictorial guides and easy-read documents to make information more understandable (Breast Cancer Care, 2010).

Community-Based Approaches:

- Outreach Programmes: Conduct community-based programmes to foster understanding and remove fears related to breast screening.
- Cultural Sensitivity: Use familiar, community-driven environments to increase comfort and trust (Sharma, Patlas, and Yong-Hing, 2023).

Impact of COVID-19:

- Resuming Services: Address the backlog caused by the pandemic by increasing service capacity and prioritizing urgent referrals.
- Maintaining Levels: Ensure that screening rates recover to pre-pandemic levels to avoid delays in diagnosis (Gathani, Dodwell, and Horgan, 2022).

Addressing Disabilities:

- Tailored Approaches: Provide individual assessments and improved communication about health needs.
- Overcoming Physical Barriers: Address physical barriers by ensuring accessible facilities and support for mobility issues (Edwards, Sakellariou, and Anstey, 2020).

Cultural and Linguistic Barriers:

- Language Recording: Record patient language preferences to improve communication and service delivery.
- Cultural Sensitivity: Understand and address cultural beliefs that may hinder screening uptake (Baird et al., 2021).

Improving breast screening services for target groups requires a multifaceted approach. By addressing cultural, linguistic, and physical barriers, and by providing tailored support and community engagement, we can enhance screening uptake and reduce health inequalities.

Appendix 4: Research tools

4/A Semi-structured Interview guides/schedules

Interview guide for Mammographers and Nurses (Frontline staff)

INTRODUCTION

The interview should take about 30–45 minutes. We will ask you questions about your views on the two breast cancer screening inequality projects delivered by the by the North London (NLBSS) and Central & East London (CELBSS) Breast Screening Services to improve screening participation amongst people with a disability (LD project) and experience for those with language support needs

(Language project). We will feedback the results of this evaluation to University College London Hospitals NHS Foundation Trust (North Central London Cancer Alliance).

No individual Mammographer or Nurse or other staff member will be identifiable in our report, however, because the sample size is small, we cannot guarantee that information provided is not traceable back to your screening site/back-office function. If you do not want to answer a particular question, you don't have to, and if you feel uncomfortable, we can stop the interview at any point.

Do you agree to take part? <u>We need you to fill in and sign a consent form. Is that OK?</u> Have you got any questions before we start?

Interviewer to complete

Researcher's initials:

Date/time:

Research participant's name:

Organization name:

Have you gained informed consent?   Yes/No

BACKGROUND INFORMATION

1. **Please describe your roles and responsibilities at the service and as it relates to the LD/Language projects?**

2. **When did you become involved in the projects?**

Prompts:

- *When did you start working at Breast Cancer Screening Services?*
- *When did you become involved in the LD/Language project?*

3. **Please describe why the projects are needed?**

Prompts:

- *Supporting vulnerable communities (LD, language support needs) in accessing breast cancer screening services and increasing the uptake of services*

PROVIDING ACCESS TO THE SERVICE

4. **Can you tell me more about what changed in your service to widen access to LD/Language patients?**

Prompts:

- *In what ways does the service work differently to provide better access to LD/Language patients?*
- *In what way have screening procedures changed to increase access or to provide better screening experience?*

➢ *How is the project being promoted to the target population?* ➢ *What have been some of the challenges so far in reaching these groups?* ➢ *What strategies have been put in place to overcome some of these challenges, and how well are they working?* ➢ *Which staff are responsible? (Some/all?)* ➢ *Someone with overall responsibility?* ➢ *What's the process for referring clients to other services?*	
COHERENCE 5. **Do staff at the service have a shared understanding of the purpose of the projects?** *Prompt:* ➢ *If yes, how was this achieved?* ➢ *If not, why not?* ➢ *Did the introduction of the LD/Language project affect the nature of your work? How?* ➢ *What do you do differently than you did before?* ➢ *What type(s) of training you attended that specifically aimed to contribute to the successful delivery of the service enhancement? (e.g. types of training and number of sessions)*	
COGNITIVE PARTICIPATION 6. **Do you think other staff members understand and support the delivery of the projects?** *Prompt:* ➢ *Are key workforce members involved in the project?* ➢ *Do staff members involved in the projects believe the potential benefits for the service?* ➢ *Do you think there is a collective (rather than individual) support from staff for the LD/Language projects?* ➢ *If they don't see the benefits, why?*	
COLLECTIVE ACTION 7. **Please explain how the projects affected the way you work with your colleagues and partners.** *Prompt:* ➢ *If improved, where, how and when?* ➢ *Collaborative working with LD teams, GPs?* ➢ *Collaborative working with the HP teams?* ➢ *What resources do you think are needed to continue to provide effective breast cancer screening services for LD and ESL patients in your organisation?*	
REFLEXIVE MONITORING	

8. **In your view which sub-groups of patients with LD/language support needs have been the most responsive to the service enhancements?** *Prompt:* ➢ *Why and how?* ➢ *Has the service been successful in encouraging the uptake and completion of breast cancer screening appointments among LD patients and patients with language support needs?* ➢ *What have been the barriers for each client groups?*	
9. **Which aspects of the projects are currently working well and not so well to increase the uptake among LD/Language patients?** *Prompt:* ➢ *In your opinion to what extent and in what ways did it affect how patients experience a screening appointment?* ➢ *What else is needed going forward to provide an effective service for LD/Language patients?* ➢ *Improved uptake among LD and ESL patients* ➢ *Increased numbers of cancers/early treatable cancer detected* ➢ *Patient satisfaction* ➢ *Quality care* ➢ *Lack of knowledge/understanding of breast cancer screening services* ➢ *Access problems (e.g. digital problems, getting to appointments)* ➢ *Lack of knowledge of local support groups, etc.* ➢ *Lack of individualized support prior to screening appointments?* ➢ *Lack of time on screening appointments?*	
10. **Is there anything else that you would like to tell that we have not covered already?** *Prompt:* ➢ *What would be the key message to consider for scaling-up?*	

Interview guide for Programme Coordinators/Managers and Booking Managers

INTRODUCTION

The interview should take about 30–45 minutes. We will ask you questions about your views on the two breast cancer screening inequality projects delivered by the North London (NLBSS) and Central & East London (CELBSS) Breast Screening Services to improve screening participation amongst people with a disability (LD project) and experience for those with language support needs (Language project). We will feedback the results of this evaluation to University College London Hospitals NHS Foundation Trust (North Central London Cancer Alliance).

No individual Practice/Programme or Booking Manager or other staff member will be identifiable in our report, however, because the sample size is small, we cannot guarantee that information provided is not traceable back to your screening site/back-office function. If you do not want to answer a particular question, you don’t have to, and if you feel uncomfortable, we can stop the interview at any point.

Do you agree to take part? <u>We need you to fill in and sign a consent form. Is that OK?</u> Have you got any questions before we start?

Interviewer to complete
Researcher’s initials:
Date/time:
Research participant’s name:
Organization name:
Have you gained informed consent?   Yes/No

BACKGROUND INFORMATION

1. **Please describe your roles and responsibilities as they relate to the LD/Language projects?**

2. **When did you become involved in the projects?**

3. **Please describe why the projects are needed?**

Interviewer probe:
- *Supporting vulnerable communities (LD, language support needs) in accessing breast cancer screening services and increasing the uptake of services*

PROVIDING ACCESS TO THE SERVICE

4. **Can you tell me more about what changed in your service to widen access to LD/Language patients?**

Prompts:
- *How is the project being promoted to the target population?*
- *What have been some of the challenges so far in reaching these groups?*
- *What strategies have been put in place to overcome some of these challenges and how well are they working?*
- *Which staff are responsible? (Some/all?)*
- *Someone with overall responsibility?*
- *What’s the process for referring clients to other services?*

COHERENCE

5. Do staff at the service have a shared understanding of the purpose of the projects? *Prompt:* ➢ *If yes, how was this achieved?* ➢ *If not, why not?* ➢ *Did the introduction of the LD/Language project affect the nature of your work?* ➢ *What type(s) of training you attended that specifically aimed to contribute to the successful delivery of the service enhancement? (e.g. types of training and number of sessions)*	
COGNITIVE PARTICIPATION **6. Do you think other staff members understand and support the delivery of the projects?** *Prompt:* ➢ *Are key workforce members involved in the project?* ➢ *Do staff members involved in the projects believe the potential benefits for the service?* ➢ *Do you think there is a collective (rather than individual) support from staff for the LD/Language projects?* ➢ *If they don't see the benefits, why?*	
COLLECTIVE ACTION **7. Please explain how the projects affected the way you work with your colleagues and partners.** *Prompt:* ➢ *If improved, where, how and when?* ➢ *Collaborative working with LD teams, GPs?* ➢ *What resources do you think are needed to continue to provide effective breast cancer screening services for LD and ESL patients in your organisation?*	
REFLEXIVE MONITORING **8. In your view which sub-groups of patients with LD/language support needs have been the most responsive to the service enhancements?** *Prompt:* ➢ *Why and how?* ➢ *Has the service been successful in encouraging the uptake and completion of breast cancer screening appointment among LD patients and patients with language support needs?* ➢ *What have been the barriers for each client groups?* **9. Which aspects of the projects are currently working well and not so well to increase the uptake among LD/Language patients?**	

Prompt: ➢ *Improved uptake among LD and ESL patients* ➢ *Increased numbers of cancers/early treatable cancer detected* ➢ *Patient satisfaction* ➢ *Quality care* ➢ *Lack of knowledge/understanding of breast cancer screening services* ➢ *Access problems (e.g. digital problems, getting to appointments)* ➢ *Lack of knowledge of local support groups, etc.* ➢ *Lack of individualised support prior to screening appointments?* ➢ *Lack of time on screening appointments?* **10. Is there anything else that you would like to tell that we have not covered already?** *Prompt:* ➢ *What would be the key message to consider for scaling-up?*	

4/B Online surveys

Practitioner Self-Assessment Form 1: Coherence and Cognitive Participation

Practitioner Self-Assessment Form 1

The purpose of this self-assessment form is to build evaluative evidence and insights into the two breast cancer screening health equity projects funded by the Cancer Alliances for North Central London, North West London, and North East London. The focus of these health equity projects is to improve screening uptake and experience amongst people living with a disability (LD patients) and for those with language support needs.

The self-assessment form is made up of eight scale questions and one open-ended question and should take no longer than 5 minutes to complete.

The areas covered in the self-assessment form are framed around implementation science principles to help us better understand what worked well and what worked less well in the planning and implementation of the LD/Language projects.

All the information provided will be fed directly into the evaluation being undertaken by the Institute for Connected Communities based at the University of East London.

Data governance

The information you provide on this self-assessment form will remain strictly confidential, in accordance with the Data Protection Act 1998 and GDPR 2018. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available here.

If you have any further questions or enquiries, please contact Prof. Darren Sharpe at d.sharpe@uel.ac.uk

1. I give my consent to participate in this project evaluation

○ Yes (1)
○ No (2)

2. Name

____

3. Team name and work base

____

4. Role within the project

____

5. Please indicate which project you are completing the self-assessment form about?

○ LD project (1)
○ Language project (2)
○ Both (3)

6. Project planned start date

____

7. Project actual start date

____

8. Please indicate how much you agree with the following statements related to the implementation of the LD and/or Language project?

	Strongly Agree (5)	Agree (4)	Neither Agree nor Disagree (3)	Disagree (2)	Strongly Disagree (1)	Not Applicable (99)
I deliver the LD/ Language project as part of a safe and effective service within the allocated resources (1)	○	○	○	○	○	○
I communicate the LD/ Language project vision with enthusiasm and clarity (2)	○	○	○	○	○	○
I provide others with clear purpose and direction, through a well stated LD/Language project vision (3)	○	○	○	○	○	○
I take time to build critical support for the LD/Language project vision (4)	○	○	○	○	○	○
I put forward ideas to improve the quality of services (5)	○	○	○	○	○	○
I take responsibility for embedding new approaches into working practices (6)	○	○	○	○	○	○
I consult with key people and groups when making decisions taking into account the values and priorities of the LD/Language project (7)	○	○	○	○	○	○
I take action when resources are not being used efficiently and effectively (8)	○	○	○	○	○	○

9. Please, describe what worked well and less well in the initial set-up and implementation of the LD or Language project?

____

Practitioner Self-Assessment Form 2: Collective Action and Reflexive Monitoring

Practitioner Self-Assessment Form 2

The purpose of this self-assessment form is to build evaluative evidence and insights into the two breast cancer screening health equity projects funded by the Cancer Alliances for North Central London, North West London, and North East London. The focus of these health equity projects is to improve screening uptake and experience amongst people living with a disability (LD patients) and for those with language support needs.

The self-assessment form is made up of eight scale questions and one open-ended question and should take no longer than 5 minutes to complete.

The areas covered in the self-assessment form are framed around implementation science principles to help us better understand what worked well and what worked less well in the planning and implementation of the LD/Language projects.

All the information provided will be fed directly into the evaluation being undertaken by the Institute for Connected Communities based at the University of East London.

Data governance

The information you provide on this self-assessment form will remain strictly confidential, in accordance with the Data Protection Act 1998 and GDPR 2018. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available here.

If you have any further questions or enquiries, please contact Prof. Darren Sharpe at d.sharpe@uel.ac.uk

1. I give my consent to participate in this project evaluation

○ Yes (1)
○ No (2)

2. Name

____

3. Team name and work base

____

4. Role within the project

____

5. Please indicate which project you are completing the self-assessment form about?

○ LD project (1)
○ Language project (2)
○ Both (3)

6. Project planned start date

____

7. Project actual start date

____

8. Please indicate how much you agree with the following statements related to the implementation of the LD and/or Language project

	Strongly Agree (5)	Agree (4)	Neither Agree nor Disagree (3)	Disagree (2)	Strongly Disagree (1)	Not Applicable (99)
I deliver the LD/ Language project as part of a safe and effective service within	○	○	○	○	○	○

the allocated resources (1)						
I communicate the LD/ Language project vision with enthusiasm and clarity (2)	o	o	o	o	o	o
I provide others with clear purpose and direction, through a well stated LD/Language project vision (3)	o	o	o	o	o	o
I take time to build critical support for the LD/Language project vision (4)	o	o	o	o	o	o
I put forward ideas to improve the quality of services (5)	o	o	o	o	o	o
I take responsibility for embedding new approaches into working practices (6)	o	o	o	o	o	o
I consult with key people and groups when making decisions taking into account the values and priorities of the LD/Language project (7)	o	o	o	o	o	o
I take action when resources are not being used efficiently and effectively (8)	o	o	o	o	o	o

9. Please, describe what worked well and less well in the initial set-up and implementation of the LD or Language project?

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Stakeholder Survey

Stakeholder Survey for the Breast Cancer Screening service enhancement

Introduction

The purpose of this stakeholder survey is to build evaluative evidence and insights into the two breast cancer screening health equity projects funded by the Cancer Alliances for North Central London, North West London, and North East London. The focus of these health equity projects is to improve screening uptake and experience amongst people living with a disability (LD patients) and for those with language support needs.

All the information provided will be fed directly into the evaluation being undertaken by the Institute for Connected Communities based at the University of East London.

This survey should take around 5–10 minutes to complete.

Data governance

The information you provide on this survey will remain strictly confidential, in accordance with the Data Protection Act 1998 and GDPR 2018. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available here.

Contact

If you wish for your personal information to be withdrawn from the evaluation you can contact Prof. Darren Sharpe *(D.Sharpe@uel.ac.uk)*.

1. I give my consent to participate in this service evaluation.
○ Yes (1)
○ No (2)

2. I am a stakeholder involved in the Breast Cancer Screening LD/Language project.

○ Yes (1)
○ No (2)
○ Other (3) ____

3. What is the name of your organisation/service?

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4. What is the nature of your organisation/service? (E.g. GP, Learning Disability Team, Cancer Screening Unit, etc.)

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5. How does the LD/Language project directly benefit your organisation/service? (E.g. widening patient access, improving patient experience, or achieving organisational goals in tackling health inequalities)

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6. How would you rate the benefits of involvement in the LD/Language project for your organisation/service?

☐ Exceeded expectations
☐ Met expectations
☐ Below Expectations

6/1. Please, explain why

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7. Do you think your voice has been heard in the design and implementation of the LD/Language project?

☐ Yes, a great deal
☐ Yes, a lot

○ Yes, a moderate amount
○ Yes, a little
○ No, none at all
○ Unsure

7/1. Please, provide an example

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8. Please describe the strengths, weaknesses, and opportunities in existing collaborations/partnerships to support your clients in accessing breast cancer screening services.

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9. What have been the historical challenges for your own organisation in supporting clients to access breast cancer screening services in North Central London, North West London, and North East London?

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10. In your opinion, how do other stakeholders who work with your clients perceive the value of the LD/Language project?

○ Extremely valuable
○ Very valuable
○ Somewhat valuable
○ Not so valuable
○ Not at all valuable

10/1. Please, explain why

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11. How would you like to see the Breast Cancer Screening service further developed over the next two years?

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12. In your opinion, what action should the Cancer Alliances for North Central London, North West London, and North East London take to better address health inequalities amongst your client group?

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Collaborate survey

Collaborate Survey for the Breast Cancer Screening service evaluation

Introduction

We are asking you to take part in this evaluation because we are trying to learn more about your recent breast cancer screening appointment. If you agree to take part in this evaluation, we will ask you to complete this short survey by answering three questions that will take 5 minutes. If you don't want to take part in this evaluation, that is fine. Being in this evaluation is up to you, and no one will be upset if you don’t want to participate.

Data governance

No one outside of the research team will know what you have said in the survey and we will not share your details with anyone, unless you are at risk of harm. We will have to inform the responsible person at the University and to get you help if we felt you were at risk of harm. The information you provide on this survey will remain strictly confidential, in accordance with the Data Protection Act 1998 and GDPR 2018. Further information about your rights with respect to your personal data is available here.

Contact

You can ask any questions that you have about this evaluation. If you have a question, you can contact **Prof. Darren Sharpe (D.Sharpe@uel.ac.uk).**

1. I give my consent to participate in this survey.

○ Yes
○ No

2. How much effort was made to help you understand your health issues?

○ No effort was made
○ A little effort was made
○ Some effort was made
○ A lot of effort was made
○ Every effort was made

3. How much effort was made to listen to the things that matter most to you about your health issues?

○ No effort was made
○ A little effort was made
○ Some effort was made
○ A lot of effort was made
○ Every effort was made

4. How much effort was made to include what matters most to you in choosing what to do next?

☐ No effort was made
☐ A little effort was made
☐ Some effort was made
☐ A lot of effort was made
☐ Every effort was made

5. What would help you to attend your next breast cancer screening appointment?

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