

LGBTQ+ South East London (SEL) Breast Screening Research Project



Summary

It is well documented¹ that LGBTQ+ people have negative experiences in engaging with the NHS in the UK². This research project was undertaken to examine the experiences of those who are LGBTQ+ in breast cancer screening³ in South East London. We consider the client⁴ journey, examining population statistics, general community health, screening invitations, screening attendance, and risk factors around breast cancer, and analyse qualitative evidence collected in a survey of residents (the South-East London boroughs of Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark). This report provides clear recommendations for the South-East London Breast Screening Service (SELBSS) and to wider urban areas; particularly those that have a higher LGBTQ+ population than the England average, such as the Greater London area, Brighton and Manchester (ONS, 2021).

Introduction

Within London, it was estimated that over 10% of the population identifies as lesbian, gay, bisexual, transgender and/or queer (LGBTQ+) (De Montfort University, 2007), and recent census data shows that a minimum of 1.5 million people in the UK identify as Lesbian, Gay or Bisexual (ONS, 2021). Recent census data puts this population as:

“The English region with the highest proportion of people who identified with a LGB+ orientation (“gay or lesbian”, “bisexual”, or “other sexual orientation”) was London (4.3%). In London, 2.2% described their sexual orientation as gay or lesbian, 1.5% described their sexual orientation as bisexual, and 0.5% wrote in a different orientation”

Different research, Office of National Statistics (ONS), and sector standard acronyms are used, and thus variability is inevitable. The census also showed that approximately 1% of the population in England and Wales identifies as transgender. Within Scotland, 4% of the population identified as lesbian, gay or bisexual with 0.44% of the overall population identifying as trans, going up to 0.91% in Dundee which is noted as having a bigger population of students and young people (Scotland’s Census, 2024). As a geographic area, South-East London has a notably higher proportion of the LGBT+ population than the London average, particularly in the boroughs of Lambeth, Southwark, and Lewisham. Thus, it is important to document community lived experiences in this area and ensure these needs are met.

Breast screening is population screening commissioned by the NHS to detect early signs of breast cancer in cisgender women, transgender and non-binary people with sufficient breast tissue who are between 50 and 70 (NHS, 2024). Those who are registered female at their GP are automatically invited for breast screening, however, those with a male patient record are not. This creates a situation whereby a patient eligible for screening is not routinely invited to the programme due to the gender marker on their NHS record. This issue is also seen in cervical screening where we see multiple compensatory measures in place⁵. However, these measures are not present in the Breast Screening Programme (BSP). This may be as cervical screening is managed by GPs, who have autonomy around the invitation process (NHS England, 2023).

¹ <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/lgbt-health/>

² European Human Rights recommendation refer to this community as being LGBTIQ+. Please note however, that much of the current research will use the term LGBTQ+, and in relation to breast screening, mostly this research will use the acronym LGBTQ+

³ We acknowledge that many trans and non-binary people will refer to this as chest screening, which may be less dysphoric

⁴ Within breast screening, those who attend are often referred to as clients vs. patients, given that the service is part of population screening, for ‘well’ people

⁵ [Cervical screening for lesbian and bisexual women](https://www.gov.uk/government/publications/cervical-screening-for-lesbian-and-bisexual-women) - GOV.UK <https://www.gov.uk/government/publications/cervical-screening-for-lesbian-and-bisexual-women>

The UK has seen an increase in hate crimes year-on-year for the LGBTQ+ community, particularly set in the context of trans healthcare for young people being heavily debated (Stonewall, 2023). It is against the Equality Act 2010 to discriminate against people based on their sexual orientation or gender identity (Legislation, 2010). This places the expectation of affirming person-centred care for the UK's LGBTQ+ people on the NHS. The NHS has gone on to acknowledge this duty in forming its key targets such as the early diagnostic goal of Core20PLUS5 that explicitly references groups protected by the Equality Act.

Qualitative research was conducted in conjunction with the South-East London Cancer Alliance (SELCA), OUTpatients¹ (the UK's only LGBTIQ+² cancer charity), and Lambeth Links³, a community forum, in the summer of 2024. Although there is some research in this area globally, there are few recent studies on breast screening experiences within the LGBTQ+ community in London. This research hopes to fill the gap and elaborate on how we can reduce health inequalities within this population.

OUTpatients and the North East London Cancer Alliance ran an awareness-raising campaign for the LGBTIQ+ community called 'Best for My Chest', aiming to increase understanding of and facilitate improved attendance of breast screening in 2022⁴. This campaign inspired this research in South-East London, and we are forever appreciative to those in the LGBTQ+ community who work with healthcare services to increase awareness amongst their communities. We would like to give a special mention to the Maidstone and Tunbridge Wells NHS Trust radiography team who are the only service to date running a transgender-specific pathway for routine breast screening (Harper & Marsh, 2022).

Data issues

It is important to note that there may be data collection issues around accessing information on LGBTQ+ people in the UK. The ONS census (2021) finds that 3.5 million people (7.5% of participants) did not answer questions on their sexual orientation. As it stands, most electronic patient records will not include sexuality or trans status on a patient's profile and thus would not be shared with breast screening systems, which are standalone (Williams et al, 2013). Current evidence shows that around 19% of LGBT+ patients are not comfortable to disclosing their sexuality or gender identity in their medical records (LGBT Foundation, 2023).

OUTpatients (2024) advocate for preparing the NHS workforce for a higher percentage of LGBTQ+ patients in the future owing to the increased disclosure rates in each generation, whilst also asking people to consider those who may be LGBTQ+ but do not "feel safe to disclose who they are, even in surveys" (OUTpatients, 2024, p. 7). This may be particularly prevalent in older and minoritised ethnic groups. Thus, it is likely that the LGBTQ+ population rate is even higher than current data suggests. Concerning older people, there is evidence that historic illegality and stigma around being LGBTQ+ means that many will not disclose this to health professionals (Bailey et al., 2022); homosexuality (men having sex with men) was only decriminalised in 1967, which is well within the lifetime of many people. However, such history and current attitudes towards those in the community, may particularly impact those who are of screening age. This stigma sits alongside a plethora of health issues across the life course that may affect LGBTQ+ people in a negative way (LGBT Foundation, 2023).

In addition, there is a lack of evidence among non-binary individuals in primary care, particularly given that currently those who are non-binary cannot be legally recognised as such (House of Commons, 2022). Further, there is little research evidence of the experiences of non-binary people who use breast screening services.

¹ <https://outpatients.org.uk/>

² OUTpatients use the acronym to LGBTIQ+ to include those who are intersex. This research did not explicitly ask around those who are intersex, nor does much of the breast screening research cover this population group.

³ <https://www.lambethlinks.org.uk/>

⁴ <https://www.nelcanceralliance.nhs.uk/news/unique-lgbtiq-breast-screening-campaign-launches>

Why South-East London?

King's College Hospital NHS Foundation Trust is based in Camberwell. The Trust has sites including King's College Hospital, Princess Royal University Hospital (PRUH) and other sites across south-east London. The Trust cares for patients in the boroughs of Bexley, Bromley, Greenwich, Lambeth, Lewisham, and Southwark. Lambeth has the second-highest LGBT+ population in London falling just behind the City of London (Southwark Council, 2023).

Within Lewisham, 6.13% of the population identify as lesbian, gay and bisexual (LGB+). For Lambeth, this rises to 8.25% and 8.07% for Southwark respectively. For these three boroughs, this was higher than the London average of 4.27%. Regarding gender identity, Lewisham had 1.02% of their population report a gender identity that was different from their sex registered at birth (i.e. trans, non-binary, or gender diverse people). For Lambeth this was 0.93% and for Southwark it was 1.27% (Lewisham Council, 2023). The Burgess Park area of Southwark had the highest prevalence of trans or non-binary people in the UK (8.3%) (Southwark Council, 2023). Although most data, as noted above, may underestimate LGBTQ+ identities, the ONS has stated this data is under review owing to *possible* misinterpretations over the question in the survey around gender identity (OSR, 2024). Based on local data accessed from ONS¹ is estimated that in the SEL boroughs, there are 796 trans women over 50, with 724 trans women aged 35-49 (and thus may come in to contact with breast screening services soon). For trans men, there are 784 trans men over 50, with 600 trans men aged 35-49. Even considering possible top surgery² rates and area average breast screening uptake, there is still a sizeable population who would not be invited to routine screening currently.

Evidence for access to healthcare for LGBTQ+ people in general

Across healthcare, there is evidence of worsening access to adequate healthcare for LGBTIQ+ people (LGBT Foundation, 2023), as well as the wider population (Dunn et al, 2023). Beyond this LGBTIQ+ people experience discrimination when accessing healthcare. Discrimination can mean that healthcare issues or inequalities are further exacerbated when individuals feel discouraged from accessing healthcare services; these experiences can become cumulative and worsen minority stress (Alencar Albuquerque et al, 2016). This is unfortunately worse for those who are from ethnic minorities (Race Equality Foundation, 2016).

Such discrimination can impact the knowledge that trans and gender-diverse people have of services or their rights regarding healthcare access (Brown et al., 2023). Furthermore, other recent research has suggested that 70% of trans people have experienced transphobia in medical settings and 14% were refused medical help (Brown et al., 2023); it is worth noting that many studies are based on the USA population. From a UK perspective a TransActual survey in 2021 found that 57% of trans people may avoid attending their GP even if they are unwell.

Ultimately, we need to focus on each patient's needs, paying attention to inequalities in wider society and within healthcare: a recent House of Commons enquiry found that "whether in mental health, cancer care or social care, the need for a "person-centred" approach was highlighted again and again" (House of Commons, 2019, p. 26).

¹ <https://www.ons.gov.uk/datasets/RM035/editions/2021/versions/3>

² <https://cavuhb.nhs.wales/files/specialised-medicine/welsh-gender-service/v6-top-surgery-leaflet-002-pdf/>

Evidence for screening access/experience for LGBTQ+ people

Beyond inequalities in healthcare access there is wider evidence within screening regarding inequities in access and experiences amongst LGBTQ+ people. There are issues in accessing screening information, invitations, and subsequent attendance. Although NHS screening information for trans people exists¹, this information² is not routinely sent out by breast screening systems, and those who are registered male are excluded. Without the correct information the patient's ability to make an informed decision or report any points of concern is limited, which may go against IR(ME)R guidelines for approved radiation exposure in breast screening (NHS England, 2017).

Regarding invitations, only those registered as female will be invited for breast screening: "gender specific screening can present particular challenges for trans individuals, and non-gendered individuals, where screening risk may be linked to their birth gender rather than the gender they identify with" (Williams et al., 2013). More research has been done around those who cannot be invited to cervical screening based on their marker not being female, "it is the design of the NHS system that is excluding people rather than any individual. Systemic institutional issues such as these are inherently discriminatory and may be the cause of unintended poorer health outcomes" (House of Commons, 2019, p. 11). Access issues such as these may be impacting lower engagement with screening: research found that within cervical screening, of those who are trans, and non-binary people assigned female at birth (AFAB), 65% of them had delayed cervical screening and 13% had never received an invitation (Berner et al., 2021). Issues such as this may be alleviated by the new self-sampling that may come into effect within the UK³. Similar barriers are not necessarily seen around bowel screening.

In LGB+ women "there is little evidence that information providers are being proactive in reassuring lesbian and bisexual women that information and services include them" (Breast Cancer Care, p. 8). Other research highlights that one of the main barriers to LGBTQ+ people accessing screening, like some other population groups, is a lack of information about screening eligibility (Haviland et al., 2020).

An earlier New York-based study found that lesbian women were four times less likely to attend their mammograms than their heterosexual counterparts (Kerker et al., 2006). Community surveys in a recent East Sussex Joint Strategic Needs Assessment showed "that whilst 90% of working age LGBTQ+ people reported they would be likely/very likely to take up screening if invited, this decreased to 53%" in those who are trans and/or non-binary (East Sussex, 2021, p.22). In another American study 70.8% of trans and non-binary participants reported at least one negative imaging encounter and around a third had to direct professionals to "receive appropriate care" (Grimstad et al., 2020). All this research points to the fact that LGBTQ+ people have poorer access to information, are less likely to be invited and are subsequently or independently less likely to attend all types of cancer screening.

There is limited documentation of experiences within breast screening; hence the need for this research. However, internal King's College Hospital NHS Foundation Trust guidance on supporting trans and non-binary patients highlights that "the screening process itself can be particularly stressful, as it can trigger profound dysphoria and distress. It can sometimes be more painful due to physiological changes or hormone therapy" (King's College Hospital NHS Foundation Trust, 2024, p. 7).

¹ See trans screening information here: <https://www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people/nhs-population-screening-information-for-trans-people>

² See information typically shared here: <https://www.gov.uk/government/publications/breast-screening-helping-women-decide/nhs-breast-screening-helping-you-decide>

³ <https://sph.umich.edu/news/2024posts/hpv-self-sampling-key-for-cancer-screening-in-transgender-patients.html>

Risk factors for LGBTQ+ people in relation to breast cancer

Screening is designed to pick up cases of cancer before the person displays symptoms. This is done to diagnose cancer earlier so that treatment can be more effective and less invasive. Populations will have a general risk of cancer, but certain risk factors can increase individual risk. It is important to note that LGBTQ+ communities have the potential to exhibit higher amounts of risk factor behaviours for breast cancer (East Sussex, 2021), although it is noted that there is limited research amongst bisexual women.

Among lesbian women “adopting lifestyle behaviours that increase the risk of developing breast cancer, such as consuming alcohol, obesity and a reduced likelihood of having children and breastfeeding” can contribute to elevated breast cancer risk (Breast Cancer Care, p. 2). LGB+ adults have lower average mental health scores, are 4% more likely to report having a limiting longstanding illness, 8% more likely to drink, 9% more likely to smoke, and are 10% more likely to be neurodivergent (NHS, 2021). More specifically, when trans populations are compared to cisgender people, transmasculine people have a higher prevalence of obesity (27.5%), HIV (0.5%), and transfeminine people were more likely to be current smokers (33.7%) and have a 0.8% higher prevalence of HIV (Brown et al., 2023). Gender-affirming hormone therapy that trans women take can also increase their risk of breast cancer (de Blok et al, 2019). The UN (2024) highlights that LGBTQ+ people have higher rates of breast and cervical cancer.

Research methods

Initially, King's College Hospital NHS Foundation Trust, OUTpatients and Lambeth Links met to discuss current issues in screening inequalities for LGBTQ+ people. The original recruitment plans were to host in-person focus groups at a suitable community venue, with remuneration for people's time being offered. The focus groups were advertised as for those who are aged 45+, living in South-East London and preferably eligible for breast screening.

Initial Eventbrite sign-ups were unfortunately targeted by bots that had been impacting one of our partner's signups for other research for the community. For this first in-person focus group we had no participants. After this, we decided to pivot to an online survey and one-to-one interviews online. Only one person was interviewed one-to-one. They were offered but declined financial remuneration.

The research study consisted of the offer of one-to-one interviews and online surveys hosted by King's Patient Experience Team. This survey was scheduled to run for approximately six weeks but was extended by another six weeks to allow for more people to finish the survey. King's College Hospital NHS Foundation Trust, South-East London Cancer Alliance (SELCA) and OUTpatients shared the recruitment information online through social media. We also carried out in-person leaflet drops to key LGBTQ+ community sites in the area, such as The Feminist Library in Peckham, Tonic Housing in Lambeth, the LGBTQ+ community centre in Peckham and the Common Press bookshop in Shoreditch. A special mention goes to our lovely colleague Lindsay Batty-Smith who also utilised her personal networks to share the research.

The analysis of the results was conducted over three weeks at the end of August 2024 and early September 2024. We took an inductive approach to the analysis, allowing for direct recommendations to come from the community's words directly.

Results

The online survey consisted of 24 questions (see in the appendices) that centred around whether individuals had attended a screening, their experiences, reported sources of information regarding screening, feelings about breast screening settings, campaigns and recommendations for improving future experiences in breast screening.

Of the 21 community members who took part in the research, 20 participated through an online survey and one attended an online one-to-one interview. Including the interview, there were only 11 full responses to the survey, which impacted the data collection. The aim was to reach 50 community members interviewing five to six one-on-ones. Although we did not reach our target, rich data was still captured, as well as important community-sourced recommendations. Below is a short summary of demographic data that was captured.

Demographics	Results
Age	Range between 37 – 66, most common ages were 55 and 66
Gender identity	8 identified as women, 1 person identified as a trans woman and 1 person as non-binary
Sexuality	6 people identified as a lesbian/gay woman, two people as bi/bisexual, and one person as straight/heterosexual
Ethnicity	6 identified as White English/British, with 2 as White Other
Religion	1 person identified as Christian, 7 as having no religion
Disability	2 people identified as having a learning/intellectual disability, 1 person with a longer-term health condition

The main themes that arose from the research were:

1. Positive experiences of screening
2. Negative experiences of screening
3. Mixed screening awareness
4. Adapted terminology
5. More NHS information/campaigns
6. Barriers to screening attendance

Positive experiences of screening were noted alongside those that were negative. When rating experiences on a scale of 1-10, 1 indicating a negative experience and 10 indicating a positive experience, results were mixed: Four were between three and five, and five between eight and 10. Positive screening experiences focussed around finding value in screening *“I’m benefiting because I’m finding out whether I’m healthy or not”*. Another participant noted that they have a family history of cancer and hence found having access to screening relieving. Further, the *“efficiency”* of the breast screening process was noted by three separate participants.

Unfortunately, several participants noted that they had negative experiences with breast screening. These mainly focussed on the general setting of screening, the uncomfortable nature of the screening itself, and perceived negative experiences. Concerning the setting, the most noted epithet was *“it’s very pink”* and *“girly”*. Participants also mentioned that the screening service was hard to find and noted the general anxiety-inducing nature of healthcare appointments. The perceived negative experiences were notable, and involved a lesbian woman stating:

"Yes, I'm a butch cis woman who is sometimes read as trans or as a cis man, and I don't shave my armpits - I haven't been invited to breast screening yet but I'm expecting that if I go then I'm likely to get awkward looks from staff".

Another person noted *"I'm not sure about going, I don't think it will be a very positive experience"*.

Screening awareness was less polarised than experiences: knowledge of screening was rated 1-9 out of 10, with the largest concentration between six and seven. Knowledge mostly came from national screening invites, followed by friends and online equally. One participant did note regarding their low awareness *"it doesn't seem like there is any proper content on this for my community"*.

This also linked to comments around the need for adapted terminology around screening, with some noting that there was a *"lack of inclusive language"*. Another participant noted:

"The language needs to be kept simple so if inclusive language is to be used it must lead with women. I would not support the introduction of entirely gender-neutral language".

Regarding the questions we had about current NHS and health campaigns, the participants indicated a lack of appropriate content (lack of posters was mentioned several times). Special mention was made to the 'Best for My Chest' campaign. One participant mentioned that although there was existence of relatable campaigns, these needed to be continual: *"there's always a new cohort of new people who need to know so important to refresh the messages regularly"*. When asked what could be done to reduce the barriers to screening access, participants cited more outreach and developed primary care support. Outreach involved suggestions of community champions in well-known settings such as queer pubs, with a t-shirt that says, 'ask me about screening' and a QR code. Primary care could allocate more *"support (money and staff) to general practice to follow up"*. Although King's College Hospital NHS Foundation Trust was referenced twice as regularly promoting LGBTQ+ awareness and inclusion, it was noted that breast screening content is *"for cis people"*.

Much of the data collected in other themes could be classed as factors that contribute to forgoing screening. However, participants also noted some systematic barriers to attendance that did not fit into the other themes. They cited common wider barriers to screening that many communities experience: appointment waiting times, not receiving invitations or not knowing when automatic invitations end and *"trust issues with hospitals, embarrassment, cultural awareness"*. Some participants noted that although the LGBTQ+ community may experience some level of barriers to attendance, there was concern for those *"in poverty and in communities that don't really engage with health services"*.

More concerningly, there were, in similar themes to the negative experiences, concern within the NHS, and likely toward breast screening given the theme of the survey that (screening was) *"very female gendered"* and staff have *"ignorance about LGBTQ+ lives"*. These experiences led one participant to state *"we can't be screened properly"*.

Discussion

There is little known about the experiences of LGBTQ+ people within NHS breast screening services in the UK; it is likely that this research is one of the first, at least, in London. It is clear that inequalities exist in general healthcare experiences, screening access, as well as increased risk factors for breast cancer. This research highlights that some LGBTQ+ people may have negative experiences of breast screening which they attribute to their identity and the attitudes of staff in clinics. Discussions of screening awareness shows that the LGBTQ+ community find content inadequate, that there is a lack of inclusive language, and they have experienced little

outreach from services. Trans and non-binary people reported that they were concerned that they cannot be screened '*properly*'.

Our research highlights a range of sentiments both positive and negative. In comparison to Stonewall's research (2023) that found high rates of transphobia in healthcare settings, this is not explicitly noted in our investigation into SEL breast screening experiences. Although some screening experiences were more negative than others, most people mentioned the South-East London Breast Screening Programme (SELBSP) was efficient, and people were aware of the benefits of screening: earlier diagnosis and detection of breast cancer. The fact that there were perceptions of a possible negative experience was noted by one person who had attended breast screening and one who had not. This points to Alencar Albuquerque et al.'s research (2016) that previous negative healthcare experiences can become cumulative. Interestingly, one participant touched on the links between being a "*butch*" lesbian and being seen as a trans person – in their reflection they noted that inclusivity benefits those who may not necessarily class themselves as gender diverse by avoiding unhelpful stereotypes that could lead to screening participants being misgendered. Further, there are some general screening barriers being reiterated here, such as location, screening information, travel difficulties. Solidarity was also expressed by participants with other groups in the SEL community who also may experience health inequality.

Pointing to other research about inclusion, breast screening services would benefit from staff receiving training on appropriately addressing clients and using inclusive language for patients. King's College Hospital NHS Foundation Trust guidance (2024) highlights the dysphoria that some clients may experience in health events such as screening – evidenced by one trans participant in this research who commented "*it is for cis people*". Beyond this, utilising outreach could help combat these perceived negative experiences, whilst also highlighting that staff have been trained by OUTpatients, a notable charity doing incredible work both in the community, with professionals and globally. This could also build on the positive impression that the community has of King's College Hospital NHS Foundation Trust being LGBTQ+ friendly. Ultimately, we want those from the LGBTQ+ community to feel safe and reassured enough to attend their screening.

The community also recommended better resources and outreach amongst the LGBTQ+ community. The 'Best for my Chest' campaign was referenced – which was designed with the LGBTQ+ community. Services would do well to re-promote this campaign and continue to highlight inclusive screening information. OUTpatients have shared data regarding this campaign with this report. The campaign had a very significant reach, with 800,000 impressions and 75,000 engagements. This shows that appropriate content does reach the community and that such partnerships should not be a one-off. Although there was some differentiation in perspectives on inclusive language, the consensus seemed to be that language could at the least be gender additive/inclusive.

Those involved in the research pointed to national screening invites as their main source of information – if efficient markers were used on National Breast Screening System/GP systems to identify trans and non-binary patients, this could mean they would a) be invited to screening correctly b) receive more appropriate screening information regarding their gender identity and c) receive adequate radiation information. Training aimed at GPs from trusted programmes or charities like OUTpatients or Pride in Practice can support patients and staff to access screening and combat the perception of negative healthcare experiences all around.

Ultimately, there are some serious barriers to attendance in screening. Some of those around appointment times, health anxiety, travel difficulties etc., are unfortunately common barriers that are noted in breast screening, for a range of communities (GOV.UK, 2024). The dominance of 'pinkness' and the running thread through themes that language is not inclusive, people weren't asked their pronouns etc. highlights that inclusivity training and waiting room adaptations to include trans visibility are imperative (NIHR, 2023). This is what the Maidstone staff also noted

in their health equity audit (Harper & Marsh, 2022). Fundamentally, the NHS Breast Screening Services in all services across the UK need to have a clear pathway so that people can access screening if they want to. Despite this population being a minority, there is a breadth of guidance around ensuring personalised care, rather than a one-size-fits-all approach.

Limitations

We called this research ‘breast screening experiences’ to make it clear what kind of cancer this is referring to, but we acknowledge that many trans and non-binary people will refer to this as chest screening, which may be less dysphoric. One person in the research noted this: *“You call it breast screening...what do you think is wrong with that?”*.

Our research, in terms of documented ethnicities, only involved white people. This is a significant limitation in South-East London, which has some of the largest black communities in London. There was not much evidence that the research was shared in Lewisham, which is one of the areas with a significant LGBTQ+ population. We did not ask which boroughs the participants were living in, which may have helped to explore inequalities at the borough level, as well as during the research to see where the promotion of the research had been more successful.

Further, we had originally partnered with Lambeth Links to share the research wider, although capacity issues meant that most of the promotion was down to the health promotion specialist in the breast screening service. Beyond this, we did not have similar comparable service data for those who are not LGBTQ+ people, although we can observe in the literature that attendance rates, access to and knowledge of screening are lower in the LGBTQ+ population overall.

Unfortunately, no trans men took part. This greatly limits the generalisability of the research (Hill & Bulley, 2023) and unfortunately means that we did not reach the community who are most excluded from screening; which is possibly evidence in and of itself that these communities are hard to reach within the NHS. Further, we also did not reach as many participants as we had hoped.

Finally, some of the answers appeared to be falsified responses motivated by anti-LGBTQ+ sentiment. One example of this included a respondent answering the question “Has anything ever deterred you from attending screening” with: *“that a man in drag might be doing the examination”*.

Future research

Future research could expand to a national LGBTQ+ experiences survey in all screening programmes. Although South-East London is the second most LGBTQ+ populated area in the UK geographically after Brighton, it would be interesting to see how regional attitudes or other intersecting inequalities impact the experiences of screening.

In lieu of this, expanding this research across London to support changes would be useful, to provide more context to this research. It would also be great to engage with more trans men and people from Global Majority communities.

Further, not much research focuses on those who are bisexual, and those who are non-binary, who may experience attending gendered screening further dysphoric.

Actions already taken

- Staff training for radiography and administrative staff in screening
- Working with OUTpatients to organise a local screening outreach event in partnership with other relevant services
- Receiving guidance from Maidstone service to initiate pathway exploration
- Promoting research at community of practice event, and at conferences such as the OUTpatients conference

Professional recommendations and wider possibilities

Locally we are exploring pathway options for trans and non-binary patients with a male GP marker who are eligible for routine breast screening, so that we can screen those who are currently missed out. The NHS national team are also conducting a review into these inequalities. Following this research, we recommend a nationwide LGBTQ+ experiences survey in breast screening. SEL is one of the most LGBTQ+ populated geographic screening areas after Brighton – it would be interesting to see how regional attitudes or other inequalities impact screening experiences beyond these hubs. At the national level we would recommend all cancer screening programmes to consider and address health inequalities that impact LGBTQ+ people. We recommend that LGBTQ+ inclusive screening programmes are made a priority across the NHS.

Although we have had staff training for radiography staff, it would also be beneficial for all local units beyond just breast screening, extending to breast care and surgery (87% of nurses reported that “they felt unprepared to deliver care” to those who are LGBTQ+ (LGBT Foundation, 2023, p. 60). Across the NHS, better recording of equity data such as sexuality and religion would support further engagement with communities not engaging with screening; this could also help tackle inequalities across intersecting identities (Breast Cancer Now, 2024).

OUTpatients and other professionals in the cancer field advocate for the construction of different markers used across NHS care: one for people’s biological sex and one for gender. We have outlined key changes for breast screening services to consider, although the evidence discussed here shows health inequalities in settings such as primary care – offers such as Pride in Practice¹ (an LGBTQ+ inclusion training programme) should be utilised. At the King’s College Hospital level, we will continue to liaise with the Kings and Queens Network to enact recommendations and promote our research. Further, as recommended by the research we will recommend and practice targeted and continual health promotion outreach within the community.

Credits

- **Francesca Fiennes (She/Her)**, Health Promotion Specialist, King’s College Hospital
- **Stewart O’Callaghan (They/Them)**, Founder and CEO of OUTpatients
- **Alice-Amanda Hinton (She/They)**, Midwife, Kings College Hospital MAU, PI Legacies+Futures Project; Co-Chair LGBTQ+ Network; Kings & Queens
- **Meaghan Hackett (She/Her)**, Equality, Diversity & Inclusion Lead, King’s & Queens Co-Chair, Kings College Hospital
- **Flora Cohen (They/Them)**, Lead Nurse at Bridge at Southwark and Clinical Nurse Specialist at UK Cancer and Transition Service
- Maidstone Radiography Team
- **Tracey Blancke (She/Her)**, Programme Manager SELBSP
- **Samantha Lewis (She/Her)**, Early Diagnosis Programme Manager SELCA
- **Stephanie Ferguswood (She/Her)**, Patient Experience Lead at King’s College Hospital

¹ <https://lgbt.foundation/pride-in-practice-for-healthcare-professionals/>

Appendix

Survey recruitment poster:

**BREAST CANCER
SCREENING
AND YOU**

Are you LGBT+, over 45, live in
South East London, and eligible for
breast cancer screening?

Join our research and be heard!

We are hosting a survey and 1:1 online interviews
around breast cancer screening experiences.

This research will be running until the end of June.

Scan the QR code for more information

A collaboration between:

NHS
South East London
Cancer Alliance

OUTPATIENTS
Supporting LGBT+ Women's Cancer Care

Survey questions

1. Have you ever been invited for breast screening (mammogram/breast Xray) appointment? (Yes/occasionally yes/Once/No/Not sure)
2. Have you ever attended a breast screening appointment? (Yes/occasionally yes/Once/No/Not sure) (if no, please specify why)
3. What do you think about attending breast screening? Do you feel positive about it? What is your experience of being screened? How did you feel about venue/waiting room/staff at your appointment? (Poor, Fair, Good, Very Good, Excellent), (Please specify with a longer comment)
4. If you have attended before, but haven't attended in the last 3 years, what were the reasons? (e.g. Not seeing the point of screening, being worried what will happen in the appointment, body discomfort or dysphoria, fear) (please specify with a longer comment)
5. How would you rate your knowledge about breast screening (e.g. what happens in an appointment, why is screening important, who should have it)? (Poor, Fair, Good, Very Good, Excellent), (please specify with a longer comment)
6. Where would you go to access information about breast screening? Options: national screening invite, GP, other health professional, friends, family, wider community, or Other option please specify
7. What do you think about breast screening information and campaigns? (please specify with a longer comment)
8. Can you think about any other health or general campaigns that support you as an LGBTIQ+ person? (please specify with a longer comment)
9. If you are trans, non-binary, intersex or gender diverse, how do you feel about the way breast screening is discussed with you by health professionals? What is discussed? (please specify with a longer comment)
10. Has a healthcare professional ever discussed breast screening with you? If so, how was this experience? (please specify with a longer comment)
11. What measures could screening services take to make breast screening better for you? What could be done to increase breast screening uptake? (please specify with a longer comment)

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