



# Barriers to Accessing Breast and Cervical Cancer Screening

April 2025

**healthwatch**  
Enfield

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## Acknowledgements

We would like to express our deepest gratitude to Dalmar, One-to-One Enfield, Sisters in Mind, Sasha Pillai at Enfield Community Gynaecology and our many community partners for their invaluable support in this project. We are also immensely grateful to the individuals and communities who generously shared their experiences, enriching our findings and enabling us to work towards improving services.

We extend our heartfelt thanks to all the volunteers and staff of Healthwatch Enfield for their dedication and hard work.

## About Us

Healthwatch Enfield serves as an independent champion for local people who use health and social care services; we lend our ears to the Enfield community and represent their voice. We team up with multiple community organisations and statutory institutions to share information and gather insights in the aim to help improve the quality of health and social care services in the borough.

We share information and advice with residents to ensure they get the support they need, acting as a health and social care champion.

We gather feedback through projects, experiences shared by residents and community groups and social listening to share with public health and social care leaders and local decision-makers to help guide local policies and strategies.

Healthwatch is for everyone that uses all health and social care services, ranging from GPs to care homes, hospitals to pharmacies

# Introduction

Cancer screening has proven to be effective in the prevention and detection of cancer at its earliest stages, saving countless lives. The NHS breast and cervical cancer screening programmes are essential to safeguard women's health.

However, since 2020 there has been a significant decline in the level of screening coverage nationally. This is especially relevant to Enfield residents as the North Central London (Haringey, Camden, Barnet, Enfield & Islington) area currently has the second lowest levels of screening coverage for these cancers in England.

- The screening coverage rate for both breast and cervical cancer is lower in Enfield than the England average.
- The NHS currently has an 80% target for both breast and cervical cancer screening coverage. However, figures released this year show only 65.3% of Enfield residents eligible for breast cancer screening are receiving it.
- For cervical screening, the picture is more mixed with a much lower rate of coverage among 25 to 49 year olds than 50 to 64 year olds, 63.3% vs 73.2% respectively.
- The rate of decline in screening coverage is decreasing more rapidly in those aged 25 to 49.

Healthwatch Enfield carried out outreach to investigate and uncover the reasons why women are not attending cancer-screening appointments and shed light on

the good practice that encourages attendance, which is encouraging people to attend screening. We want to know how much Enfield residents know about the adjustments that are already available to them and if these make a difference.

We are also aware that this can be a culturally sensitive issue and so have tried to ensure we reached as wide a cross section of the population as possible.

# Methodology

To gain a greater understanding of the complex experiences and views of Enfield residents regarding breast and cervical cancer screening, a mixed-methods approach was employed. This approach combined quantitative (surveys) and qualitative data (focus groups and surveys) with the qualitative data being key to this project.

## **Data Collection:**

- **Online Survey:** A structured online survey was disseminated through various channels, including social media, email, the Healthwatch Enfield website and during outreach activities in the community. The survey included both closed-ended and open-ended questions to gather demographic information, reasons for attending or not attending cancer screening appointments, and experiences of attending cancer screening appointments.

- **Focus Groups:** Focus group discussions were conducted with small groups of participants to delve deeper into their experiences and perceptions. These discussions provided opportunities for participants to share their stories, discuss their concerns, and explore the underlying reasons for their experiences.

The survey provided a broad overview of the population's experiences, while the focus groups allowed for a more nuanced understanding of individual perspectives and underlying factors.

# How did we conduct the engagement?

- We made visits to leisure centres, libraries, and community organisations, and attended events to encourage survey participation, offering paper formats.
- The survey was actively promoted and shared through various digital channels such as social media, email, newsletters, and other online platforms. We also promoted the survey with 'Love Your Doorstep' which sends out a weekly newsletter promoting Enfield community events.
- We organised face-to-face focus groups to discuss residents' experience of breast and cervical cancer screening with specific community groups and members.
- We actively participated in community events to promote the survey. During these events, we distributed surveys, engaged with community members, and were able to encourage a wider audience to participate. We were also able to ask a wider variety of questions and listen to people's experiences.

## Organisations we reached out to:

One To One Enfield	All People All Places
Dalmar	Enfield Community Diabetes Service
Sisters in Mind (Women's Group)	Tea & Toast (Enfield Council)
ROJ Women Association	Southbury Leisure Centre
Palmers Green Library	Enfield Integrated Learning Disability Service

# Findings of Survey

The survey ran from the 28<sup>th</sup> of January to the 7<sup>th</sup> of March 2025. We collected a total of 149 responses.

Findings are summarised below:

## Cervical Cancer Screening

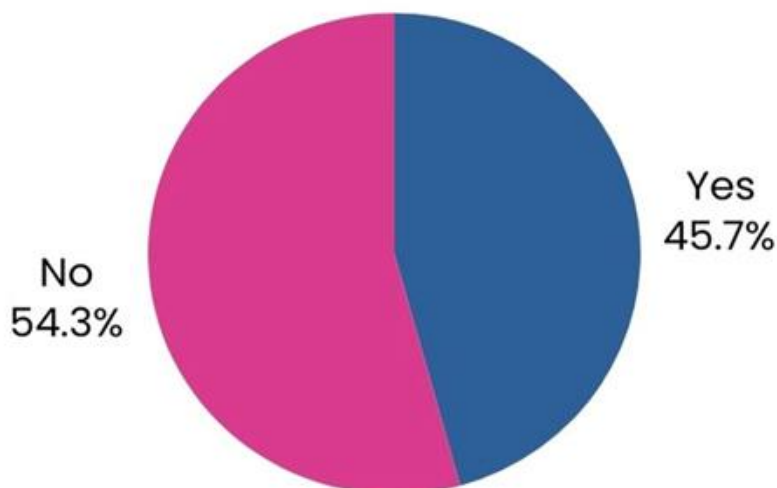
### General Results

- Just over half of the women surveyed (54.31%) were unaware that they could bring a friend, family member, or ask for an NHS chaperone to be in the room with them whilst the procedure was taking place.
- Around half (49%) of women said an at home self-test would make them more likely to participate with some women expressing that they were worried about performing the procedure incorrectly.



Figure 1 – Split of respondents who were and were not aware that they could bring a chaperone.

Were you made aware that you could bring a family member or friend or request an NHS chaperone for support?

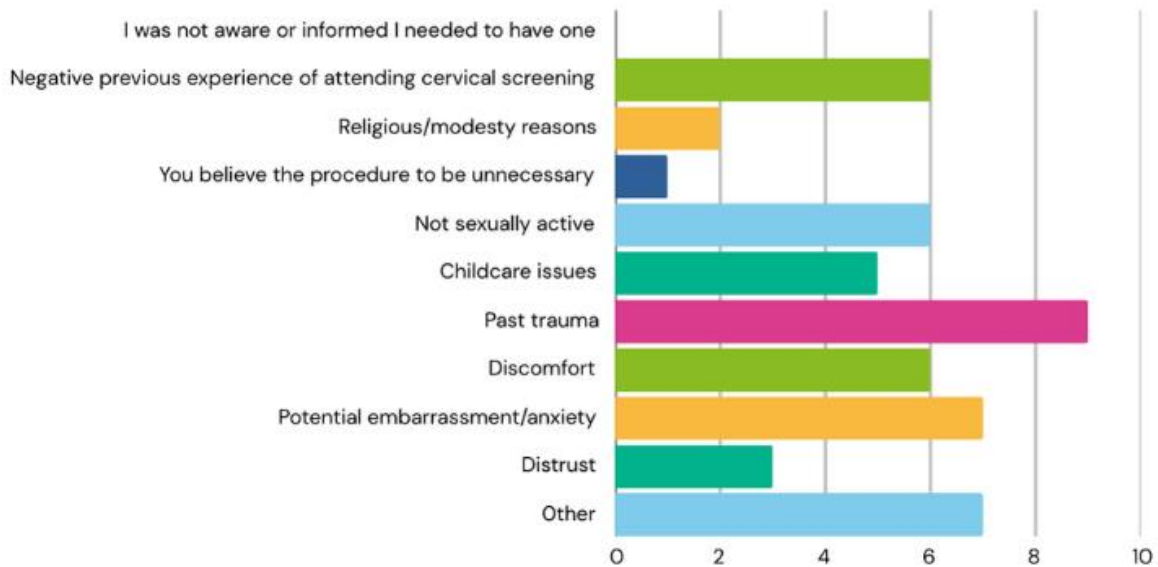


### **Responses from those who have not attended cervical cancer screening in the last 5 years**

- 20% of eligible respondents had not received cervical cancer screening in the past 5 years
- The most common reason given for not attending screening was Past trauma with 39% percent of women who were not going to screening citing this reason. Other common reasons given were potential embarrassment/anxiety, discomfort, negative previous experience of attending cervical screening, and childcare issues. Respondents were also given the option to use the other box to select an unspecified reason and scheduling issues around work came up twice.

Figure 2 – Reasons respondents gave for not getting cervical screening

### If you did not attend, what stopped you from going?



- When asked what would make it easier for them to attend over half (55%) of women indicated home testing suggesting that rolling out home testing may increase uptake of cervical screening. Of the four respondents who selected 'other', 3 cited more convenient appointment times, highlighting the need for out of hours screening appointments.

### If you did not attend, what would make it easier for you to attend?

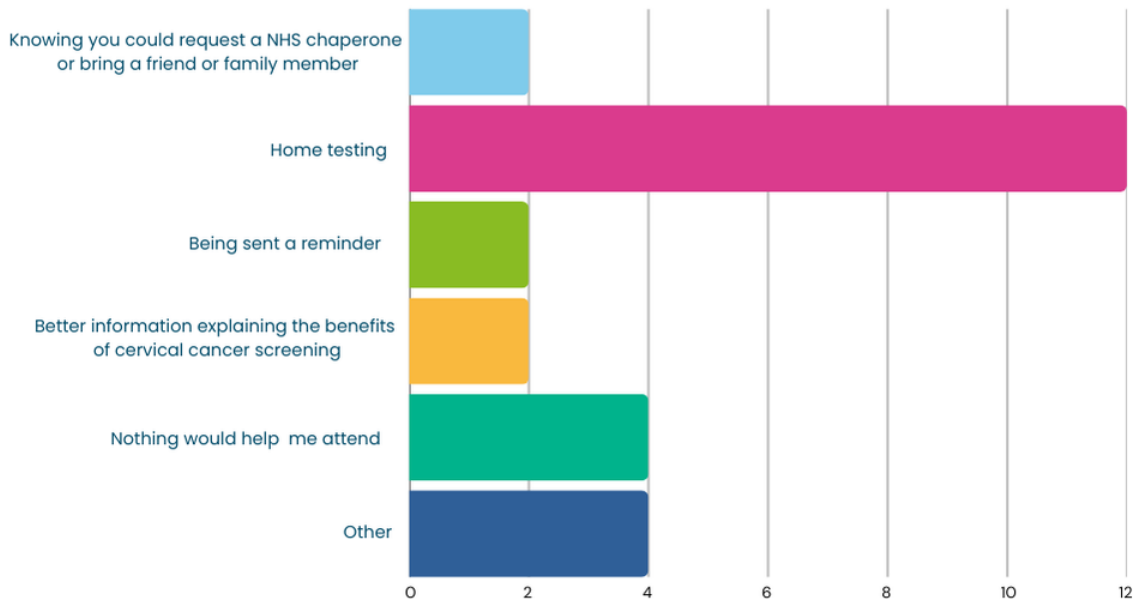


***“The staff being gentle to avoid further trauma”***



Figure 3 – Respondents answer to ‘what would make it easier for you to attend.

## If you did not attend, what would you make it easier to attend?

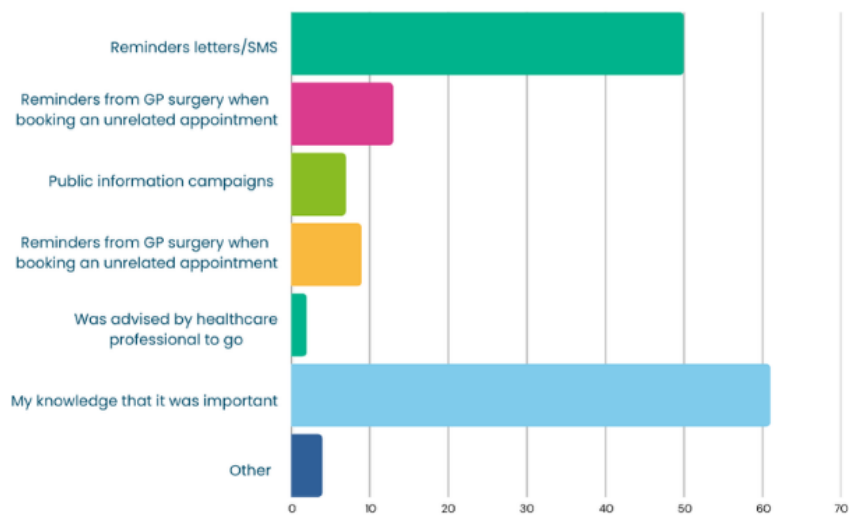


### Responses from those who have attended cervical cancer screening in the last 5 years

- 80% of eligible respondents had attended cervical cancer screening in the past five years.
- Of those who did attend screening 67% stated that it was their own ‘personal knowledge that that procedure was important’ encouraged them to attend. 59% of respondents said that reminder letters/SMS also encouraged them to go to screening.
- Despite personal knowledge of the importance of the procedure being key only 8% said that public health campaigns encouraged them to go suggesting that these are only somewhat effective.

Figure 4 – Respondents reasons they were encouraged to go to cervical cancer screening

### Was there anything that encouraged you to go?



- The vast majority of those who attended screening in the past 5 years said their experience was in the range of positive-neutral. However, the comments did paint a more varied picture with individuals reporting a range of experiences over the years.
- Some respondents expressed that they found it difficult to book appointments which is especially challenging considering that appointments need to be scheduled around menstrual cycles.
- Additionally, there were indications that not all surgeries were offering reasonable adjustments such as a double appointment.
- When respondents did have a good experience the expertise of the nurse was often praised, suggesting that staff competencies are key to a good cervical screening experience

## Patient experiences of cervical screening



*“Depends entirely on the nurse. For years the senior nurse at my surgery really hurt me, took ages, made me bleed. The nurse I’ve had lately has been brilliant and it was over before I felt anything. Technique is everything.”*



*“First ever screening felt traumatising due to staff. However next screening was much better as the healthcare professional was much better with communication and behaviour.”*



*“At the point of booking, I asked for a slightly longer appointment for personal reasons but I was told this wouldn't be possible. This lack of flexibility really puts women off attending. It is a very intimate exam and GP staff should be trained to handle appointments delicately.”*



*“No appoints are ever available the same week, but you can’t book too far ahead. Balancing that with your cycle effectively means that you have to call up on the first couple of days of your period. I have ADHD and remembering to do that is honestly a nightmare.”*



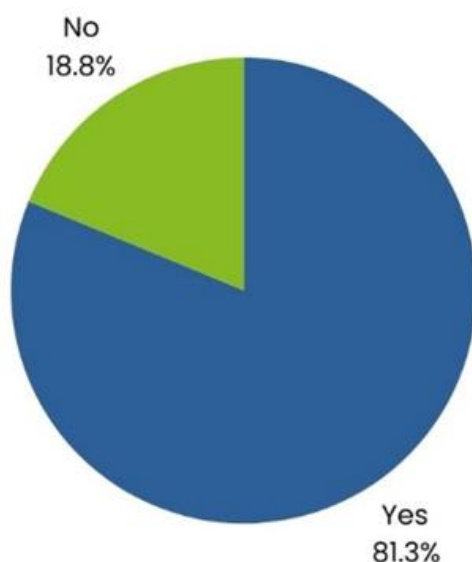
# Breast Cancer Screening

The results for this part of the survey were more varied with less clearly observable trends, suggesting a greater variation in care received.

- Almost 19% of women who believed themselves eligible had not been invited for breast screening with some women commenting that this had not been an issue until 2020 and the Covid-19 pandemic. This observation is consistent with NHS data which shows a sharp decline in coverage in Enfield from 2020 onwards. The latest data shows that coverage is still not back to pre-pandemic levels.

Figure 5 – Pie chart showing the number of people believed themselves to be eligible but were not invited for screening

Have you been invited for a breast screening appointment in the past 5 years?

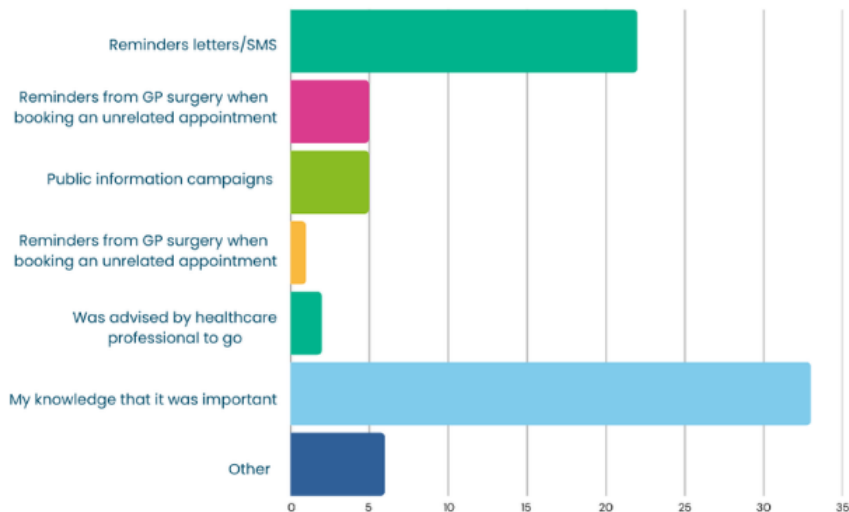


- 80% of those who had been invited attended their appointment.

- Of those who had been invited but did not attend reasons for not doing so were very mixed with 'other' being the most common choice. Three respondents cited issues related to physical disability causing an inability to stand. Two respondents cited travel related issues and another two cited past trauma.
- Of those who did attend 'personal knowledge that the procedure was important' was by far the most common reason people gave for attending screening. Reminders from the GP was also often cited.

Figure 6 – Respondent responses to what encouraged them to attend breast cancer screening

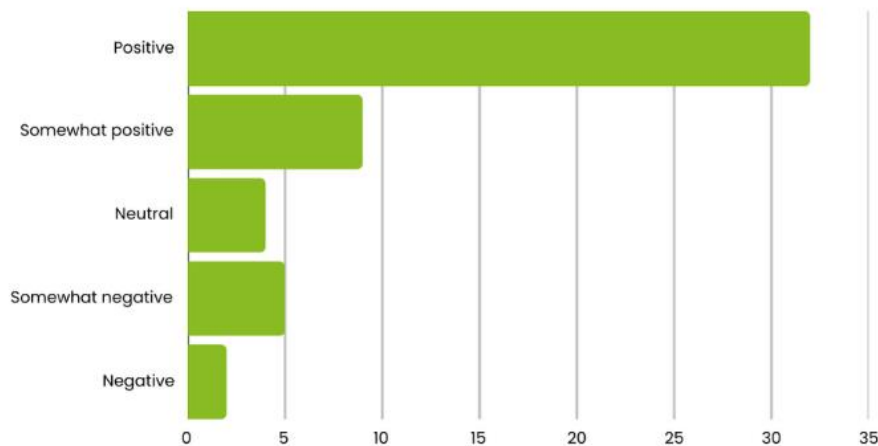
### Was there anything that encouraged you to go?



- Most who attended their breast cancer screening had a positive experience. However, over 13% said the experience was negative or somewhat negative which is double the number for cervical screening in the same category. Many respondents reported that they found the procedure painful/uncomfortable.

Figure 7 – Respondents experiences of breast cancer screening

If you did [have breast cancer screening] in the last five years how was your experience?



### Patient experiences of breast screening



***“I don't have a car and it was not easy to find an available appointment that was easily accessible by public transport on a date I could attend. When I did go, the sign posting to the screening van was very confusing and it was hard to find. When I was screened, the staff were very efficient and it was a relatively positive experience.”***



***“It was quite impersonal and robotic. Although the nurse was polite, I did feel somewhat like a piece of meat.”***



***“Pain, being pulled about, and frankly rough and disrespectful operative. Bordering on assault.”***



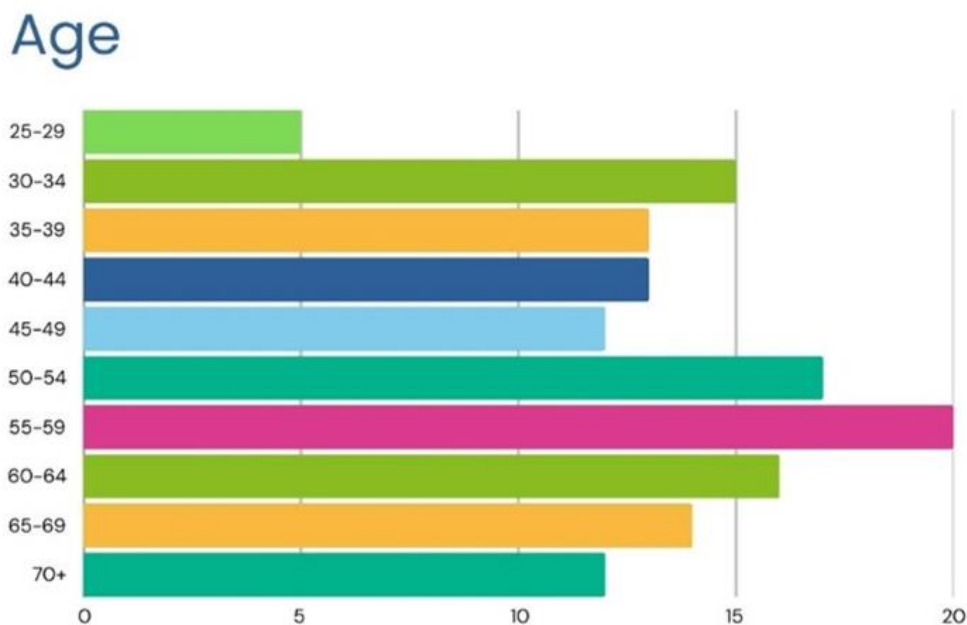


# Demographics

We prioritised trying to speak a diverse array of people. We did this by ensuring that there was a range of ways people could participate in the survey such as paper copies of the survey and leaflet with a QR code.

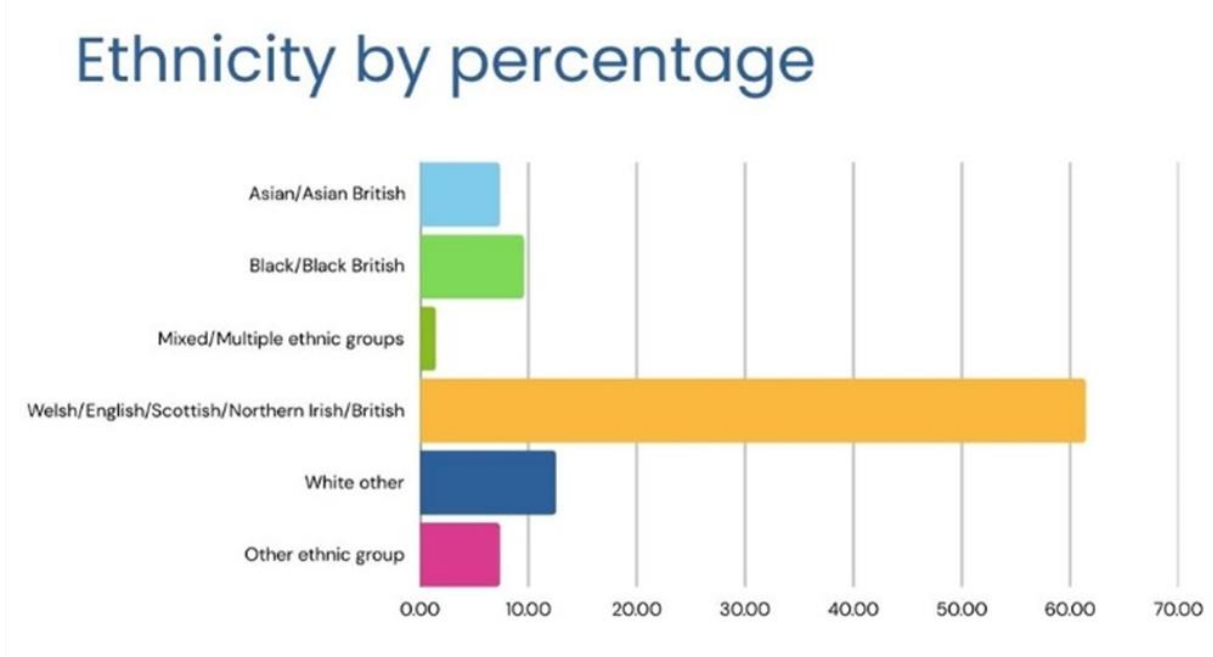
- Though we got more respondents over 50 years than under 50 years, all relevant age ranges were well represented.
- The experiences of women both over and under 50 seemed to be relatively consistent.

Figure 8 – Age breakdown of respondents



- The vast majority of respondents identified as White British but 39% were from various other ethnic groups

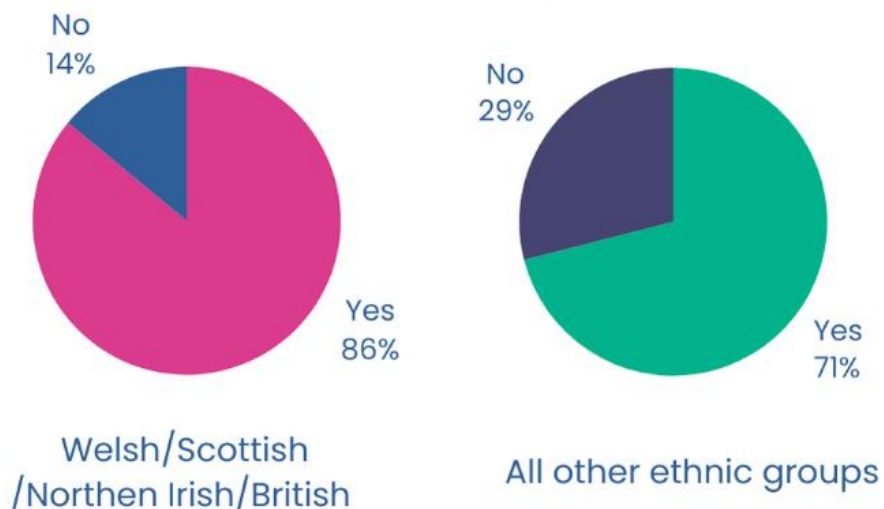
Figure 9 – Ethnic breakdown of respondents



- The demographic with the lowest uptake of cervical screening was Asian/Asian British with 70% of respondents having been screened in the past 5 years, 10% below the survey average.
- The survey data on breast cancer screening showed that 86% of white British respondents had been screened in the last 5 years but this dropped to 71% for those who described their ethnic origin as Black/Asian/Mixed/White other, or 'Other'.

Figure 10 – Pie chart showing the gap in screening coverage between white British and all other ethnic groups

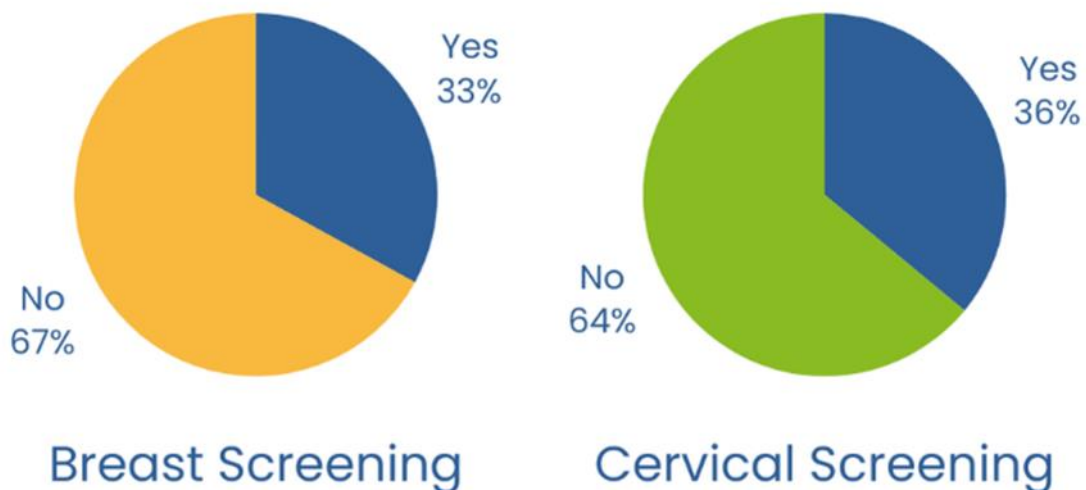
If you have been invited for breast cancer screening,  
did you attend the appointment?



- We were also interested in the views of those with a disability, learning disability and people who identified as neurodivergent.
- As indicated by the qualitative data those who considered themselves disabled were much less likely to have attended both breast and cervical cancer screening, 33% and 36% respectively.
- We did not get enough data to meaningfully report on learning disability (see the focus group later in this report). However, we did find that of those who considered themselves neurodivergent, only 50% had been screened for cervical cancer in the past 5 years.

Figure 10 – Percentage of breast and cervical cancer screening uptake for respondents who identified as disabled

If you have been invited for a screening, did you attend the appointment?



# Focus Groups

In recognition of the demographic and qualitative data limitation of the survey format, it was essential that we also carried out focus group to ensure that we were listening to underserved groups and getting an accurate and nuanced picture of their experiences.

Organisations we conducted focus groups with	Number of participants
Dalmar	4
Sisters in Mind (Women's Group)	19
ROJ Women Association	8
One-To-One Enfield	4

## One-To-One Enfield

*One-to-One Enfield is an Enfield based charity that works towards inclusion of people with Learning Difficulties and Autistic Adults.*

**Date: 11/03/2025**

**Number of participants: 4**

**Age range: 35-67**

**Ethnic backgrounds: 1 black British woman and 3 white British women**

**Findings:**

All eligible women had received cervical and breast cancer screening.

Participants were not aware of the reasonable adjustments they could ask for. One participant explained that she had previously had a positive experience of cervical screening when this procedure was conducted by a nurse who had known her for a long time. However, now she needed to see a different nurse the experience had become more negative, she didn't feel listened to and felt rushed stating: "I don't like it, I feel anxious."

Appointment letters were also an issue for this group. They felt that the letter they received informing them they needed screening went into too much detail and that they would prefer to receive the letter in an easy read format. Participants preferred simple language, image guidance, but no explicit diagrams as these could cause potential embarrassment.

### Participants comment on appointment letters



*"Language is not simple"*



## Dalmar

*Dalmar is a dedicated Somali community organisation that extends its support to other Black and Minority Ethnic (BME) communities within their reach.*

**Date: 04/03/2025**

**Number of participants: 4**

**Age range: 45-69**

**Ethnic background: Somalian**

## Findings:

This focus group highlighted the need for materials to be translated or at least easier to understand. Women often discarded the letters inviting them for screening because they could not understand them.

None of the women knew about the reasonable adjustments that they could ask for.

The group said that there was a mistrust of the NHS in the Somali community with a preference for 'natural' medicines. One participant recounted an experience that their relative had where nurses had not been patient, and a translator was not offered. Additionally, there was a cultural belief that virgins should not receive cervical cancer screening.

When asked what would improve their experience the group suggested translation services and pointed to the lack of diversity in NHS messaging and a lack of advocates from the Somali community. There was an impression that the NHS was just for 'white people'.

### Comment on seeking NHS support with general breast health



***"I found once lumps in my breast, so the doctor gave me medication. But now my lump is back. I don't know if I can go back."***



# Sisters in Mind

*Sisters in mind is a women's organisation based in Enfield. It has a diverse membership with women from various backgrounds.*

**Date: 24/02/2024**

**Number of participants: 19**

**Age range: 50+**

**Ethnic backgrounds: Black African, Turkish, Greek, White British**

## **Findings:**

Some in the group were concerned about cancer screening not continuing after the age of 64. They did not understand why this was the case and felt screening should continue past this age. One woman's cervical screening had been 'stopped' at 61 despite her request to her GP to continue with screening. Another said her doctor had told her that she did not need cervical screening as she had never been sexually active but still wanted to have cervical screening.

There were a few women in the group who had never been to cervical screening. These reasons varied; one woman did not want to go due to a negative previous experience of cervical screening and another who didn't want to go as she was no longer sexually active.

Many in the group were aware that they could ask for reasonable adjustments but in reference to breast screening said there were not enough female doctors. Some women were reassured by being able to have another woman in the room when being examined by a male doctor but for others, this was not enough. Disability also came up again, with one woman struggling with the breast screening equipment

due to her disability. The group emphasised the need for staff who were calm, and compassionate and did not make them feel rushed.

### Participants comment on attending breast cancer screening



*“I am disabled and the equipment is not right. I could not get into the position they wanted me to be in. I’m also very small. Nurse has been rough and rude.”*



## ROJ Women Association

*ROJ Women's Association is a non-profit grassroots organization dedicated to supporting and empowering Kurdish, Turkish, Cypriot Turkish, migrant, and refugee women in London.*

**Date: 20/03/2024**

**Number of participants: 8**

**Age range: 40s – 70s**

**Ethnic backgrounds: Turkish speaking women**

#### **Findings:**

This group were generally satisfied with their experience of both breast and cervical cancer screening. Everyone in the group reported receiving invitations and regularly attending relevant screening. However, as has been the case with many of the people we spoke to, they were unaware of many of the reasonable adjustments they could ask for.



On the topic of a self-test the group did not like the idea of this option. Again, concerns about performing the procedure correctly were raised.

Difficulty of booking appointments was brought up with some in the group expressing that they found newer digital appointment systems less convenient.

Appointment times were also an issue with the group suggesting out of hours screening appointments would be helpful.

# Recommendations

Based on the findings outlined in the report we make the following recommendations:

## 1. Better Language support

### **More accessible invitations to appoint.**

The focus groups made it clear that the format in which women are currently receiving their screening invites is not accessible to everyone. Overwhelming letters with too much information can be off-putting. Having letters and other communications sent out in easy-read formats and community languages will help those eligible to make informed decisions about screening.

### **Ensuring that patients are aware they can have an interpreter at their appointment.**

In populations where distrust of the NHS is already prevalent, it is even more important that women understand exactly what is being said to them when they are at a screening appointment. For many this is not possible without an interpreter.

## 2. Supporting women to improve their screening experience

### **Promotion of reasonable adjustments such as double appointments, a smaller speculum etc.**

Most of the women who took part in this project were not aware of the reasonable adjustment they could ask for and there was a report of someone being denied a double appointment. It became clear during the project that

feeling rushed was a common experience, something that women found off-putting.

### **Promotion of services that support women who have experienced trauma.**

The survey found that the most common reason for women not attending either type of screening was past trauma. It is likely that these women will need extra support to access screening. Support from charities such as My Body Back may help but easy access to double appointments and knowing they can ask the nurse to stop at any time may also be helpful.

### **Staff taking a patient, trauma-informed and culturally aware approach.**

Most of the women who positively commented on their experience of cancer screening praised the expertise of the staff involved. Ensuring that staff remain patient and empathetic is key to patients having a positive experience. Staff taking a trauma-informed approach may also be key to supporting the many women who have experienced past trauma.

## **3. Easier access to screening**

### **Better appointment systems**

Both parents of young children and those in full-time work raised issues with booking appointments, with many citing it as their reason for not going to cervical screening. Some comments suggested some women found booking an appointment difficult and others that said they had not been invited for breast screening when they should have.

Arranging appointments can be more difficult for those who are neurodivergent. Difficulties in navigating appointment systems may contribute to the lower cervical screening rates for that demographic.

### **Cervical cancer home testing kits**

Though not universally popular about half of the women who completed the survey and that we spoke to would prefer an at-home screening option. This was especially popular among those who had not been for screening in the past 5 years. Rolling out this option seems likely to increase uptake but health professionals would need to address concerns regarding the accuracy of the test.

### **Out-of-Hour Screening Appointments**

Both the survey and some of the focus groups highlighted difficulties in attending appointments for those in full-time work and those with young children. The creation and promotion of more out-of-hours screening appointments may support easier access to screening.



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