

Patient perspective on the breast screening programme in Surrey

Project Rationale

The NHS Breast Screening Programme began in 1988. It aims to invite all women aged 50 – 70 years for breast screening once every three years to detect breast cancer at an earlier stage, often before the woman is aware of any problem. Early detection may mean simpler and more successful treatment. Scientific evidence shows that regular breast screening, between the ages of 50 – 70 years, reduces the death rate from breast cancer. (www.breast-screening.surrey.nhs.uk)

Breast screening programmes were paused in March 2020, in a bid to reduce the risk of COVID-19 spreading and to free up emergency resources for the NHS. In Surrey, the screening programme is now working towards getting back to its pre pandemic levels. As reported in July 2022, the proportion of women eligible for screening in Surrey who have had a test with a recorded result at least once in the previous 3 years is 65.6% in 2021, compared to 74.7% the previous year.

Objectives

The overall project objectives were to engage with women in Surrey who had been invited for breast screening, hearing their perspectives to explore how the service, including access and uptake, could be improved across Surrey Heartlands HCP. There was particular emphasis on experiences around how appointments were made, access and their screening appointment with the aim of investigating whether further support could be provided, or changes made to improve the service, uptake and access for all.

Method and Sample

Recruitment considered a number of parameters, including ethnicity group, language barriers, physical and learning disability and living setting. The Citizen Ambassador spoke to six participants which included two in-depth interviews, three email responses and one verbal contribution. Within this sample, three of the women were White British, aged between 50-56, two with no additional needs and one who is blind. Three people did not wish to disclose their demographics.



Research Questions

To inform the optimum uptake of breast screening, discussions took the form of a semi-structured interview based on the following topic areas:

- Location/Access
- Appointments
- Information/Advice
- Additional Needs/Access
- Experience on the day
- Other thoughts/suggestions

Making the appointment myself was more empowering and allowed me to make a convenient appointment for me.

Findings: What is working?

- Locations are easy to locate by car and have plenty of parking.
- Booking system is easy and most people prefer being able to phone and make an appointment that is convenient for them, people also find the text reminders useful.
- The information, advice and maps sent before the appointment are appreciated and helpful.
- Staff are friendly, professional and relaxed and put people at ease .
- Screening is quick and efficient. The turnaround from receiving the invitation letter to given results was reported as being impressive and reassuring.

The Jarvis Centre felt reassuring and more comfortable, mobile sites can feel a little temporary.

I was invited for breast screening – they didn't know I've had a bilateral mastectomy.

Findings: What could be improved?

- Initial invitations are sent via post and are not accessible to all. Whilst letters say to let them know if additional needs / alternative formats are required this requires someone to read the letter in the first instance which is not always possible.
- Invitations are not personalised, so are not sent in the correct format or sometimes sent in inappropriate circumstances. Lack of communication between GPs and the service to identify or update about those with differing needs.
- The sites are not near public transport and only accessible by car which is not convenient or possible for everyone.
- The mobile sites have a lot of steps and are not accessible for all. There is nowhere comfortable and dry to wait.
- Lack of communication about people's needs and staff are not made aware of these before arriving for screening. There is little opportunity to discuss any concerns on the day of screening.

It was in the middle of nowhere, not near a train station. I had to ask someone to take me, which takes away your independence.

Case study: Sharice's story

Sharice* is blind and attended her first breast screening appointment at a mobile unit in Surrey 5 years ago. She was not asked if she had any accessibility requirements or offered a choice in the location of her appointment, "it was in the middle of nowhere, not near a train station. I had to ask someone to take me, which takes away your independence". This was also not a familiar location to her, which she would have preferred.

Sharice did not receive any information ahead of this appointment "I wasn't sent anything. Unless it was a paper copy which I would have missed. It would have been better to know what to expect and have information in a format I could read beforehand". On the day of her appointment, Sharice was informed by a member of staff that they 'didn't know you were blind' - they weren't informed by the GP and Sharice felt this needs to be joined up. "They didn't have a clue how to guide me, I felt I was being shoved one way or the other, I should be taking their elbow, but they never offered it. They didn't explain the room - in one room to change then another, and not described - I was a bit disorientated at one point".



Sharice said "I've not been asked to return since 5 years ago before lockdown", her next scan is now 2 years overdue and she has not been sent an invitation for her next scan, unless again, she has missed a paper copy which she cannot read. Her GP is aware of how to contact her (text, email, braille or telephone) and Sharice felt that this was not joined up with other services.

Sharice is "now put off going again" because "the first experience was so awful and they didn't really understand how to deal with a blind person. I'm petrified of going again to be honest".

Sharice said the following would improve her experience:

- An initial invite in a format a person who is blind can read and follow up with SMS text.
- Information/advice beforehand in a format a person who is blind can read.
- Reassurance that her needs are understood.
- A familiar location near a train station.
- Staff who are aware she is blind beforehand and know how to guide a person who is blind or visually impaired with confidence. (Training with simple sighted guiding techniques - guidedogs.org.uk describes it as a useful life skill much like learning how to perform first aid).

What next – Our recommendations:

- Ensure that the individuals details and needs are recorded on the GP system and agreed with the individual.
- Ensure that invites are sent out in an appropriate and accessible format such as text and where possible reflect up to date medical information i.e not sending to women with a double mastectomy.
- Ensure that sites are in a geographically accessible location i.e near rail station or bus route and the site is physically accessible to people with a disability.
- Ensure that the radiographer/unit staff are aware of the individuals needs and have the training/skills to provide support during the appointment.

For more information, please contact julie.callin@healthwatchsurrey.co.uk.

A huge thank you to the individuals who took part in this project.



You can contact our Helpdesk to share your experience of health and social care or for advice and information about these services in Surrey.

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