

Experiences of North Tyneside breast screening programme

November 2022

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Section 1 - Summary and suggested actions

Introduction

Healthwatch North Tyneside is focusing some of its activities on understanding women's health issues during 2022/23. We decided to focus on the breast screening programme in North Tyneside as we heard that there was lower take up than in previous years and local residents told us that the programme was working less well than in previous years.

During the evidence gathering exercise, we worked closely with the Public Health team at North Tyneside Council and providers to provide regular feedback about what people were telling us and highlight ways services could be improved. This included ways that the invitation system could be improved, issues about parking and issues that individual women raised with us about their personal situations.

Several changes to the breast screening programme were implemented during the time this survey was open. Some of these were as a direct result of the feedback gathered here.

The purpose of this report is to provide a summary of the feedback received and further reflections about the breast screening programme based on discussions with residents and partners.

The Breast screening programme is designed and commissioned nationally, and there is limited local control of how some elements are delivered.

We would like to thank the residents of North Tyneside for sharing their views, the services involved for listening to what people are saying and particularly the Public Health team at North Tyneside Council who have prioritised improving this screening service for residents. Our thanks also go to our partners for their support in sharing the survey, our volunteers for helping to gather feedback from the public, and the staff of the mobile screening unit at North Tyneside General Hospital for giving our survey to people attending their screening appointments.

Highlights of the information gathered

People were grateful to have access to the screening process and felt the experience was very good. For most people, the process ran smoothly from start to finish, information was clear and accessible, and the staff were kind, reassuring and efficient. However, for some, the booking process was difficult and the choice of venues was inconvenient for both travel and parking.

It is clear from the feedback that the service makes a significant effort to reduce barriers to participation. The invitation/ booking process was improved during the survey period, and many people said it was easy to change their appointment time or venue to a more convenient one.

Those not invited to participate in the programme would like to be better informed of when to expect their screening and notified of delays. There is an appetite for widening the scope of the programme and/or sharing the reasoning

for the cut-off points and publicising how to access the service for people outside the age range.

- There is a strong sense from the people that responded that they wanted to access the screening programme. Although we know from our wider engagement activities that people less keen on the screening programme did not complete the survey.
- Of 314 people responding to the survey, 64% (200) had been invited to participate in the breast screening programme. Of those invited, 75% (147) tried to book an appointment.
- The programme is generally felt to be of very high quality and people are grateful to have the opportunity to participate.
- Ratings are very high for all aspects of the process:
 - Being invited - **4.6** out of 5 stars
 - Booking an appointment - **4.5** out of 5 stars
 - Attending an appointment - **4.8** out of 5 stars
- Methods of invitation changed during the survey period. The majority felt that all worked efficiently. There are examples, however, where people have been contacted multiple times by several different agencies.
- A small number of people were frustrated by difficulties making phone and online bookings, or about the appointments that were available. Many more people said these systems could be improved.
- Some people told us that they were contacted on multiple occasions by different teams ‘chasing them up’ to book an appointment. Some of these chase up calls were to people who had not been invited or had already booked their appointment or had been screened. Data from North Tyneside Council’s public Health team indicates that 30% of the 936 women they spoke to had already booked their appointment.
- Responses were particularly positive about staff at screening appointments. People felt staff were kind, reassuring, respectful and efficient.
- Comments suggest that the screening process itself runs smoothly and efficiently.
- Travel and parking concerns were mentioned as a cause of worry when attending appointments.
- Some people would like to be able to access screening outside the age criteria of the programme. Not everyone was aware this could be requested.
- People would like to know when their screening is due.
- Responses from 25% (50) who did not book an appointment show 15 were put off by problems with access (either booking or venue) or previous bad experiences.

Suggested actions

The following suggested actions are based on what we have heard from local residents, including the responses to the survey. They aim to improve the experience of the screening programme for local residents. We recognise that some of these actions would take significant re-design of the screening programme at a much broader scale than North Tyneside and highlighted which actions we think are within the control of the local system.

Local System

1. Continue to remain open and responsive to feedback, particularly that which may put people off participating in the programme.
2. Continue to monitor invitation and booking systems, so they work efficiently for users. In particular, continue to offer timed appointments at first contact with a resident rather than asking them to contact the service to make an appointment - this change was introduced due to local lobbying by partners to this project.
3. Improve coordination of the invitation process to improve take up of screening opportunities. Currently, Public Health teams, GP Practice teams and the Screening Programme team all work from copies of the same patient list which is not automatically updated between the three teams. This can result in some individuals being invited multiple times or invited after they have already been screened.
4. Review the location of venues across the borough, considering travel, free parking and accessibility, and including clear instructions on where to go and where to park. Since this survey closed, an additional screening unit has been sited in the Whitley Bay area.
5. Review the staffing of the booking line to ensure users get a consistently prompt response to their enquiries.
6. Invest in an online booking/change booking system that allows people to select a time and venue that works for them, rather than the online form that generates a call back from a member of the booking team. Look at ways this could be integrated with other online and app developments within the NHS. This exists in other parts of England.
7. Improve information about the practicalities of an appointment - choice of venues, public transport, location, parking arrangements, support with travel costs etc - at the point of invite.
8. Continue to support the staff teams to provide the high level of care we have heard about.

National

9. Consider re-designing the trigger for people being called for a screening appointment so it is based on when an individual is due rather than the programme being focused on the rolling programme of GP practices as is currently designed. This would help people to know when they are due as an individual and avoid women who switch practices missing out.

Local and National

10. Improve the availability of information about the screening programme and how to access screening outside the age criteria of the programme.

Section 2 - Detailed report of survey results

Method

A survey was prepared to gather feedback about people's experiences of the North Tyneside breast screening programme since Autumn 2021. Questions were included to enable people who had not yet been invited, were not eligible, or who had chosen not to take up the offer of screening to also share their views. This approach was chosen to provide a 360° perspective of views around breast screening, as well as a clear picture of people's experiences of the current local screening programme.

The survey was available online and on paper. Two paper versions were available: one that included all questions and one specifically for people attending their screening appointment. It was promoted by our partners online and via QR code postcards, and at our general engagement events. Postcards and paper surveys were handed out by staff at the mobile screening unit at North Tyneside General Hospital.

Who we heard from

We had 314 responses to our survey which included responses to both online and paper surveys.

NB: Respondents had the freedom to answer the questions they wanted to and leave others blank. For those completing the paper survey a greater number of questions were available than via the online version which bypassed irrelevant questions based on earlier responses. For these reasons, numbers do not add up to 314 for each question.

What we heard

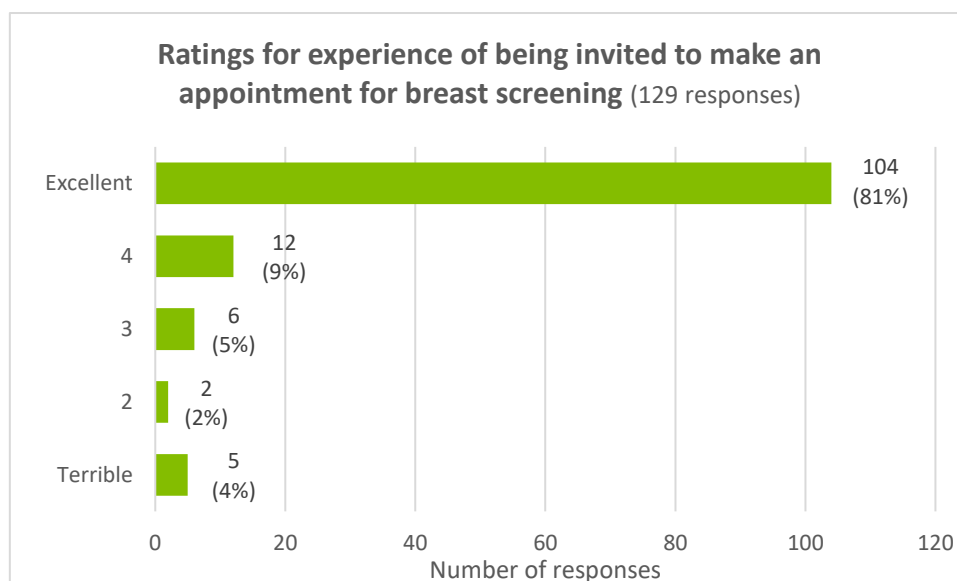
64% (200) of respondents had been invited to participate in the North Tyneside breast screening programme. 36% (113) said they had not.

Recent experiences of screening

Of the 200 people who had been invited for screening, 75% (147) said they tried to book an appointment.

Invitation for screening

129 people rated their experience of being invited for screening. The average rating was 4.6 out of 5. 90% of respondents gave ratings in the top 2 categories.



Many people commented on their rating. People were generally very grateful to be invited. Comments indicate that those giving the lowest ratings were making this judgment based on other aspects of the process that had not worked for them rather than their invitation to participate in the programme. 4 out of 5 had problems getting through on the phone to book their appointment.

It was clear from responses that the process for invitation and booking changed during the course of the survey. Some people received a letter inviting them to book an appointment, while others were sent a pre-arranged date. A few received a phone call instead. Whichever process was involved, the majority of people felt that it worked efficiently. Several people commented on the quality of the letter and information sent.

“Letter in the post with clear instructions, information and advice“

2 people said they received multiple contacts about their invitation that caused them concerns. One said they had received a letter plus 3 phone invitations. Another received a text in error. They were asked to call to book only to discover

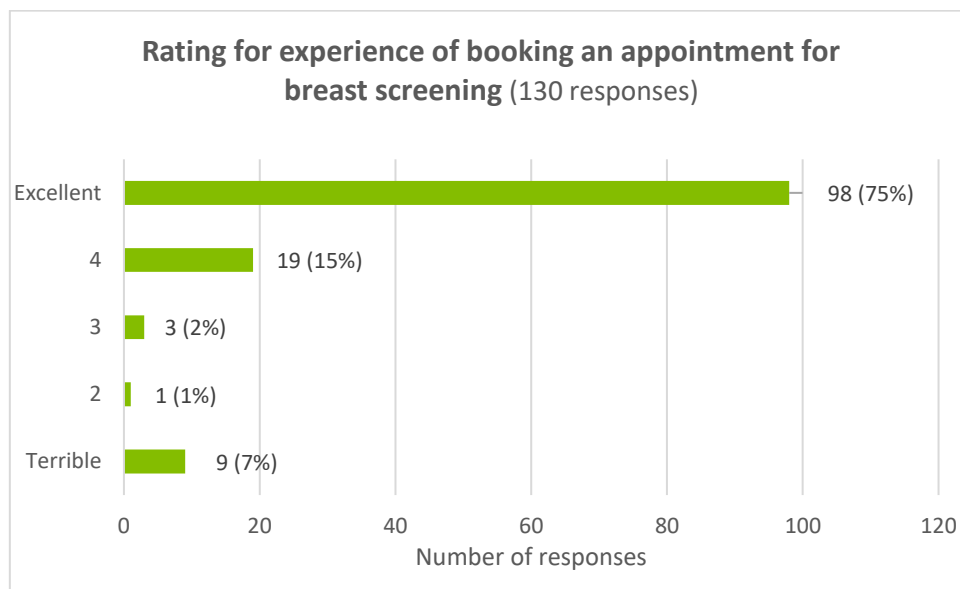
they were not due until 2023. We heard about similar issues outside of this survey.

3 people noted that their screening had been delayed due to Covid, but ratings were still high. One person told us they contacted the service to ask why their screening was delayed and received a “very good explanation”.

6 people said they would have preferred a different venue. 5 of these went sent their appointment and were able to easily change to somewhere more convenient. (4 out of 5 still gave an ‘excellent’ rating). 2 people in the Killingworth/Forest Hall area felt that none of the venue options were as easy for them as the Oxford Centre had been in previous years.

Booking an appointment

130 rated their experience of booking a screening appointment. The average rating was 4.5 out of 5.



While the average rating for booking an appointment is slightly lower than for being invited to take part in the programme, the combined percentage for the top 2 rating categories is still 90%.

Responses suggest that the booking system works well for the majority of people. It is “simple” and “efficient”, and enables people to easily reschedule or change location. Being offered a choice of venue and appointment time was valued, enabling people to fit appointments around work commitments and ease of travel.

“Easy to get an appointment that fitted around work”

“It was seamless from booking the appointment to rescheduling the appointment”

People said staff were “friendly” and “helpful”. One person, who was beyond the age for being called for standard screening, told us that they phoned to request an appointment and were able to get one immediately, “no problem”.

However, 11 people described a number of issues with booking, mainly regarding problems getting through on the phone. People told us of long queues and making

multiple attempts. While some got through eventually, others gave up and either tried an alternative method of booking or waited to be contacted directly.

“I tried the number given on FOUR different occasions. Every time I was told to call back and was cut off. NO facility to leave a message. I will keep trying but it is extremely frustrating and very poor service”

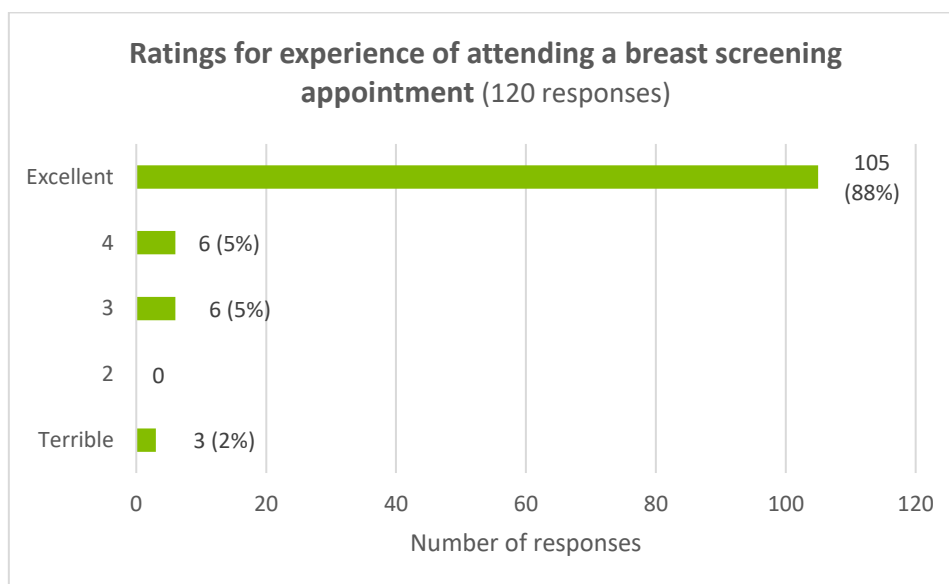
4 people said online booking was offered as an option in their invitation letter but that it didn't work when they tried. One person further explained that they could choose a morning or afternoon slot online but would then have to wait for someone to get in touch to arrange an appointment time. They did not regard this as being able to book online and ended up ringing up themselves which they said was easier. 2 others said they would like to have had the choice to book online, one specifying that it was not offered in the text they received. Conversely, 2 people gave 'excellent' ratings for the online method for booking and rescheduling, demonstrating greatly differing expectations.

A further person said they tried to make contact by email after failing on the phone but got no response.

In addition, 2 people said their appointment was rescheduled 3 times, and 3 people complained about the appointment times available: One had to wait 4 weeks, which was longer than they expected, one had limited choice, and the other couldn't get an appointment at all and was asked to ring back again.

Attending an appointment

120 people provided a rating for attending their screening appointment. The average rating was 4.8 out of 5.



Respondents were very complimentary about their experience at the screening unit. Many people said staff were “really friendly”, “talked me through the whole experience” and “put me at ease”. They were “seen on time” and staff were “courteous and helpful” and treated them with “kindness”, “dignity” and

“respect”. One male attending the RVI commented on how much he valued not being made to feel out of place and how much it helped to be able to see his wife go through the process first.

The screening process was felt to be “very efficient”. People said they were “in and out within 10 minutes” with “no waiting around” and were told clearly “what happens next”. A few people who arrived early said that they were accommodated without fuss.

“I messed up time and arrived early. The girls were wonderful and slotted me in as if I had arrived at the right time”

One person who arrived to discover their booking was not on the system, simply showed their letter and was able to be screened within 10 minutes. They gave an ‘excellent’ rating.

The kind manner of staff goes a long way to making a potentially uncomfortable experience much less stressful. “Lovely staff, makes the experience so much nicer”

“The service was outstanding from beginning to end”

4 people mentioned covid safety measures, 3 positively commending mask-wearing, distancing and the ‘one in, one out’ system. This was very reassuring to one respondent who was immune-suppressed. However, another was not happy about waiting outside.

2 people commented about privacy. They felt they had enough privacy within the unit and preferred not having to walk through the hospital.

Ratings were very high overall for the screening experience and comments were very positive. “Overall a positive experience” (RVI). One person said it was “a massive improvement on the last time I attended” (NTGH). Comments suggest that the screening process is finely tuned to run smoothly and efficiently, and be pleasant as possible.

A handful of lower ratings provide possibilities for minor improvements. Parking was mentioned by 11 people, who gave various ratings, down to whether it was an issue on the day or not.

“Nowhere at all to park... it was quite stressful.”, “Impossible to park” (North Tyneside General Hospital [NTGH], both ratings of ‘3’)

“Arrived a little before appointment time as parking can be an issue but it was not and I got my appointment completed earlier than booking” (NTGH)

“Really quick - within the 20 mins free parking! :)” (NTGH)

What was clear though was that it was a worry. People said they left earlier or travelled to a more distant venue due to concerns over parking spaces and costs. Some seemed pleasantly surprised when they were able to find a space and the screening was completed within the free 20 minutes parking. This highlights that even though efforts have been made to address barriers presented by parking

problems and costs, it takes time for the message to filter through. Often people prefer shopping centre/supermarket car park locations for this reason.

“The screening unit is in the hospital car park which incurred a fee to park (was previously located in local supermarket car park, free)”

3 people said they found the screening very painful; 2 of whom gave a rating of ‘3’ and the other ‘terrible’. However, most people did not mention pain or discomfort as problem.

Where people attended for screening

Location	Percentage (of 120 responses)	Number of responses
Tyneside General Hospital mobile screening unit	89%	107
RVI	7%	8
Westgate Walk-in Centre breast screening unit	3%	4
Hexham mobile screening unit	1%	1
Stanley mobile screening unit	0	0

When people had the experience



What could be improved about the breast screening programme?

76 people commented regarding possible improvements to the screening service. 42% (32) of these were either positive, N/A or said there was nothing that could be improved.

Key areas highlighted with room for improvement were all related to access in one form or another:

- Physical location of screening unit - travel, parking, finding the unit (19 responses)
- Physical access to the unit itself - waiting area, stairs (3 responses)
- Access to appointments - booking process, ease of contact, availability of appointments, rescheduling (13 responses)
- Access to the screening programme - over 70s, not eligible (2 responses)
- Access to the screening equipment - lack of adjustment for some mobility issues, height needs, less painful procedure (4 responses)

Location of screening units

Providing options for having screening at different locations is valued, as noted in earlier feedback. However, the location options may not suit everyone and any changes to venues between years can take a while for people to get used to as they may benefit some more than others. While a very small number of people said they liked having the unit at NTGH, there was a greater call for mobile units at supermarkets or shopping centres where there was plenty of free parking. People in the Killingworth/ Longbenton/ Forest Hall area missed the screening unit at the Oxford Centre, as other options were further away. One person said they did not understand why there were referred outside the area to the RVI.

While some people said they had no problems parking at NTGH and were screened within the free 20 minutes parking, others were unable to find a parking place at all. Worries about parking and costs do seem to cause stress and people have to leave earlier to take this into account. Information on the exact location of the unit and parking availability and cost would be helpful.

Access to the screening unit

People commented on the lack of seating or anywhere to wait outside mobile units, and the difficulty with stairs for people with mobility issues. One person suggested that instructions could be tweaked to note that people should go straight to the NTGH unit and do not need to check in at Outpatients.

Access to appointments/ communication processes

3 people said it would be preferable to provide people with appointments, which they could then change or confirm, rather than inviting people to arrange their own appointments from scratch. This was felt to create a potential barrier to people taking up the screening offer, confirmed by reports of difficulties getting through on the phone. However, feedback suggested that the service identified this as a problem and adjusted the invitation/ appointment allocation system accordingly. One person suggested sending a text that allows confirmation of attendance by responding with a 'Yes' could also work well.

2 people said they would have liked an online booking system for appointments with email confirmation of booking.

Other comments included the following:

- Updating of records - receiving multiple calls to book after they had attended for screening
- Lack of response to email request for appointment
- Availability of evening appointments
- Rescheduling of appointments by service - can be difficult to rearrange time off work
- Ability to book further in advance
- “Quicker result”

Access to the screening programme

Only 2 people mentioned access to the screening programme outside the age criteria but it was brought up at other points in the survey by people both below and above the age range. The following quote sums up the feeling for people once they are no longer called to participate.

“I do feel very vulnerable now that I can no longer be screened and do wish there was an alternative”

Others said it would be helpful to know when their screening is due.

Access to screening equipment

For a very small number of people, the height and position of the screening equipment makes the screening process very awkward and potentially more uncomfortable or even painful. One person said they were unable to attend because they could not stand or raise their arms. They wondered whether more accessible/comfortable methods of scanning were available.

Other suggestions for improvement

A few miscellaneous suggestions were received from individuals:

- Unit could be warmer
- Room was small and building would benefit from updating
- Feeling of vulnerability being undressed “The one thing I hate is sitting stripped to the waist waiting. For how long it takes to undress could this not wait till the technician is ready? I find it degrading”
- Comments by reception staff on length of time since last visit/ previous missed visit are not helpful.
- “I do think people should also take responsibility and make sure they have the screening and check your breast regularly ... I keep a check list for all my checks so I know when I should be scanned” Could an app help with this?

Other comments about breast screening services

97 respondents gave additional comments when asked if there was anything else they wanted to say. Some responses covered more than one point.

- 34 were ‘no’, ‘N/A’ or similar responses
- 42 were positive responses about the quality of the service, appreciation for having access to the service and getting results back promptly.

- 6 people commented about screening beyond the age of 70. 3 of these said they were aware they could access screening by request; 4 felt screening should be ongoing. **“Why the screening stops at 70 should be publicised. The screening after 70 shouldn't just be on request, it should continue. People feel they're forgotten about when screening stops”**
- 5 people mentioned the importance of screening being at places that were local, easy to travel to and park at. Parking at NTGH and the Westgate Unit were felt to be a particular problem.
- 5 noted the discomfort and/or pain involved in the procedure. 2 of these said it wasn't a problem as they knew the procedure was worthwhile. However, one said that this along with issues booking would put them off have screening in the future.
- 6 people stressed the importance of encouraging people to attend screening and trying to identify factors that put people off or make the process more difficult. **“More research required to find out why women ignore this essential health check” “More comfortable surroundings and more support and information why screening is necessary”**

Other points:

- A date on the results letter would be helpful for future reference
- **“Better booking system is essential”**
- **“Horrible caravan service”**

Feedback from people who did not take up the offer of screening

25% (50) of those people invited to take part in the screening programme chose not to book an appointment. Numbers given below give some indication of where there is room to improve take up - 15 responses.

Reasons given for not booking a screening appointment

- Given appointment rather than having to book (9 responses)
- Been screened recently (5 responses)
- Bad experience in the past (4 responses)
- Location - Distance/travel/parking/parking costs/privacy of location (4 responses)
- Personal circumstances - inconvenient timing (4 responses)
- Communication issues (2 responses)
- Waiting for appointment to be sent (2 responses)
- Double mastectomy (2 responses)
- Too old or too young (2 responses)
- Referred by GP (1 response)
- Physical issues - unable to maintain position required for screening (1 response)

Suggestions to improve take up

People were asked if there was anything that would have helped them take up the offer of screening.

24 people responded with the following comments:

- Positive comments/up-to-date with screening e.g. “I always take up offer of screening and always attend” (7 responses)
- No or N/A (6 responses)
- More convenient venue/easier travel and parking - Killingworth/Longbenton mentioned (4 responses)
- More appropriate location - hospital rather than car park (1 response)
- To know when appointment is due (2 responses)
- Improved communication between screening service and service sending invites (1 response)
- More flexible screening equipment “If the screening could take place sat down and without having to raise my arms” (1 response)

It seems that generally there is a greater preference for shopping centre/car park locations as these are often convenient to access and have plentiful free parking. One person felt that a hospital setting would be preferable to a mobile unit in a car park.

Of the 4 people who said they had had a poor past experience, 3 said they had no suggestions about what might help them take up an offer in the future “I don’t think I want to put myself through what I went through the last one”.

Views of breast screening from those not invited to participate in the programme

Is there anything you would like to tell us about the breast screening programme?

53 people commented, 6 (11%) of which were a “No” response.

- 16 (30%) of comments were positive, praising past experiences of screening and expressing gratitude for the service in detecting cancer early.
- 20 (38%) talked about uncertainty over when they would be contacted. There was particular concern from people who were 52/53 who had never been called before, and people who were expecting contact earlier. The impression is that everyone would like to be kept better informed about the invitation process and when they are likely to be called. Some people worry that they will be missed. They get in touch with the service to find out more and are told to wait to be contacted. Perhaps sharing the local screening schedule more widely would be helpful.
- 7 (13%) of responses were regarding eligibility for the programme. These were mostly from people who were 70 years plus, but also 2 from people below 50 years. Not everyone knows that they can request a screening over the age of 70, and they would prefer to continue to be included in the general screening programme. They would like to be informed about the reasoning for stopping general screening at this age. Some feel it gives the impression that their health is no longer important, particularly those who know people diagnosed with breast cancer beyond the age of 70.
“It would be helpful to let people over 70 know the reason why screening stops. If it is based on a risk factor this should be made clearer. My mum is

in this age bracket and certainly had a feeling of just being too old to be important or bothered with when her screening stopped. Not a nice feeling for someone to have.”

- 3 (6%) commented on location of screening: 2 wondering why screening was no longer available at Morrisons car park; 1 noting that mobile units are not always suitable for people with mobility issues. Perhaps it could be made clearer in the list of venue options which sites are fully accessible.
- 1 person, whilst commending the responsiveness of the local service in checking a lump, said that the process in Gateshead appeared to be quicker and suggested looking into this further for potential ways to improve.
- 1 person said they would be put off attending in the future because they were too anxious.



healthwatch

North Tyneside

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