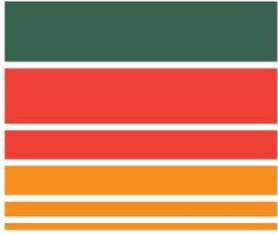


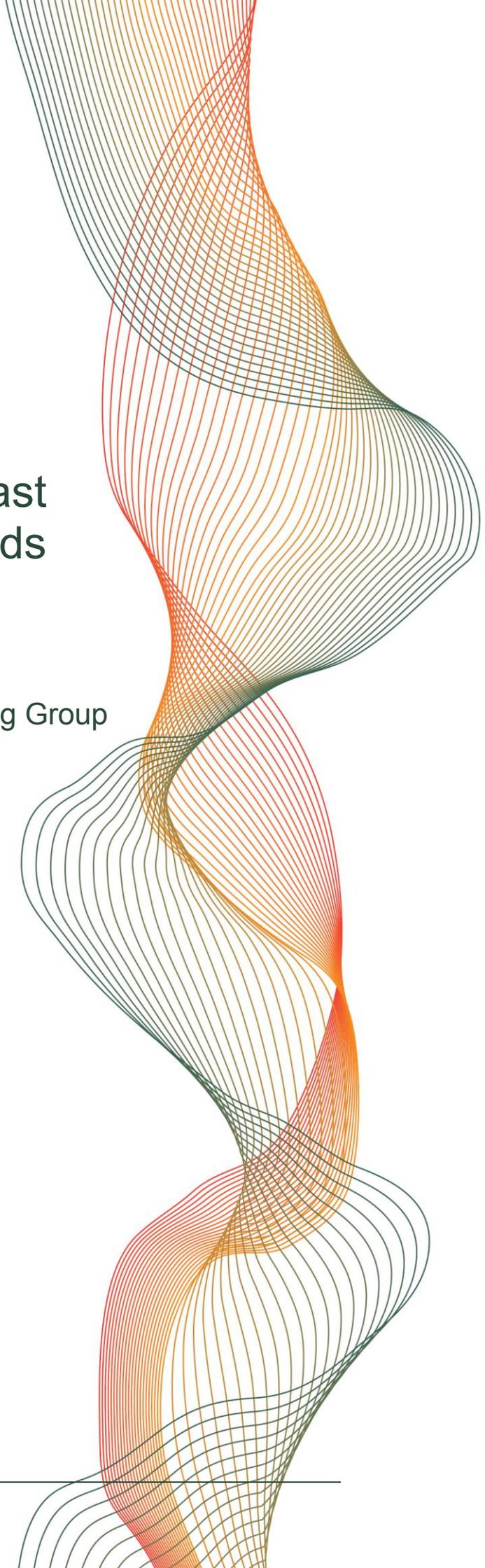
Brainbox Research



Patient insight research to inform redesign of the Breast Diagnostic Pathway in Leeds

Final report
NHS Leeds West Clinical Commissioning Group

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1. Executive Summary

This report describes patient insight research with the breast diagnostic unit at St James's University Hospital. The research was commissioned by NHS Leeds West Clinical Commissioning Group (CCG) on behalf of Leeds Integrated Cancer Services as part of the review of breast diagnostic services. The review aims to develop and deliver an integrated, coordinated and personalised service, providing high-quality care that meets patients' needs and has the capacity to meet projected increased demands in the future. The review is a collaborative process involving commissioners, secondary and primary care. By re-designing the service with patients and clinical staff, the review provides an opportunity to develop a service that could be radically different to the current offering while ensuring continuing high standards of clinical care that meets the needs of the patients who use it.

We took a mixed-methods approach to the research, with the main focus being qualitative, based on focus groups. This enabled us to develop insight into people's experiences of using the service, their beliefs about how their experience could be improved, and ideas for how an innovative new service could operate. The results from the focus groups were used as a basis for patient interviews conducted in clinic, and a survey, which was distributed to people who had used the service. In this way we combined in-depth insight into people's experience with feedback on new possible service design and delivery ideas generated by a larger number of patients.

Thirteen focus groups were conducted, involving a total of 87 women. Participants including women of different ages, ethnicities, communities and geographic areas, those who had used the cancer diagnostic service and future patients with no experience of the service. Interviews in the breast

clinic were conducted with 13 women, sometimes also with the people accompanying them. Qualitative data were analysed using theoretical thematic analysis. The survey was distributed in paper format in the clinic and via GPs, and a link to the online version was sent to the Leeds Citizens' Panel and was publicised using social media. It attracted 401 responses.

The patient insight research shows that the breast unit delivers a service that most patients believe is excellent and so the challenge is how to change the service so that it can meet current and future demand while retaining what patients value.

Currently, patients access the service by GP referral. While patients who had been diagnosed with cancer appreciated the continuity of care this provided, most participants would like to access the breast clinic directly. There could be a nurse-led helpline or clinic to triage patients, and participants wanted a combination of bookable appointments and a drop-in clinic. Participants would prefer the breast unit to be located away from the hospital in an area with good transport links and free parking. They want it to have extended opening hours, particularly into the evening.

Women find the unit very clinical and would prefer a more relaxed environment. They made several suggestions for changes that would improve their experience, including having volunteers to orient them when they arrive and make sure they feel confident and have not been forgotten, making more facilities available, and re-organising the waiting area. The breast clinic could be combined with a healthy living service where visitors could access advice and interventions to help promote a healthy lifestyle and to help them with concurrent health

concerns, such as menopausal symptoms, exercise and diet, and mental health.

The biggest cause of negative experiences is lack of communication, especially about how long people will be waiting, how the clinic is organised, and believing that staff lack empathy. It is particularly important that radiographers are sensitive to the difficulties that patients with disabilities or limited mobility have. Participants would like more information about the breast unit and the tests conducted there. A clinic website would provide an ideal opportunity to provide this in a format that patients find accessible and engaging, rather than overwhelming. Alternative formats should be available for patients who do not have easy access to the internet.

The wait between having tests and getting the results is full of anxiety. Reducing this wait would have a substantial impact on improving the patient experience. At present most patients return to the clinic to receive their results, although a new telephone results service is being piloted. Patients wanted to be able to choose how they receive their results and this may include face-to-face, by telephone, by letter, or via the internet. Patients who were not diagnosed with cancer wanted clarity about how any symptoms, especially painful ones, would be addressed. All patients wanted information about what to do in the future should the same symptoms recur.

We have produced a set of recommendations about how the service could develop to take into account the patient experience.

2. Background and Methods

2.1 Context

This patient insight research informs a radical review of cancer services that aims to develop and deliver an integrated, coordinated and personalised service providing high-quality care that meets the needs of the people who use it. While NHS Leeds West Clinical Commissioning Group (CCG) has ambitions to re-design all cancer services, the starting point has been breast cancer diagnostic services, with a focus on how people are referred and the diagnostic pathway they follow. While the current service is of high quality, it faces increasing pressure as the number of people referred onto the diagnostic pathways increases. It is likely that numbers will continue to increase as people live longer and so have an increased risk of breast cancer. Assuming that NHS budgets continue to be limited, the service will need to become even more cost-effective. A review therefore provides an opportunity to develop a service that could be radically different to the current offering while ensuring it can maintain high standards while continuing to meet demand into the future. A steering group was set up to contribute to the review and oversee the research underpinning it. This group included representatives from commissioners, managers, breast unit clinical staff, GPs, communications staff and patients so that so that the review was able to explore and discuss many different perspectives on service design, thereby ensuring a truly joined-up approach.

To design excellent and innovative services that deliver patient-centred care, the steering group also needs insight and understanding into patients' experiences to understand how the service could be redesigned to deliver more positive experiences whilst maintaining or enhancing the high quality of care received. Our approach was informed by the tools used in Experience-based Co-design (EBCD) – a technique that uses patient and staff experiences to re-design services. Through group discussions and other data collection methods, researchers and patients explored important emotional experiences and service 'touch points' (significant points for the patient).

The 'Ladder of Engagement and Participation'^[1] shows that a collaborative approach between Commissioners and patient service-user groups is key factor in meaningful participation in service development and redesign. It is essential that alternative service options and care pathways solutions are developed in close partnership with patients through close in-depth consultation. A fully collaborative process delivers patient-generated insight into how services can be improved to enhance patient experience of the breast diagnostic pathway and improve patient health outcomes.

The outcome of this research is patient insight into which aspects of the diagnostic service contribute to an excellent experience, and which to a negative experience, and patient-driven suggestions of how the service could be radically redesigned.

^[1] NHS England (September 2013): Transforming Participation in Health and Care. Accessed at: <http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

2.2 Methods

We took a mixed-methods approach to the research, with the main focus being qualitative, based on focus groups. This enabled us to develop insight into people's experiences of using the service, their beliefs about how their experience could be improved, and ideas for how an innovative new service could operate. The results from the focus groups were used as a basis for patient interviews, conducted in clinic and by telephone, and a survey, which was distributed to people who had used the service. In this way we combined in-depth insight into people's experience with feedback on new possible ideas generated by a larger number of patients.

Participants

Because the NHS is committed to addressing inequalities in health outcomes it is important that the service meets the needs of diverse groups of people. NHS England best practice guidelines for participation^[1] suggest that to thoroughly engage service users, insight gathering must go beyond those that are already engaged with health services. This means proactively working with local voluntary and community networks to involve people who experience the greatest health inequalities. We also reviewed the Equality Act protected characteristics and identified age, disability and religion/belief as being particularly pertinent to this research. We therefore ensured that our participants were from diverse groups including those who are economically disadvantaged and those who are in communities that can be typically reluctant to seek healthcare, including ethnic minority communities and the Gypsy and Traveller communities. Leeds GATE also commented on the report recommendations to ensure that they would increase inclusivity for Gypsy and Traveller communities. We monitored the age of participants and also, for the focus group participants, asked them if anything makes it more difficult to access healthcare services. There was a wide range of ages, from below 25 to 85+, and most who chose to reveal their age were over 45.

We included three groups of participants:

- People who have used the service and did not have a breast cancer diagnosis (around 90% of all those on the pathway);
- People who have used the service and who were diagnosed with cancer;
- People who have not used the service, i.e. potential future patients.

Focus groups

We held five separate events in which participants discussed their experiences and ideas in focus groups. Each focus group comprised between four and eight participants and each lasted around 90 minutes. This small-group approach is useful so that participants feel comfortable about talking about their experiences, which encourages honest discussion and creative ideas about what can be a very worrying time in people's lives. A total of 13 focus groups were held across these five events, shown in Table 1.

Recruiting participants to the focus groups was challenging. Because of data protection concerns, Leeds Teaching Hospitals NHS Trust wrote to patients who had attended the breast unit and asked them to contact Brainbox Research directly if they would like to take part. A total of 1,200 patients were contacted, 200 of whom had

received a diagnosis of cancer and 1,000 who had not. The response rate from patients with a cancer diagnosis was high, with over 60 patients wanting to take part. The response from patients without a cancer diagnosis was much lower, with only 20 patients volunteering. The Brainbox team requested to attend the breast clinic to recruit patients directly but delays in gaining approval meant that this was not possible. Instead, interviews were conducted with patients in clinic (see below). We also worked with local community organisations, including a women’s centre for the Bangladeshi community, to encourage women to take part.

Table 1: The focus groups at each event, their locations and the number of women participating.

Event 1	Event 2	Event 3	Event 4	Event 5
Five focus groups, with women who had used the breast unit. Four were with women who had been diagnosed with cancer.	One focus group with women who had used the breast unit. Most had been diagnosed with cancer.	Two focus groups with ethnic minority women who had not used the breast unit. Focus groups were conducted with interpreters.	Four focus groups with women who had not used the breast unit.	One focus group with women who had used the breast unit and who had been diagnosed with cancer
Headingley	Middleton	Harehills	Headingley	St James’s Hospital
22 women	7 women	22 women	32 women	4 women

We developed a series of small-group activities to generate a wide range of views and ideas. We used a “patient character pathways” technique in which we developed a series of fictional characters with a range of health concerns or conditions that participants discussed. Each character had a series of encounters with services:

- Noticing symptoms;
- Visiting the GP;
- Making and receiving a clinic appointment;
- Visiting the clinic;
- Having tests;
- Waiting for the results;
- Leaving the pathway.

For each of these contacts participants discussed the character’s possible experiences and how an optimal outcome and excellent service experience for that patient might be achieved. This technique allows participants to project their own thoughts and feelings onto the characters and therefore reduces the pressure to give “socially acceptable” opinions, and also avoids participants talking at length about their own health. Participants also completed an activity in which they discussed how they would want to feel while at the breast unit and what could happen to make them feel that way. Finally, they completed a post-it note exercise in which they wrote down what they would like the breast unit to start doing, stop doing and keep doing, and what they think the service will look like in 50 years’ time. Data collection tools are shown in the Appendix.

Interviews

Because of the relatively high response rate from women who had received a diagnosis of cancer there was a danger that the results would not reflect the experiences and needs of those who had not received a diagnosis of cancer, who make up the majority of those using the clinic. We therefore conducted interviews with women in the clinic. We visited the clinic on four separate occasions and conducted 13 interviews. Interviews took place in a quiet, private area of the clinic waiting room. They lasted up to 30 minutes and explored experiences and ideas for improving how to access the pathway, visiting to the clinic, and receiving results. Interviews were audio recorded, with each participant's permission. In addition, we engaged with Leeds GATE, the Gypsy and Traveller Exchange, who conducted an interview and included the perspective of women from this community.

Survey

To allow people to contribute their views without attending a focus group we also conducted a survey for people who had attended the breast unit. The survey was available online and in paper formats or it could be completed during a structured interview in the clinic or over the phone. It was distributed in the breast clinic, by GPs to patients they had recently referred onto the pathway, by the CCG, by the Leeds City Council citizens' panel, and by the Leeds Society for Deaf and Blind People. The survey content was informed by the results of the focus groups. It contained a mix of open and closed questions that explored preferences for accessing the clinic, where the clinic should be located, how to improve the experience of visiting the clinic and receiving results. A total of 402 women completed the survey: 265 online; 120 in the clinic, and 16 via their GP.

Data analysis

The qualitative data generated by the focus groups and interviews were analysed using theoretical thematic analysis. This analysis technique is based on pre-determined questions that we use to analyse the data, for example, "What are patients' experiences of getting their results?" In this technique the data collected from the focus groups were broken down into units of meaning and grouped in to themes that describe people, their health needs, their expectations of care, and their views about how breast cancer diagnostic services can be developed to improve their experiences and outcomes. Responses to open questions on the survey were analysed using content analysis, and closed questions were analysed using descriptive statistics.

3. Results

We report the results in six sections. The first five sections report qualitative results from focus groups and interviews and are illustrated using quotes. The code after each quote indicates which event (E1, E2, etc) or interview (I1, I2, etc) the quote is from. The first section explores what participants discussed around noticing and acting upon symptoms. The second explores discussions around experiences of the GP. The third is about discussions around accessing the breast unit, including where it is situated, and the support they would like to access before they attend. The fourth explore people's experiences of and ideas for visiting the breast unit. The

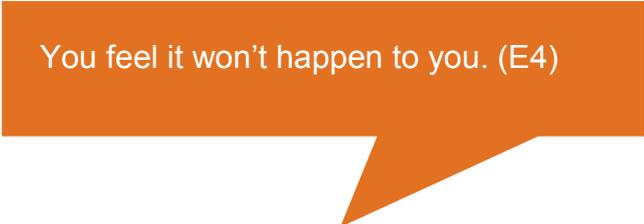
fifth section is about experiences of receiving results and the support participants would like access to after their results. The sixth section reports survey results.

3.1 Noticing and acting upon symptoms

Participants discussed a wide range of emotions that both the fictional character, and for previous patients, they themselves had experienced when they first noticed symptoms. Most of these ranged from feeling anxious to feeling absolute dread and panic. Participants talked about finding a lump or some other symptom as being something they have always feared happening, yet at the same time not really believing it will happen to them. Women from the Gypsy and Traveller community have a particular fear of cancer and are likely to be especially apprehensive. Finding symptoms can therefore be a very frightening experience which can make people feel very alone.



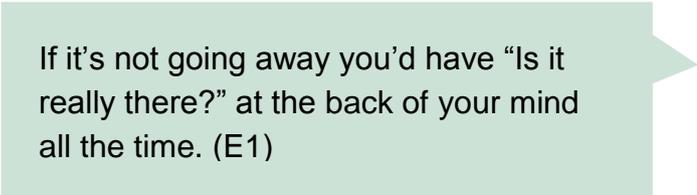
She'd feel terrified, frightened, alone, scared. (E4)



You feel it won't happen to you. (E4)

Some of the younger participants talked about their symptoms being very unexpected because of their age and therefore they felt very scared.

In contrast, some participants talked about feeling embarrassed at the idea of going to their GP in case their symptoms were normal or if they couldn't find the lump when they tried to show their GP. They worried about wasting their doctor's time. They suggested having a specialist nurse attached to a group of practices that they could see instead of a doctor. The nurse could tell them whether their symptoms are something that need further investigation.



If it's not going away you'd have "Is it really there?" at the back of your mind all the time. (E1)

Some participants talked about how busy people's lives can be and this makes it less likely that you act on any symptoms. This was particularly the case for one of the characters (Michelle, see Appendix). Participants talked about how it can seem too difficult to find the time to act on concerns, as there is always somebody else or something that needs attention and everybody else in their life gets priority. For this reason they believed that people can put symptoms to the back of their mind and delay help-seeking indefinitely until either they have more time, which rarely happens, or the symptoms have become sufficiently worse to trigger action.

I work and my initial thing was - I haven't got time for this, I'm too busy... Let's see what things are like after my next period. I put it off and didn't tell anybody and then I forgot because I was so busy. (E1)

Participants talked about using the internet to search for information on symptoms, which can be more worrying than reassuring. Participants discussed how it is important for people to have access to an advice service that can reassure them, where appropriate, or advise them to seek help. They thought that this might be a nurse-led clinic, either attached to a group of GP practices, or at a specialist centre. Alternatively they suggested a telephone helpline or webchat might be a good way to enable busy people who have work or family responsibilities to take action sooner.

It would be good to have a walk-in centre staffed by an experienced nurse. (E2)

There should be advice available immediately, maybe a telephone helpline. (E1)

You could phone the breast clinic, or phone McMillan. (E3)

A GP is too general. The surgery should have a specialist nurse – you should make an appointment with her. (E4)

3.2 Visiting the GP

In line with current practice, all the fictional characters had gone to their GP about their symptoms. Participants talked about the merits of going to their GP, including that it is the usual thing to do if you are concerned about your health. Some thought that a visit to the family doctor is reassuring, as they know you, your family and your medical history. However, some highlighted how it is becoming increasingly unusual to have a family doctor as most practices are large and many use locum GPs, so seeing your own GP can be the exception rather than the rule.

Participants who had visited the breast unit described how they had felt reassured by first visiting their GP. In nearly all cases their GP had told them that it was probably nothing to worry about but to be on the safe side, they would be referred to the breast unit. However, some had experienced difficulties in obtaining a GP appointment

and had felt frustrated at this delay. Some communities are less likely to be registered with a GP and so a GP referral system makes it difficult for them to access the breast unit.

I had to wait three weeks to see a GP because I wanted to see a lady doctor and there is only one lady doctor in my practice. (I2)

Participants who had gone on to have a breast cancer diagnosis were particularly glad they had gone to the breast unit via their GP. They perceived the GP as an advocate who could ensure that they received the most appropriate referrals and did not get lost in the system. They were concerned about their appointment being lost or having to wait for a long time for an appointment.

It's important to have my GP taking charge of the referral. Someone who knows the system and can stop you falling through the gaps is important throughout. (E4)

The GP can demand you are seen within the two-week period. It's good to have strong person when you are feeling vulnerable. (E4)

I don't want to make the appointment, I want someone who knows the system to do it. (E1)

However, some participants were sceptical of the merits of having to first see a GP and considered that this is just how the system has traditionally worked, rather than offering any benefit to patients themselves.

Going to the GP has mainly administrative value. It's so they have it in your records. (E2)

It may be better to cut out the GP and go straight to the clinic. (E4)

3.3 Accessing the clinic

Participants who had received an appointment for the clinic mainly described a very fast and efficient service and were impressed by how quickly their appointment had arrived and how little time there was between being referred and being seen in the unit. While they talked about feeling nervous while they waited, overall they were not unduly frightened over this period. Some had recurrent thoughts of “What if?” which made them feel anxious but this wait was not a particularly dreadful one. Participants described that they, or their character, would feel reassured that they had an appointment quickly.

Some participants had received an appointment through the post and others had been telephoned with an appointment slot. They were satisfied with this arrangement. However, through discussing the characters’ experiences, they identified many ways in which the current system is not ideal. Participants believed that it is important for individuals to have some choice over how they make their appointment. They talked about how if you are having to juggle different commitments, for example work and family, or if you have a job where it is difficult to take a day off, then it is important to be able to choose an appointment, rather than have one allocated to you. One of the participants described how she had been allocated an appointment in the school half term, which had meant she had to bring her child to the unit, which she would rather not have done. There was a lot of support for a walk-in clinic without the need for an appointment.

A drop-in clinic would work best, or you can use choose and book. (E4)

Some participants also suggested extended clinic opening, with some early morning or evening appointments. Less frequently suggested, but also popular, were weekend appointments.

Participants talked about the things that the characters, or they, would like to know before coming to the unit. This included what to wear, where to park, how long to park for, what would happen when they arrived, to bring a book and something to eat, and that there would be a wait in between having tests.

A Leeds Breast Unit patient “idiot’s guide” about what happens, bring a book and something to eat. (E2)

It would be reassuring to know what to expect, do you need to take anything? How long will you be waiting for? What happens in the clinic? What to do while you are waiting? How long do you wait for the results? (E4)

Some participants suggested a Leeds Breast Unit website with information on what would happen during their visit and about what the possible outcomes might be. Some suggested a video would be useful so that they could see the clinic and its staff and would help them feel better prepared.

Participants with experience of the breast unit described receiving an information leaflet that gave them some advice about what might happen and how long they might be in the clinic. However, many felt unprepared for what they found there, both in terms of how they felt, and the practicalities involved.

You need to feel fully prepared – they need to explain how you may feel. (E2)

Participants highlighted, though, that they would not want too much information before their visit as it might frighten them and they might feel overwhelmed. Therefore a “before you visit” section of a website could contain appropriate levels of information, with links to extra information for anybody who prefers to know more.

She should be given clear information about what to expect on the day. The tests and the examination, how long it will take. But not too much information. This is important. She needs signposting where to go for the detail if she needs it but not swamping. You can't take it all in. (E1)

One of the characters has a husband who uses a wheelchair, and participants suggested it would be useful to be able to telephone the unit with questions such as whether it is accessible by wheelchair, and whether the waiting area would be suitable for him to wait in. They believed there may be lots of people with specific questions about the clinic that it would be useful for them to find out the answers to before they arrive.

Someone to call and ask questions, and available out of hours. (E4)

An appointment line to call but make sure it's well staffed and it would be nice to get through quickly. (E4)

Most participants who had attended the breast clinic talked about how difficult it was to tell their family about their appointment. Many decided against telling anybody and confided in friends instead. Many participants talked about how they would have appreciated the opportunity to talk to somebody who had been through the same experience.

Participants had a range of preferences as to where the breast unit should be situated. Some, particularly those who had been diagnosed with breast cancer were reassured that it is within St James's Hospital. They talked about the Leeds Cancer Centre having an outstanding reputation and they felt relieved that they had been referred there. There were more participants, however, who did not find it convenient to go to the hospital. Provided they could have all their tests in one day and in the same place, they preferred to attend a clinic in the community. They believed that this would be easier to travel to and they would have fewer anxieties over parking.

It's worrying that it is in the hospital. You think you have cancer. Hospital's for sick people. You think "Why are they sending me there? I've got cancer." (E4)

It has to be in a specialist unit – where everyone is in the same position – but it might be daunting. It can be depressing. If something just says "oncology" it can be scary. (E4)

One major disadvantage of the current location is parking restrictions. There is a multi-storey car park in which visitors pay on departure but many women described having parked in Beckett Street and spent a lot of time in the unit worrying about receiving a parking fine. Some highlighted that there is a four-hour maximum stay and it is quite possible to be in the unit for longer than four hours, although you don't know that until it is too late.

It feels silly talking about it now, and I know it's small, but I was really concerned about car parking and getting a ticket. This made me anxious while I was waiting for my tests. (E1)

I was panicked about parking. There are only four hours allowed on the car park. (E2)

3.4 Visiting the breast unit

Most participants were full of praise for the care they had received, and appreciated all the tests being done on the same day. Nevertheless several ways of improving the unit were suggested. Participants wanted to feel welcome and confident when they arrive at the clinic yet, despite describing the staff as friendly, many had felt lost, confused and anxious. A solution to this, and one suggested by several participants, is a "guide" who could meet and greet women when they arrive and explain how the unit operates and the options available to them. For example, that if you leave a mobile number at reception it is possible to leave the clinic, and that a corner of the clinic has information leaflets to browse or take away.

It should be a warm, welcoming, relaxing reception. (E4)

It was only when I left that I noticed you can leave your number at reception if you want to nip out. It would have been great to know that before because I wanted to get a drink. (I5)

Participants talked about feeling anxious in case they had been forgotten or they had not heard their name being called. They suggested that the guide could “watch out” for them and make sure that their tests are scheduled. Participants suggested that the guides could be volunteers, especially if they were people who had attended the clinic as a patient previously and therefore understood what they would be feeling. These guides could also tell women where to go after each of their tests. Some participants interviewed in the clinic described how they did not know where they were supposed to go or what they were supposed to do after each test. An orientation session by a guide would help this, or alternatively, staff could escort patients out of each test and tell them what happens next.

I had an idea of what was going to happen but one person to help me through the day, to stop me being forgotten about – would be very helpful. (E4)

Feeling that you might have been forgotten about because you’ve been waiting a long time is an issue. Someone to keep you informed like a buddy or your named nurse would help with this. (E4)

All participants expected that visiting the unit would make people feel anxious. Women who had visited, though, identified many ways in which their anxiety could be reduced. They described the unit as a very busy clinical environment and they would like some changes to make it feel more relaxed. It being busy was not necessarily a problem, and indeed it reassured many people that they were not alone. However, it made the unit feel noisy and confusing, particularly when they did not understand how it works.

There are so many people, it’s full-on and you can’t hear anything. There’s not enough seats and you can’t sit with the person you’ve come with. (E3)

While there is a television and a fish tank, participants had many more suggestions, especially when they were encouraged not to worry about cost but to imagine an ideal clinic. Most important to them is a better way of letting people know how long they are likely to wait. Participants talked about feeling constantly on edge while they listened out in case their name was being called. They had no idea if they were next on the list or if they had another hour to wait.

You don't know how many people are in front of you. (E3)

You're too scared to go to the toilet in case they call you while you're away. (I4)

Participants suggested having different zones within the clinic, with a different focus in each zone. One might be an area in which people are encouraged to talk to one another. Volunteer "buddies" could sit here and get people talking. One could be a quiet zone for reading, one for watching television (with the volume turned up) and another might provide desks and wifi for working. Participants also wanted an area in which they could make a hot drink, or buy something to eat. Another suggestion was an area or room where you could go into to talk to your relatives and tell them the results. A zone for quiet reflection, or "headspace" was also suggested.

You need a mix of private spaces, relaxed areas, and areas where you can watch films or play games. (E4)

You want to be able to sit in a comfortable room, to be able to get a coffee or tea, not just a corridor. I want to read magazines or other information (E4)

There's nowhere to go to get a drink or anything to eat. (E3)

There should be refreshments and toilets easily available so as not to delay staff when they need you. (S)

I don't want to feel on my own when you get there. I want to meet other people. (E3)

You need a room to fetch relatives into so you can tell them what's happened. (E3)

Participants also talked about having inspirational stories around the room, for example showing women who had been diagnosed with cancer yet were continuing to live a happy fulfilling life. However, given that only about 10% of patients have cancer, there is a risk that these stories could be unnecessarily worrying.

It could be a nice environment with poems on the wall, something nice to read, mind games, a word search, creative things, something that you can really concentrate on and would take your mind off it. (E4)

Given that patients are often in the unit for several hours, many participants suggested it would be good to have access to both pampering and practical facilities. Some participants suggested they would like the unit to feel more like a spa, perhaps with patients in dressing gowns and slippers. Some wanted to take their own, others thought it would be better for the hospital to provide nice gowns. This would mean they do not need to get undressed and dressed several times. When encouraged to consider more innovative ideas, some suggested they would like a nail bar and a hair stylist on site, so they could use the time spent at the unit to indulge themselves, especially when they may not get the time to do this in their everyday lives. Some suggested having exercise facilities, such as exercise bikes in one of the zones. Some suggested it would be useful to have a mini supermarket on site. All these would require the facility for patients to place their position in the queue "on hold" and to reactivate it when they are ready to be seen again.

Getting dressed and undressed takes time. It would be better to take your clothes off and for them to stay off. You could bring a dressing gown and slippers – your own, not a hospital gown. (E4)

While there are zones in the unit at the moment, these are based on diagnosis, and some participants talked about feeling "labeled" that they had to sit in the "cancer chairs".

Visiting the breast unit provides a valuable opportunity to give women health promotion advice while they wait. Having a health scare can increase motivation to implement lifestyle changes and so patients in the clinic are likely to be more open to receiving advice and behaviour change interventions. Areas that participants suggested were about healthy eating to help them lose weight, advice on exercise, how to handle the menopause, and a medicines review to reduce the number of prescription medicines they take.

Some participants suggested the unit could be situated within a healthy women centre, which would contain several different clinics and a range of different healthy living activities, workshops and advice clinics. However, as the breast unit also sees men, and male partners accompany women, a more general healthy living centre may be better.

3.5 Results and afterwards

While participants spoke of waiting for their appointment as being an anxious time, they described the wait for their results as being agonising. This is a period of extreme anxiety and reducing this wait would have a major impact on people's experience.

That week not knowing is the worst week of your life. (E1)

Most women would prefer to get their results on the same day, even if this means waiting much longer at the unit.

Participants had mixed views about the best way of getting their results. Women who did not have a diagnosis of cancer are, of course, very relieved. But many would prefer not to have to come to clinic to get their results.

My test results were negative but having to travel and park in the hospital for a five-minute appointment was a waste of resources and time for everyone concerned. There should be an option that if your test results are clear they could phone you with the results or you could still choose to come to the hospital if preferred. (S)

Participants understood that the unit prefers patients to receive their results face-to-face but they described how that doesn't always happen as intended. Several participants described how they knew which women have a cancer diagnosis as they are called by nurses not in uniform, who they assumed were Macmillan nurses. Several described how they could not bear to wait any longer for their results and phoned up and asked to be told over the phone, even if the result was cancer.

You see it's a Macmillan nurse who's called you and you know it's cancer. (E3)

Participants described how, if they anticipate or hear they have cancer, they cannot take any information in when they see the doctor – they feel too shocked to hear or comprehend what they are being told. There could be benefits, therefore, of patients finding out their diagnosis before their consultation with a doctor. They would then be in a better position to ask questions and to have a conversation with a doctor about their cancer and their treatment options.

Having somebody with you when you get given information, who is taking it all in, would help. Because you are often in shock. (E1)

Participants who had been diagnosed with cancer very much appreciated their time with the breast cancer specialist nurses, especially the warmth and empathy they showed and the practical advice they provided. However, some talked about being asked to sit back in the waiting area, or being walked through the waiting area with a nurse who was talking about treatment or support, which they found embarrassing as everybody could overhear. They suggested having a quiet zone where they can sit and take things in, and think about any questions they would like answering before they leave the unit. They also suggested having somebody with them during their consultation with the doctor who could listen for them and remind them what the doctor had said.

Participants who did not have cancer, particularly those who were experiencing painful symptoms, wanted further support after their diagnosis. They wanted to know what would happen next to treat their symptoms. They also wanted information about what they should do in the future should their symptoms recur: should they ignore them or seek help again. Some would prefer to get their results from a nurse, as they believed that nurses would have more time to spend with them.

If you went for a lump, even if it's not cancer it's still there. You still need to see somebody. (E4)

Participants imagined it would be difficult to tell their families. Bangladeshi women and those from the Gypsy and Traveller community believed it might be linked to their culture, but all the focus groups discussed how this would

be very difficult to do. Women who received a diagnosis of cancer talked about how it is very difficult to tell their family and they would welcome advice or support to help them.

I couldn't believe it. I worried about telling my family, or not telling them. What would the consequences be? (E2)

You don't tend to worry the family members, we don't tend to. It adds pressure to the family, especially when you are the mother, you expect them to depend on you, not you depending on them. (E3)

People in this community, if they have got cancer of any type, they don't want to discuss it with their families or extended families. It's not a stigma, I don't know, I just don't see them disclosing it to friends. (E3)

Participants suggested that all patients, both those with and without cancer, would appreciate having a telephone helpline they could use to ask questions after they have received their results. Participants who had cancer described mixed experiences of contacting their breast cancer nurse. Some found them accessible and supportive, and others described how they could only get through to an answer machine and messages were not always returned.

You should have some point of contact and people you can contact night and day. (E4)

You need to know where to go for more information. You want to find things out when you have come to terms with your diagnosis. You need somebody to call with questions when you wake up in the middle of the night thinking about all the things you should have asked at the consultation but were too shocked and scared to do so. (E1)

Many women spoke positively about being paired with a woman who had been through the same process, and who could offer practical and emotional support, including talking about what had happened to them, advice on how to cope with the different situations and treatments they would face, and who could listen to and understand what they were going through. Those who had experienced this were extremely positive about the support it provided.

I don't think she really appreciated, the lady I was paired with, just how much she helped me. She was just so good, telling me what to expect, and just listening. (I1)

3.6 Survey responses

The survey addressed how respondents would like to access the breast unit, their experiences of the breast unit, and how they would like to access their results.

Accessing the breast unit

Respondents were asked what they would prefer to do if they were worried about their breasts. They could choose from: making a GP appointment; making an appointment directly with the clinic; drop in at the breast clinic with no appointment needed; or phone a helpline that can tell them if they need to go to the breast clinic. The percentage giving each response is shown in Figure 1. The most popular options were to engage directly with the breast clinic, either by making an appointment or by using a drop-in clinic.

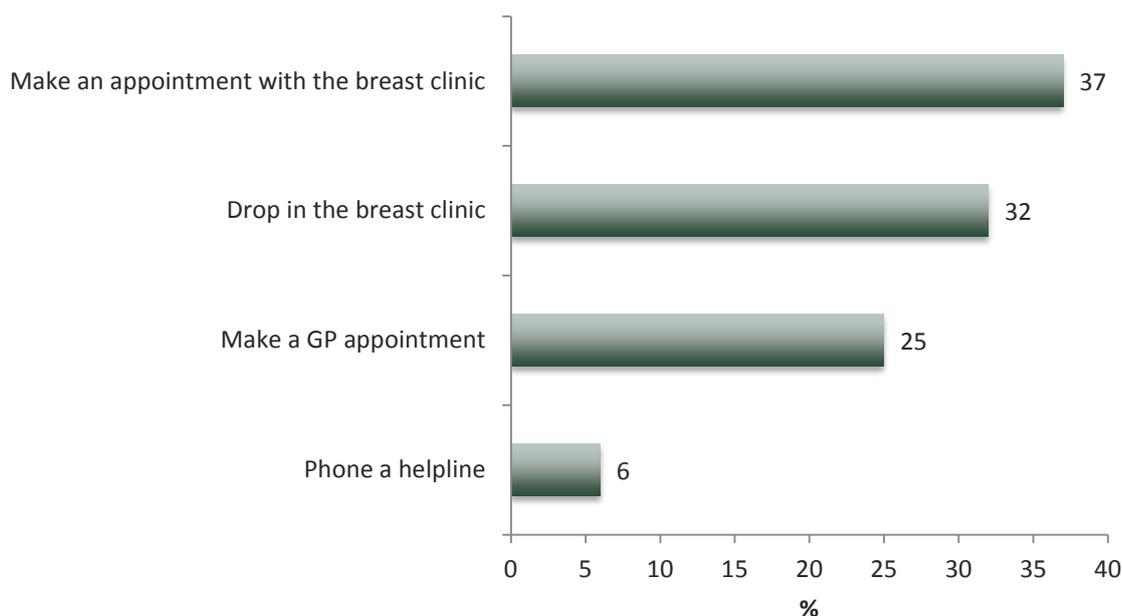


Figure 1: Respondents' preference for accessing the breast clinic.

Respondents were asked where they would like the breast clinic to be located: a clinic at the hospital or at a clinic in the community. Note that the question did not suggest that there would be multiple community clinics but simply

asked about whether the breast clinic should be located within the hospital or in the community. There was very little difference in preferences with 49% preferring a hospital location and 51% a community location.

Respondents were invited to leave further comments about their experience of accessing the breast clinic and their responses were content analysed. A total of 77 comments were made and the proportion of responses in each category are shown in Figure 2 and described below.

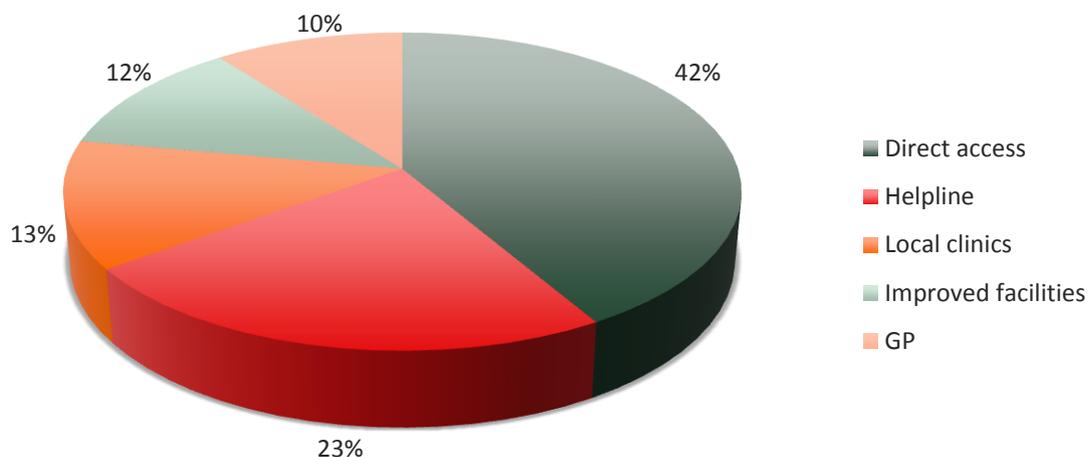


Figure 2: The percentage of comments about accessing the breast clinic in each category.

Direct access (42%)

These responses highlighted how much more convenient respondents would find it to contact the clinic directly to make an appointment that fits in around their family, work and other commitments. It would mean less delay waiting for a GP appointment and no need to take time off work to attend a GP appointment as well as the clinic. They also suggested it would be convenient to have some evening clinics so that people who find it difficult to take time off work could attend. Some respondents suggested an online booking system as they thought it would be more efficient and cost-effective for the NHS. Some respondents preferred a drop-in system to one in which they needed an appointment, but most commented that this would mean longer waits to be seen, and so on balance, they would prefer to have an appointment.

It's more convenient for working women to know when the appointment will be so they can work their job and family around this, especially if they do not wish to divulge they have a problem to an employer. Drop-in would be better but it may be that you would have to wait for several hours to be seen and this could be difficult for workers.

For those of us with “cyst-prone dense tissue” where it’s unlikely to be anything other than a cyst requiring draining it would be good to make an appointment in a 14-28 day window so you can give work more notice you’ll be away from the office for a morning.

Helpline (23%)

These responses are about the benefits of having a telephone helpline that people could contact for advice. They highlight that being able to speak to somebody could result in substantially less worry. They thought the helpline staff would understand how they felt. Many noted, though, that people staffing the helpline would need to have expertise and be able to give accurate advice. Some described previous experiences of phoning NHS Direct / Call 111 when the operator lacks expertise and the default is to refer people to a doctor or to A&E. Respondents suggested it would be most useful for answering queries about whether changes to the breast need to be seen in clinic, and if so, people could book an appointment straight away. They thought that a helpline would reduce the possibility that their GP makes a mistake and doesn’t refer them when they should have been. Some respondents thought it would be reassuring to be able to ask about what happens at the clinic. Some comments were about not using an 0845 telephone number.

It would be great to have a service where you could access advice. I have a family history of breast cancer and sometimes I am not sure about / or have anxiety about breast changes and dropping in and being able to speak to someone who is a specialist such as a nurse would be great. But I would also like to know that if there was a problem I could be referred really quickly, have all the tests and know the result asap, with any follow up treatment not being delayed by waiting lists etc.

A telephone helpline with wide hours of operation (not just 9-5 Monday to Friday) would be helpful as when I was worried about my breasts I was also slightly embarrassed that I was making too big a deal about something that ended up being nothing. To make a call to someone patient and kind would mean saving time for serious cases and would have saved me time booking an appointment with my GP then waiting for an appointment to be booked at the hospital and going there for several hours. Cutting out the “middle man” is a good idea. Phone a helpline first then make an appointment directly with them.

Local centres (13%)

Rather than a telephone helpline, some respondents suggested having local clinics where they could seek advice about their breasts. They thought that this would be a faster more convenient way of finding out whether they would need to be seen at the breast clinic. They particularly liked the idea that it would be easier and cheaper to travel to a local clinic than to go to a hospital. However, some were concerned that it would not be possible to have the same level of skill and expertise in local clinics, and they highlighted that this might mean they lack confidence in the abilities of staff in local clinics. There was therefore some scepticism about how well this could work in practice.

It would be more convenient if the clinics were local for transport and time, if only for the first examination.

Improved facilities (12%)

Some comments were about making it easier for people to visit the breast unit, most often around providing free and plentiful parking. A few also suggested having childcare facilities there would make it easier for them to attend. Some respondents noted that they would prefer the clinic not to be based in a hospital as the environment could be made more relaxing and less austere, especially as most are not "ill". A few commented that the current facilities for people with disabilities are inadequate.

Lots of free parking!

Access via GP (10%)

A few respondents described how they would prefer to access the clinic via their GP. This was primarily because of concerns that if people could access the clinic directly it might be overwhelmed by people who do not really need an appointment, therefore a GP referral system reduces waste. Some respondents preferred to speak to somebody they know. One respondent suggested that you would get a quicker appointment if your GP refers you. One thought that because the GP co-ordinates care it is better that the GP makes the appointment.

Referrals should be through the GP. This is a clear access route and does not rely on knowing numbers or addresses. It also means that initial concerns are raised with a familiar professional and not one unknown.

Visiting the breast unit

Currently, where possible, patients receive all their tests at the breast clinic on the same day. Respondents were asked whether they prefer this or if they would prefer tests spread out over more than one day. There was a very strong preference for all tests to be completed on the same day (98%). They were also asked what would improve their experience of visiting the breast clinic, with a series of options for them to choose from (they could choose all applicable), plus the ability to make additional comments about their own experiences. The options were: knowing more about how long I would have to wait; knowing more about what would happen during my visit; having an explanation of each test at each test room; having access to a “buddy” during the visit who has had a similar experience to me; having separate areas for talking reading, working, relaxing, etc; having refreshments available; an evening appointment; a weekend appointment. The percentage selecting each options is shown in Figure 3.

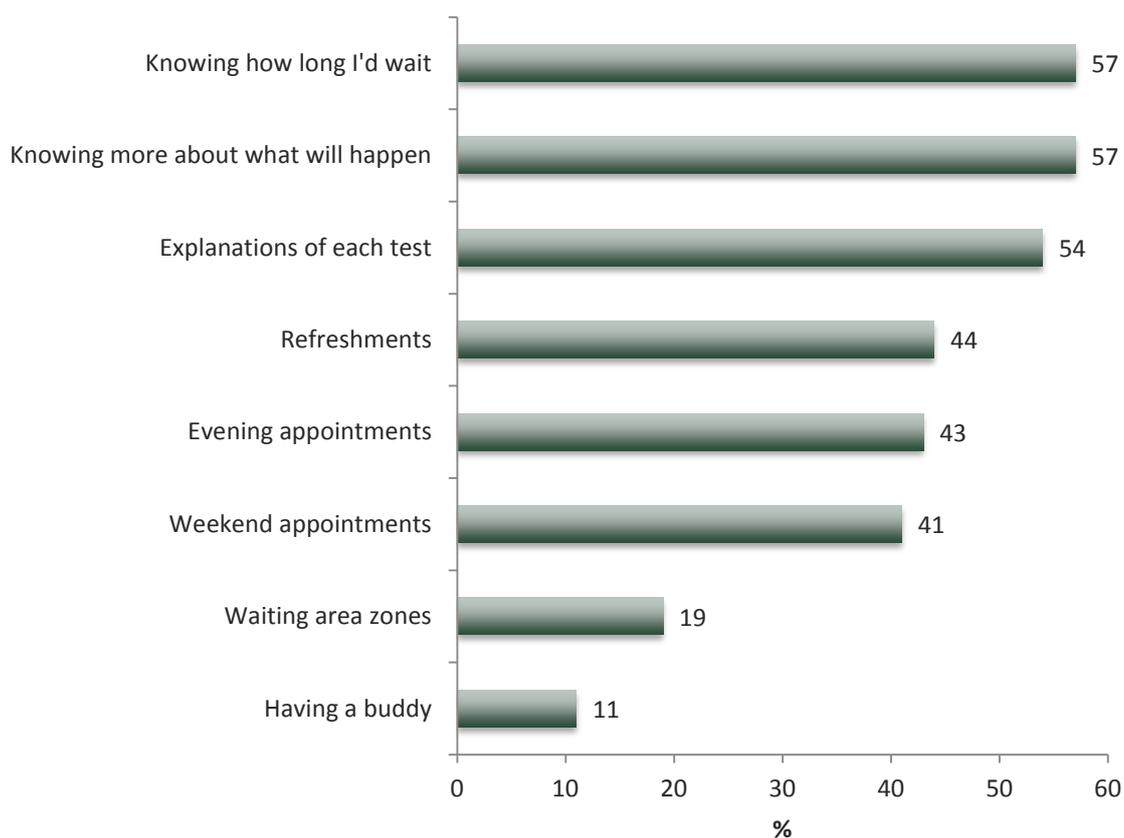


Figure 3: The percentage of respondents who agreed with each suggestion for improving the clinic.

Comments respondents made about their experience of visiting the breast clinic were content analysed and the proportion in each category is shown below. A total of 107 comments were made. Categories are described below.

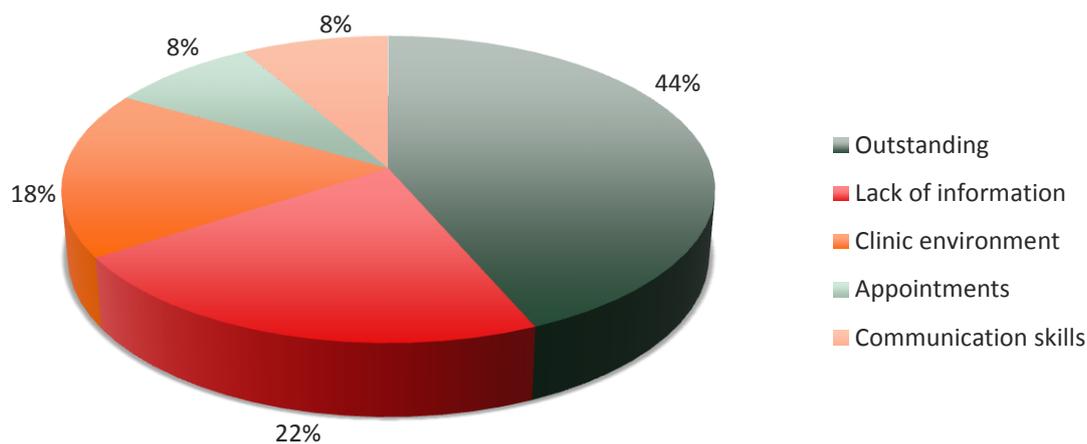


Figure 4: The percentage of comments about visiting the breast clinic in each category.

Outstanding (44%)

Nearly half the comments made praised the breast clinic. It was described as excellent, first class, outstanding, professional and faultless. The service was described as fast and the staff as expert. Staff were also described as being friendly, caring and reassuring, which was thought to be particularly important given the stressful nature of the visit.

My experiences have been thoroughly positive, full explanations, all tests on the same day, really delightful staff, nurses who were extremely kind, patient and helpful. The team was amazing.

Lack of information (22%)

This category contains most of the negative experiences of the clinic and they arise because of a lack of information about what is happening. Respondents described the clinic as being very busy with a lot of waiting around and not knowing what is happening. Some stated they felt they were on a conveyor belt but with little idea of the process or what would happen next or when it would happen. Some reported that many people had the same appointment time, or that they felt confused about when they would be seen and that the staff did not tell them what was going to happen or did not keep them informed about delays. Because of the uncertainty about what was happening respondents described the situation as frightening. Some respondents reported they had not received any information about what would happen in advance of their appointment, and others that the information they received wasn't detailed enough, or did not tell them how long they would be there. Because of the uncertainty about how long they would be in the clinic for, some were anxious about parking. Two respondents believed their

treatment was very unsatisfactory but most were simply dissatisfied because they did not feel they had been kept informed.

The tests at the hospital were grim. It is similar to being on a conveyor belt but not knowing what's happening. Not a pleasant experience at all.

Clinic environment (18%)

These comments are around the clinic environment being an area for improvement. They included the waiting area being crowded, the chairs uncomfortable, and it being difficult to hear staff calling names. Despite the clinic being busy, some respondents commented that they had felt very isolated. Some suggested having quiet areas in the waiting room so that people who feel upset or who have received bad news can have somewhere more private to wait. Some suggested different clinics, e.g. for inpatients and outpatients, or those who are recovering from cancer. Finally, some suggested it would be easier not to have to get undressed and dressed after every test, and it would therefore be easier if they got undressed when they arrived and wore a dressing gown until the last test.

The waiting is stressful and some people get so upset and there is nowhere for them to go.

It's soul destroying having to wait for so long with so many worried people. It's all very scary.

Appointments (8%)

These comments are about respondents having received inconvenient appointments and not being able to change them. This made it more difficult for them to attend, and in some cases, more stressed while they were there. Evening and weekend appointments were also suggested.

Weekends/evenings would be good for people who work.

Communication skills (8%)

These comments were about wanting the staff to have better communication skills, most commonly showing greater empathy, taking into account that women feel vulnerable. The need for good communication skills when doctors give bad news was also highlighted. Some respondents noted that it is important to recognise that people with disabilities or decreased mobility can have difficulty getting into the desired position for a mammogram and staff should be better equipped to know how to handle this sensitively and compassionately.

Members of staff need to be more empathic to women's needs, i.e. respect their privacy at a vulnerable time.

Getting the results

Respondents were given a series of options and asked which would improve their experience of getting their results. They could select as many as applied. The options were: a shorter wait to get results; getting my results on the same day as my tests are completed, even if this means waiting longer; a clinic contact I can phone with questions while I'm waiting for my results; seeing a nurse instead of a doctor to get my results; getting my results by phone if they show I don't have cancer; and information about what to do if I have concerns in the future. The percentage who agreed with each option is shown in Figure 5.

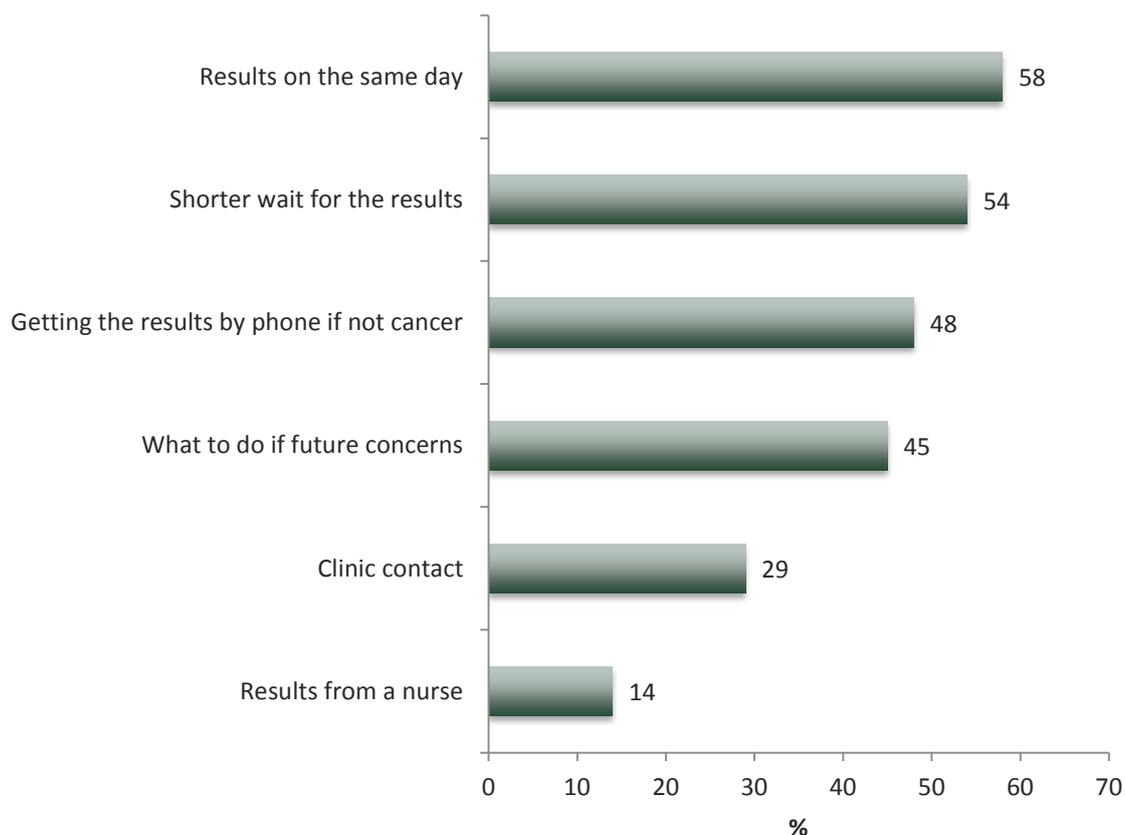


Figure 5: The percentage of respondents who agreed with each suggestion for improving their experience of getting their test results.

Respondents were asked if they had any comments about getting their results. The 66 responses were content analysed and the proportion of comments in each category are shown in Figure 6 and are described below.

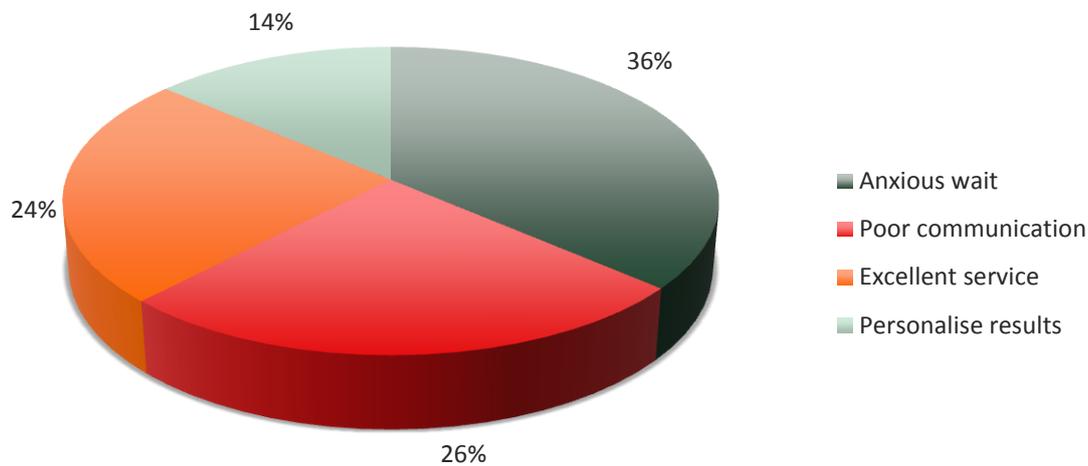


Figure 6: The percentage of comments about getting results in each category.

Anxious wait (36%)

Respondents described how dreadful they found the wait for their results. This time was full of anxiety and uncertainty. They commented that anything to reduce this wait would be important to implement. Some also noted that sitting in the clinic waiting to be called and find out the results is also very stressful.

After being told that “It seems you have cancer” I had to wait two weeks to find out for definite. It was hell – the worst two weeks of my life. I was terrified.

Poor communication from staff (26%)

Comments about poor communication included doctors lacking empathy when giving results, not explaining things fully, using jargon, or not allowing people time to ask questions. It also includes using a channel of communication that the patient did not want, for example phoning them with bad news when they were expecting a letter. A few comments were about delays of months in receiving non-cancer results.

My results were that I didn't have cancer but the doctor gave me no opportunity to discuss why I had a lump in my breast. I was shunted out in one minute and told to be relieved!

Excellent service (24%)

Many comments praised the staff and their excellent communication skills. The clinic was described as efficient and the staff as expert. Those respondents who had received their results on the same day were particularly appreciative, although several respondents who had waited for two weeks for their results were also happy with the service they received.

The process was only a couple of weeks, which I thought was realistic.

I got mine on the same day delivered by a doctor which is very reassuring especially if you have questions.

The specialist doctor was excellent – thorough, kind, reassuring and able to deal with my questions and worries. But – especially if being given bad or complex information, having my husband or family member present would help.

Personalise how people receive results (14%)

These comments illustrate that individuals have different preferences for receiving their results. Some would be happy to receive an email or visit an online portal to get their results. Others would prefer a phone call, and others would prefer to get their results in person. Some prefer to see a nurse in person, especially if it means they can receive their results earlier, and others would prefer to wait to see a doctor.

I believe it is important to receive information by letter where possible.

Online would be good or via email.

Quite a long wait for an unnecessary appointment to give me the all clear which was a worrying time. Could have been a phone call.

Overall suggestions for change

Respondents were asked an open question about what they would change about the breast unit. Of the 401 respondents, 105 made suggestions and 24 stated they couldn't think of any improvements. The 105 comments encompassed a wide range of suggestions for change. They are listed below, together with the number of respondents who suggested them.

- Speed up the system so that there are shorter waits in clinic and a shorter wait for the results (22)
- Encourage the staff to be friendlier, more patient, more compassionate, more personal and more approachable (14)
- Make the clinic less "clinical", more relaxed, more supportive, and more comfortable (10)
- Keep people informed if there is a delay (9)
- Enable people to book their appointments directly with the clinic and to choose their own appointment slot (8)
- Provide more and better information on the clinic process and the tests (7)
- Personalise the service by allowing flexibility for people to get the results in the way they prefer (5)
- Improve the parking (4)
- Improve awareness of and access for people with disabilities (4)
- Encourage the breast care nurses to be more involved with patients and make it easier to speak to them rather than leaving an answer machine message (3)
- Have separate waiting areas for people getting their results and people going for tests (3)
- Offer services in local clinics (3)
- Offer more continuity of care by enabling people to see the same doctor (2)
- Give people more information about what symptoms to look out for in the future (2)
- Undertake breast aware work in the community (2)
- Provide refreshments or have a café in the clinic (2)
- Provide wifi (1)
- Allow people to access support from the clinic in between appointments (1)
- Share the results with other hospitals (1)

4. Conclusions

Our patient insight research gives rise to the following conclusions around what a patient-centred service would look like. We have grouped them into the different stages of the diagnostic pathway.

Noticing and acting upon symptoms

1. At present participants access the breast clinic through GP referral. Generally, women are able to get a GP appointment quickly, although some experience delays. Women can choose to delay seeking help because they're not sure about their symptoms and don't want to bother their GP, who is perceived as being very busy. Some communities are less likely to be registered with a GP.
2. Participants prefer to be able to access the breast clinic directly rather than going through their GP. Most prefer an appointment system as they fear that a walk-in clinic would involve long waits, although some walk-in slots should be available. Extended opening hours are required, particularly evening clinics.
3. Many women who were diagnosed with cancer are happy they were referred by their GP because their GP is aware of what is happening and can offer support throughout. The GP is perceived as their advocate and somebody who can contact the clinic on their behalf if they become "lost in the system". Any direct-access appointment system would need to make women feel confident that they are in control and clear about what to do if they don't hear anything from the breast unit. A few participants had concerns that a direct-access breast clinic would be overwhelmed by women seeking help unnecessarily.
4. Participants would be happy to access a specialist nurse-led clinic, either attached to a group of GP practices, or to the breast unit, that can answer questions. This could be a drop-in, appointment, telephone or webchat service. Nurses would advise women about whether they need to go to the breast unit. The service would need to offer extended opening hours. While a telephone helpline was the least preferred option for accessing the breast clinic, women would use it if they believed its purpose is to advise them on whether their symptoms indicate they need to visit the clinic. It should be staffed by expert clinical staff rather than call centre operators, who can give accurate advice and who can understand how anxious patients can feel.

Accessing the clinic

5. This wait to come to the clinic is a worrying time but not overwhelmingly so.
6. Overall, the current appointment system works well for most women who participated. They were impressed by getting an appointment within two weeks. However, many women want to book their own appointment so that they can organise it around their commitments and, if they wish, arrange for somebody to accompany them. Some would prefer to arrange their clinic visit with more than two weeks' notice so

that they can make plans to be away from work/family. Participants did not want their appointments to be changed by the clinic as it means plans for childcare/work/being accompanied can be ruined.

7. Participants wanted information about what to expect at the clinic. This doesn't need to go into a lot of detail about the potential outcomes for them, but they need to know what to expect. A breast unit webpage would be useful, including a video of the clinic, the staff you might meet, and the tests you might have. The challenge here is to give a realistic overview of the clinic when waiting times vary so much. The website would act as a credible source of information which could help patients to avoid feeling unnecessarily anxious from googling symptoms and tests. Alternative formats would need to be available for patients who do not have easy access to the internet.
8. Women want to be able to phone the clinic if they have any special needs for their visit or any queries.
9. Most women who had a diagnosis of cancer appreciate that where they go for tests is the same place as where they go for surgery. Most others, however, would prefer to go to a health clinic rather than a hospital. Many women talked about how they would like – for ease of travel – to be able to access a small local clinic for tests, most recognised that this could be difficult in practice as it would mean less experienced staff in the greater number of clinics. They would prefer the breast unit – in its entirety – to be relocated away from the hospital to an area with good transport links and plentiful, free parking.
10. Parking is a major anxiety for women as they don't know how long they will be at the breast unit for and the nearest car park has a four-hour maximum stay. They worry they will get a parking fine. While they recognise this is a relatively small problem, it can cause a great deal of anxiety in what is already a frightening situation.

Visiting the breast unit

11. Participants, on the whole, reported having an excellent experience at the clinic. Nearly half of all survey responses about respondents' own experiences were about the service being outstanding. Most problems were underpinned by a lack of communication, especially about procedures and delays, and staff not showing empathy.
12. Participants were clear that they wanted to feel welcome when they arrived at the clinic, and while the staff were generally praised for being friendly and supportive, a lot of participants described feeling lost, confused, and anxious.
13. A "meet and greet" or "guide" system, potentially run by volunteers, would greatly enhance people's experience. Women need somebody to orient them when they arrive, explain to them how the unit operates, and the options available to them (e.g. leaving your phone number and going to the canteen), and that there is a corner of the clinic that has information leaflets they can browse. This guide would "look out for" women and help reassure them that they have not been forgotten if they have been waiting a long time.

14. Some participants were not sure about what they were supposed to do and where they were supposed to go when they come out of a test. The orientation when they arrive, and help from the guide would address this, although staff could accompany women out from the test and tell them what happens next. People's experience of the clinic would be improved if they had more information about the tests during their visit.
15. Participants with disabilities and restricted mobility described difficulties in getting in the positions required for the mammogram and that the radiographers could be impatient, insensitive or lack compassion.
16. Participants described feeling on edge, waiting to hear their name called. They found it difficult to hear which name was being called by nurses because the waiting area is big and noisy. A scrolling list of names or a number system would enable them to see where in the queue they are, and so enable them to relax until their name is towards the top. This would also enable women to leave the clinic for a while if they wished to. Some talked about not feeling able to go to the toilets in case they missed their name being called.
17. Women find the unit very clinical and would prefer a more relaxed environment. They would like the volume on the television turned up, chairs that are more comfortable, and some would like different areas based on what people would like to do, such as for reading, for talking to other people, for working, for getting some headspace (e.g. having a bit of quiet time to think about things or to recover composure after receiving bad news). Wifi would be valued. These zones should be explained to people when they arrive by the guide. Women who have cancer don't like the way they are "labelled" by sitting in a different area of the clinic.
18. Given that women are at the unit for several hours, they would like access to some practical facilities, such as a café and a mini supermarket. When encouraged to think about a radically different service they suggested having pampering facilities, such as a nail bar, or a hairdresser, or exercise facilities such as exercise bikes. However, if they decided to have a manicure or visit the shop they would need to be able to put a hold on their test slot, and to rejoin their place in the test queue when they are available again.
19. Visiting the breast unit provides a valuable opportunity to give women health promotion advice. Having a health scare can be a galvanising time, in which people are more motivated to make changes to their lifestyle. Many would appreciate being able to talk to somebody about diet, exercise, the menopause, or to have a medicines review. Participants believed that this would be a good way of spending the time they are waiting in the clinic.
20. The breast unit could form part of a healthy living hub, in which different clinics are satellites from a centre that offers a range of healthy living activities, workshops and advice clinics. Some participants suggested having the breast unit within a well-woman centre, although given that men use the unit, and men often accompany women, a more general healthy living centre may be better.

Results and afterwards

21. The wait between having tests and getting the results is full of anxiety and reducing this wait would have the biggest impact on improving the patient experience. Most participants would prefer to get their results on the same day, if this is possible, even if it means waiting much longer.
22. Some women described how they found the wait so agonising they phoned up to find out if their results were available and asked to be told over the phone, even if it was cancer. Therefore the system of telling people face-to-face does not always work as intended. Participants had different preferences for receiving their results, including face-to-face, telephone, text, email and online. They wanted a flexible system that could provide results in their preferred format. One possible alternative is that women get a text, letter or email to tell them when their results are ready. They can then choose whether they come to clinic or phone up for them. If they choose to phone they can make sure they are in a safe place with the support they want available to them, e.g. they can phone from home rather than while at work. However, this would require the results service to be available in the evening.
23. Many women said they knew they had cancer when a non-uniformed nurse called them for their appointment. They then found it difficult to hear or understand what the doctor told them because they felt overwhelmed. Indeed, many women who had cancer described not being able to take in what the doctor told them. They would like a quiet zone where they can sit and take things in. They also find it useful to have somebody with them in the consultation with the doctor who can listen for them. Some participants with a cancer diagnosis would appreciate advice on how to tell their family as they can find this very difficult.
24. Many women who had been diagnosed from cancer wanted a buddy system in which they are paired with another women who has had a similar experience. Those who had experienced this were extremely positive about the support it provided.
25. Women who do not have cancer but nevertheless have symptoms, especially painful ones, need to know what will happen next. Women who do not have cancer want to know more about what they should do about any future symptoms. Some would prefer getting their results from a nurse so they feel they have more opportunity to ask questions, as they are aware that the doctors don't have much time.

5. Appendix: Data collection tools

We used three character sketches, and each focus group discussed one of them. Groups were audio recorded and the sheet overleaf completed with the group.

Naseem

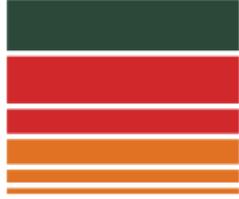
Naseem is 62 and lives at home with her husband in Headingley. They are both retired and she provides full-time childcare for one of her grandchildren. She is not a confident English language speaker and struggles to read and write in English. She usually asks one of her daughters to attend healthcare appointments with her. Her breasts had been painful for about three months before she went to see her GP. At the Breast Unit Naseem had a physical examination then a mammogram. She was very worried about the results as one of her friends has recently had an abnormal diagnosis and is undergoing chemotherapy. When she got her results they showed she had breast cysts.

Michelle

Michelle is 49 and works part time as a careers adviser. She lives in Horsforth with her husband for whom she is a carer. Her husband has multiple sclerosis and uses a wheelchair. She also provides childcare one day a week for her two young grandchildren. Michelle is generally quite worried about her health and has recently experienced some symptoms that she thinks are the menopause. When she noticed some dimpling on the skin of her right breast, she assumed this was part of the menopause symptoms too. After waiting two weeks to see if it disappeared she decided to make an appointment with her GP, who referred her to the Breast Unit. During her appointment she had a physical examination, a mammogram and a biopsy. Her results showed she had breast cancer.

Nadyah

Nadyah is 27 years old and lives in Gildersome with her partner and her 5-year-old daughter. She works full time as a lawyer and has always considered herself to be healthy. Nadyah has had small lumps in her breast for several years but went to see her GP when she noticed that one of them was getting larger. She was referred to the Breast Unit where she had a physical examination and ultrasound. When her results arrived they showed she had fibroadenomas.



SHE NOTICES SYMPTOMS

What help should be available?

What would work best for her?

SHE GETS A CLINIC APPOINTMENT

How could the appointment system work?

What would work best for her?

SHE GOES TO THE GP

How else could things work with her GP?

What would work best for her?

SHE GOES TO THE CLINIC

How else could the clinic be organised?

What would work best for her?

SHE HAS TESTS

How could the tests be organised differently?

What would work best for her?

SHE RETURNS HOME

What should happen next?

What would work best for her?

SHE WAITS FOR RESULTS

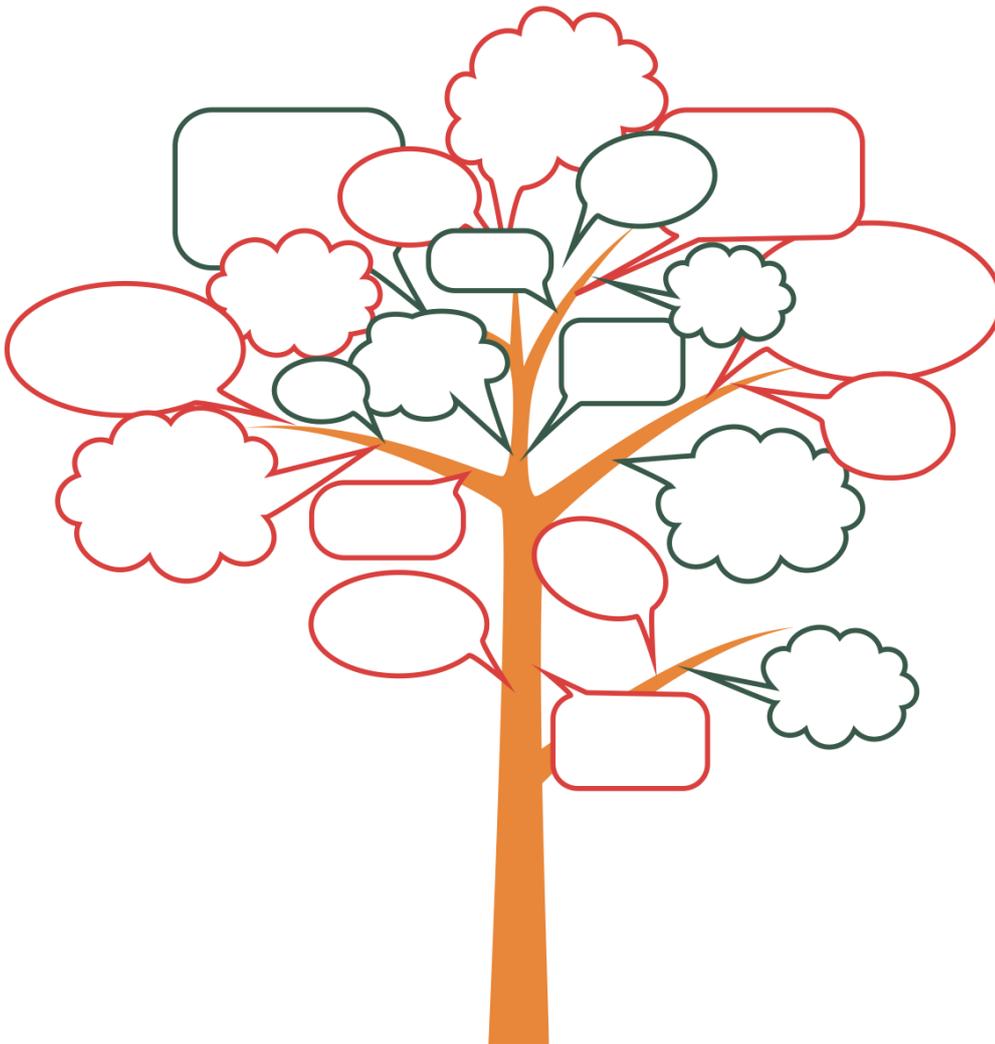
In what ways could she be told the results?

What would work best for her?

How-What exercise

We're going to explore HOW you would like to feel when you use the breast diagnostic service and WHAT about the clinic would make you feel that way. For example, if you want to feel relaxed, what could the clinic do to make you feel relaxed? We're going to create a tree with speech bubbles. The red speech bubbles represent how you feel when you use the service and the green ones are what aspects of the service make you feel like that. Remember:

- Red speech bubbles are HOW you want feel.
- Green speech bubbles are WHAT about the service could help you feel that way.



Post-it-note task

On these post-it-notes, write down up to three things to answer these questions. Use a separate post-it note for each idea. Stick them on the walls

1. What would you: Stop doing? Start doing? Keep doing?
2. What little things would you change to make a difference?
3. What do you think the service will look like in 50 years time?

Interview topic guide

Briefing. My name is..... from Brainbox Research. We're working with the hospital to help them develop a brand new breast clinic to give people the best possible experience. In the clinic today we've got questionnaires for people to fill in and we're interviewing people too about what they think of the breast clinic. The interview will last around 10-15 minutes. We'll go somewhere quiet and we'll make sure that the clinic staff know you're being interviewed and you won't miss your tests. Is this ok? Or you can come and find us after all your tests, if you've got a few minutes spare before you leave. You don't have to take part, and whether you do or you don't, your care at the clinic won't be affected in any way.

If yes.

We're speaking to around 10 women in the clinic. We'll summarise the main things that people say, but nobody will find out who took part or what individual people say. Is that ok? And if it's ok with you, I'm going to switch on this audio recorder, just so that I can concentrate on what you say, rather than taking notes as we go. Only the researchers will hear the recording, and I don't ask your name. Is that ok? You can change your mind about being interviewed at any time – it's no problem and you don't need to give a reason. Just say "Stop" and we'll stop the interview. Ok? But it's a quick interview and it's just about what you think about the clinic.

1. First of all, I'd like to know what you think about coming to the hospital for your tests.

- What are you here for today? How does coming to the hospital make you feel? Would it be any different if you went to a clinic in the community? Why/why not? (prompts – travel, confidence in care received, feeling as relaxed as possible).
- At the moment if you are worried about your breasts you first make a GP appointment and your GP refers you to the clinic. What do you think about you being able to come directly to the clinic without first seeing your GP? (prompts – more or less delay in seeking help, preference for a drop-in clinic or appointment, views on a telephone helpline).
- Did you get enough information on what was going to happen at the breast clinic today? (prompts – what did you want to know, how did you find it out, how useful and understandable was the information). Is there anything you know now that would have been useful to know before you came to the clinic? Is there anything that you're still not sure about?

2. Now I'd like to talk about the clinic itself.

- How could the clinic be changed so that is a better place to wait for your tests? (prompts – when you first arrive, facilities while you are here, being kept informed while you wait).
- Would you like to be able to get any more general healthcare information or advice while you are here? Why/why not? If yes – what sort of advice? (prompts – diet, exercise, women's health, medicines you're taking, general health).
- What about the tests themselves – is there anything you'd like to change about them? (prompts – what you are told about them, where they take place, the staff who do them).

3. Finally, I'd like us to talk about getting your results.

- At the moment everybody comes back into clinic to find out their results. Is this ok, or would you prefer to find out some other way? (prompts – through your GP, a letter, a phone call, online, seeing a nurse instead of a doctor here in the clinic, anything else,).
- What information would you like to get with your results? (prompts – what happens next, what to do if the symptoms continue, what treatment options there are, a contact if you have questions).

That is all the questions I wanted to ask. Thank you very much. Is there anything that we've not yet talked about that it would be useful for me to know? Can I just ask your age? And the first part of your postcode? And have you had your test results yet? (if yes, what was the outcome?)

Debrief. Thank you so much. We'll summarise all the comments and suggestions and feed them back to the hospital. I really appreciate your help. Do you have any questions for me? If you change your mind about taking part, and you don't want us to include your suggestions, just get in touch to let us know today or tomorrow. Also, get in touch if you have any questions at all, or you think of anything else you'd like to add.

Help us re-think the Leeds Breast Unit

We are currently looking into the services provided at the Leeds Breast Unit based at St James's University Hospital. We want to develop a brand new service, designed around the needs of our patients, and ensure that people have the best possible experience. We want you to help us decide how we can do things differently. Please answer these questions to tell us what you think.

1. Where would you like to access breast clinic services? (please tick one option)

- Hospital Clinic in the community

2. What would you prefer to do if you are worried about your breasts? (please tick one option)

- Make a GP appointment
 Make an appointment directly with the breast clinic
 Drop in at the breast clinic, with no appointment needed
 Phone a helpline that can tell me if I need to go to the breast clinic

If you have any comments about how you would like to access the breast clinic please tell us here.

3. When you visit the breast clinic which would you prefer? (please tick one option)

- All tests completed on the same day Tests spread out over more than one visit

4. What would improve your experience of visiting the breast clinic? (please tick all that apply)

- Knowing more about how long I would have to wait
 Knowing more about what would happen during my visit
 Having an explanation of each test at each test room
 Having access to a 'buddy' during the visit who has had a similar experience to me
 Having separate waiting areas for talking, reading, working, relaxing etc.
 Having refreshments available
 An evening appointment
 A weekend appointment

If you have any comments about your experience of having tests at the breast clinic please tell us here.

5. What would improve your experience of getting your test results? (please tick all that apply)

- A shorter wait to get results
- Getting my results on the same day as my tests are completed even if this means waiting longer
- A clinic contact I can phone with questions while I'm waiting for my results
- Seeing a nurse instead of a doctor to get my results
- Getting my results by phone if they show I don't have cancer
- Information about what to do if I have concerns in the future

If you have any comments about your experience of getting your test results please tell us here.

6. What would you like to change?

If you would like any changes to the clinic to improve your care or experience please tell us here.

Could you help us further by telling us more?

We'd love to find out more about your views on how our service could be different in the future. You don't need any special experience to take part. We can interview you here in clinic – just speak to the researchers who gave you the questionnaire – or you can speak to us at a later date. Would you like to:

- Be interviewed on the telephone
- Come to a focus group

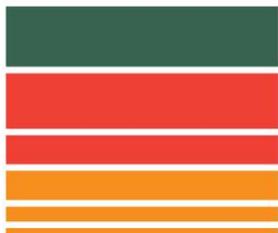
If yes, please leave your contact details.

Name..... Phone.....

Email.....

Please give this questionnaire back to the researchers or collect a reply-paid envelope to post it back to us for free. Thank you.

Brainbox Research



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