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# Exploring Low Uptake for Breast Screening in West Sussex Report

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# Context

Currently, women registered with a 'GP – general practitioner, or family doctor – are automatically invited for their first breast screening between the ages of 50 and 53 and are invited every 3 years until the age of 71 years. After 71 years women can request the screening.

If you have not been invited for breast screening by the time you are 53 and think you should have been, contact your local breast screening service.

## For West Sussex, the service contact details are:

The Breast Screening office

Call: 01903 239757

Email: uhsussex.westsussexbreastscreening@nhs.net

## West Sussex breast screening programme

If you are male, <sup>2</sup>trans man, trans woman or are non-binary you may be invited automatically, or you may need to talk to your GP surgery or call the local breast screening service to ask for an appointment.

The West Sussex data for Breast Screening coverage shows that the take up of the invitation for Breast Screening was 66% in 2021/2022, a reduction from 72% in 2019/2020.

The NHS provide a number of **tools** to help women decide if they would like to attend the screening and about the process.

The aim of this project is to understand what the possible barriers are to taking up the offer of the Breast Screening invitation. This will enable appropriate changes to be considered or made to improve the experience and increase acceptance of the invitation.

I hear many people say, they are too busy to attend routine mammogram screening, or they find it uncomfortable or embarrassing, my response is you cannot afford not to go.

### Survey response

I was diagnosed with breast cancer from my first mammogram at the age of 50. If I had not gone, I wouldn't have been so lucky as I had no lump and no symptoms.

1 <https://www.nhs.uk/conditions/breast-screening-mammogram/>

2 <https://www.nhs.uk/conditions/breast-screening-mammogram/when-youll-be-invited-and-who-should-go/>

# Our approach

This project is a partnership between West Sussex County Council Health Protection and Screening Manager, NHS England, NHS Southeast Cancer Screening and West Sussex Breast Cancer Screening.

The approach consisted of a survey and follow up telephone conversations. The information contained in this report is from the Breast Screening survey responses and the follow up conversations.

The survey was open from 18th July until 29th October 2023. 12 telephone conversations were conducted with local people who had completed the survey and provided their contact details.



The survey was widely promoted across West Sussex, supported by the partnership.

The survey has been fully or partially completed by 531 people -484 responses are from West Sussex residents and 47 responses were received from residents living outside of the West Sussex area and do not form part of this report.

A specific flyer was created with a QR code to speed up access to the survey.

## Thank you

We would like to 'thank' all of the local residents who have supported this work, those who reviewed the initial survey, completed the survey, and the 12 people we spoke with who shared their stories, to support this important work.

# Findings

The survey and telephone conversation responses highlighted one recurring theme, that staff at the Breast Screening Centre's conduct the Breast Screening process in a professional way and are efficient throughout – from the initial contact to the final letter.

The survey informed that 66% (322) responses do attend the Breast Screening appointment when invited, which is in line with West Sussex data for Breast Screening coverage 2021/2022.

I go to the mobile unit at Sainsbury's or K2 here in Crawley. I receive a letter with a date and time to attend and can change this by telephoning if not suitable. I prefer to receive a proper appointment than a drop in type, as you know how long you will have to wait and do other things. With regards to what might help the process, very little as the mobile unit is close to where I live, I can drive in 10 minutes and walk to the K2. I have privacy in the unit and the staff are great.

**Conversation Crawley resident**

Experience was fine. Staff nice and reassuring. Quick and painless procedure. I cannot understand why 25% of women do not take it up. Screening saves lives and detects undetectable lumps.

**Survey response**

## The top 3 reasons why Breast Screening invitations are not taken up.

1. Personal or work commitments (n29, 24%)
2. Fear and embarrassment (n20, 17%)
3. Lack of on-line booking. (n15, 13%)

The reasons given for not attending when invited include, experience of the service (negative), reasons why they do not attend when invited, administration and information issues, staff, not being invited for the screening as over 70 years, not being invited for screening as under 53 years, transport and parking, dignity, pain and discomfort, disability, and accessibility of the screening unit, working age, and personal choice.

Other reasons were location of appointment, unsure about the breast screening examination, inconvenient appointment, lack of suitable appointments, and lack of support.

It is important to note that 20% (n98) responses are from carers, and 4.5% (n22) stated that being a carer would affect their ability to attend an appointment due to; time, transport considerations, appointments (which need to be flexible), and work commitments.

The survey also captured that 16% (n79) of respondents have a disability, 33% (n160) stated they have a long-term condition. 5.7% (n28) stated that their health condition would affect them attending a screening. The main reasons cited, impact of health condition, difficulties accessing the screening and needing more flexible appointments and support.

Disappointingly, people stated they experienced poor communication from healthcare professionals. This included some people feeling not listened to, not treated with dignity by the process, how staff communicated instructions during the procedure and when giving results.

# Suggestions to increase Breast Screening take up

Suggestions were provided as to what might help the take up of the invitation; more flexible appointments such as being able to book a specific appointment – *a bit like booking a table in a restaurant.*

To have an on-line option for appointments. A drop-in session and appointment being available in evenings and at weekend. This was especially important for those with work and caring responsibilities.

The location of the appointment needs to be provided locally and consider transport, parking, and location environment.

Someone raised the issue of public transport in rural areas, which could offer an opportunity of partnering with local community transport schemes.

Another respondent stated that the mobile unit can be too hot during the summer as there is no air conditioning.

Other ideas shared included promoting the service through social media and wider promotion within local communities. Maybe, a road show to various women's health, using videos, including a short quote from a patient in the invitation letter, a description of the process and links to information and to promote reassurance that the screening is done by women only. To have on-site or remote access to a nurse or health worker, running internal health and wellbeing campaigns.

Responses to the survey suggested promotion using celebrities and TV stars such as from Strictly Come Dancing, who have been diagnosed with Breast Cancer. Case studies or a quote was suggested to be included in the appointment letters.

A slight change could be made to the screening letter for those approaching 70 years, from the current wording of 'not automatically invite you.' To add the <sup>3</sup>contact details of who to contact to continue the screenings. This would be more helpful and supportive to attendees.

It was really easy to access, I went to a community centre, with free parking where there was a breast screening van: I waited 5 minutes and was seen by some lovely friendly staff. The whole screening was pain free and done in 10 minutes. Then I got a letter in the post a few weeks later with the outcome which fortunately for me was ok.

Survey response

I found the experience really professionally run and positive. Women are not clear on the risks associated with breast cancer and the benefits of early screening.

Survey response

Confirming the appointment by message along the lines of; if we do not hear from you to confirm the appointment, we will offer it to someone else.

I couldn't make the first appointment due to work commitments, but it was very easy to change the date - I emailed and got a reply almost immediately with a date the following week.

**Survey response**

With regards to accessibility, the letter could state that 'if you need support, do let us know,' as this would make people feel more comfortable to speak with the team and for the team to expect another person.

It is worth saying to the receptionist that you are in a wheelchair as this stopped a lot of anxiety for me.

**Conversation Adur resident**

The age of the screening beginning, and end was a cause of concern, as cancer does not always have a physical signs of a lump regardless of age.

A number of people suggested that the screening should be clearer as to when it begins and continues until the age of 80 years.

Many younger women are scared because they think the screening can cause cancer. This message needs to be debunked.

**Survey response**

# Summary

**In summary, there are many reasons as to why invitees attend the Breast Screening invitation such as the process, arranging an appointment, location, age range and access.**

The top reasons stated for not attending included: due to work commitments, fear and embarrassment and the booking process. The system does need to consider a more flexible appointment approach for those with caring responsibilities and disabilities.

From the suggestions shared by responders, minor changes to the invitation letter are needed, more flexible appointments, considerations for locations with better parking and transport access. Promotion of the service through social media, and local communities, maybe local roadshow to promote that women complete the screening, to reassure.

One area that came through very strongly was how much responders appreciated the professionalism and efficiency of staff throughout the breast screening process.

## Next Steps

**This report has been shared with West Sussex County Council Health Protection and Screening Manager, NHS England, NHS Southeast Cancer Screening Lead and West Sussex Breast Screening Lead.**

Our aim is that the findings contained in this report and supplementary information (not published) will help inform appropriate changes to be considered to improve the service. Ultimately to increase the take-up of the Breast Screening invitations for the service.

# Appendix a

## Conversations by themes.

12 telephone conversations were conducted with local women who had completed the survey and provided their contact details. These conversations covered the whole of the West Sussex area.

Adur	1	Arun	1
Chichester	3	Crawley	2
Horsham	3	Mid Sussex	1
Worthing	1		

The main themes from these conversations were, appointments, work and appointments, transport and appointments, location, process, aged over 70 years, accessibility of the screening unit, and staff.

## Appointments

There were many reasons stated as to why the appointment was not attended, from misplacing the letter, not being offered a suitable date and time. For some people not having someone to support them during the screening.

The time of year was also an issue for some due to being very busy.

I went for my first scan in March but was sent the request to make an appointment about 5 days before Christmas, at that point of time it is the last thing you are going to do, as trying to get organised for Christmas. When I did get round to making the appointment they had moved out of area. The person on the phone seemed to want me to say 'oh I will leave it' I had to ask, are you in any other area of West Sussex as am happy to travel. I was then informed about being in Crawley. I did travel to Crawley for the appointment, but I think some people would not bother. It is the same as sending out appointments in the summer when people are going on holiday

**Horsham resident**

## Work and appointments

Employer flexibility helped some to arrange medical appointments. Equally employer inflexibility created challenges for some women to fit the appointment around their working day. Some employees felt uncomfortable requesting time off.

Even though the employer is committed to staff health and wellbeing. This may affect staff ability to request other necessary routine medical appointments.

If working, it may be more difficult. If people do not get time off work and have to take as annual leave this may make it more difficult.

**Horsham resident**

## Transport and appointments

The mobile unit although sited at key points within the community can be difficult for some to attend due to not having transport and time of the appointment. The site of the unit needs to be in a more central location.

The mobile unit in Crawley is at K2 and would be better for some people especially those living in the Bewbush or Broadfield areas as the buses do not connect easily.

**Crawley resident**

The first time I visited the mobile unit I did not know what to expect but it was fine. If the suggested date and time is not suitable you can always ring the number and change it.

**Chichester resident**

I have never found the location an issue, at hospital and I do have to pay for parking. I can also use the bus (one runs every 20 minutes) to get there and live rurally in the Chichester area.

**Chichester resident**

The location is fine as I have a blue badge and can park. If I did not have a blue badge, it might be trickier as the car park is small.

**Adur resident**

## Location

When booking appointments some women were offered an appointment many miles away from their home and not for the one closest to them. This increased the difficulty of attending for some due to lack of transport and time needed to get to and from the appointment.

Just the location. Haven't been to a screening since it moved from Bognor, but I would make every effort to get to Worthing if that's the nearest one when I need to go again.

**Arun resident**

## Process

The main concerns around the process were having to wait for the result, and the directions given by staff during the screening for some was difficult. There was also some miscommunication as to why the screening was being completed.

I receive a letter in the post within 10 days and when the next screening will be due.

**Crawley resident**

I have heard that some people think that breast screenings are only needed if you have checked and found something.

**Mid Sussex resident**

Really smooth service.

**Adur resident**

## Aged over 70 years

The main issues for those aged over 70 years was not being invited for the screening automatically. The final letter received does not state who to contact to continue to receive an invitation.

The response letter states; 'not automatically invite you.' There are no contact details of who to contact to continue screenings.

**Crawley resident**

Having recently spoken to a friend managing a cancer diagnosis, the person admitted to ignoring the signs. Although the reason for this is unclear, it may have been due to fear.

**Chichester resident**

I got to the age when I wasn't called automatically but I self-referred and they were very helpful. It is important to me.

**Chichester resident**

## Accessibility

The main areas of concern under accessibility were not being sure if they could bring someone along to support and help them and to feel more comfortable about the process. Some women cited that access to the mobile units can be difficult, slippery when wet, high kerbs from car park to where the unit is.

Some people might feel more comfortable if they are able to take someone with you.

**Chichester resident**

I am in a wheelchair, and they ensured that the screening was on the ground floor, and they adjusted the machine, so all was ok.

**Adur resident**

I did have someone push me from the car park to the unit as the curbs are high in the car park, not in the centre.

**Adur resident**

For me no, but the stairs on mobile caravans can be a bit of an issue for those with mobility problems, especially if it's wet as they are metal and can get slippery.

**Worthing resident**

## Staff

The 12 women we spoke with stated that, all staff they engaged with were supportive and professional.

Health Care Assistants and Radiographers have all been welcoming. Apprehensive the 1st time but put me at ease. Last time the changing room was in the same room. Really well organised.

**Arun resident**

The technicians are always very helpful.

**Worthing resident**

## Other comments

Don't understand why people would not want to. If you catch it early, it is treatable.

**Horsham resident**

I think younger women should be called for screening as women much younger can get breast cancer and it's better to check things out before they happen. Prevention is better than cure. .

**Worthing resident**

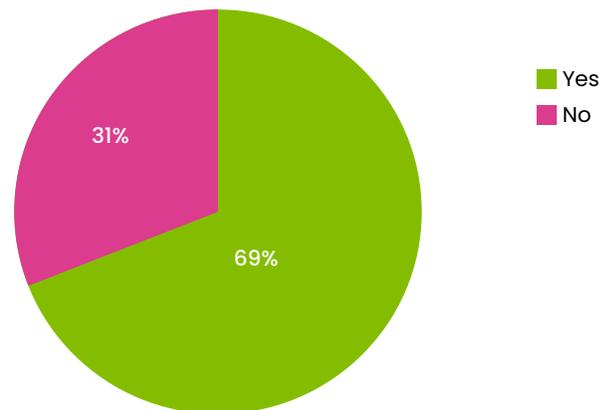
# Appendix b

## Survey responses in detail.

### Q1. Do attended Breast Screening appointment

322 (66.5%) people confirmed they **do attend** the appointment when invited for Breast Screening.

Attend Breast Cancer Screening appointments



There were 261 individual responses received covering the following themes:

- Experience of service (positive, n104),
- Reasons why they attend when invited (n14), experience of service (negative, n22)
- Reasons why they do not attend when invited (n8)
- Administration and information (n29)
- Staff (n26)
- Not invited for the screening as over 70 years (n44)
- Not invited for screening as under 53 years (n15)
- Transport and parking (n14)
- Dignity, pain (n5) and discomfort (n22), disability and accessibility (n6)
- Working age (n4)
- Personal choice (n5)

I was nervous when I went to my first appointment, as had been told by family and friends, it's very painful, a 'mangle gram.' However, the nurses put me at ease and although a little uncomfortable, definitely not painful! I have told my younger family and friends about this and insist on them going.

**Survey response**

# There were a number of suggestions offered and comments.

## Process – positive experience

- It was much easier and less invasive than I thought it would be.
- Mobile unit parked locally made it easy to attend. They kept appointments to time.
- Always efficient, discreet, professional, and gentle during scan.
- Could not have been more thorough and quicker.
- It's always a very pleasant experience.
- Brilliant. Considerate. Informative. Amazing.
- Very happy with the service – intend to request continuance after age 71.
- Very professional service.
- Very quick took less than 10 mins for the screening process. The radiographer was very professional and put you at ease. Not at all embarrassing and can save your life by detecting changes.
- Excellent, arrived on time, scanned on time, gentle radiographer. Prompt results.

It is straight forward, and the screening ladies always explain what will happen and they are very patient and helpful. There is nothing to be scared about and it is something that I believe every female of screening age should have done.

Professional, efficient, relevant information given, felt looked after and put at ease. I was able to rebook my appointment to attend at my place of work (hospital) therefore more convenient.

## Comments as to why they attend when invited

Experience was fine. Staff nice and reassuring. Quick and painless procedure. I cannot understand why 25% of women do not take it up. Screening saves lives and detects undetectable lumps. Due to family history of breast cancer and having previously found a lump. I have had yearly screening appointments during my 40's.

Quick, easy, and painless – I have attended Breast Cancer Screening appointments regularly throughout my life. Although it feels unnatural to me to have my breasts touched by a stranger, I have always been treated with the utmost respect. I have noticed that as I have aged and my breasts have gotten bigger, it feels less painful to have this procedure. It has sometimes felt a bit like a factory line process, but I don't think this can be helped if it is to remain efficient.

There was no waiting, and the screening only took 5 minutes. The radiographer was very kind and gentle as she could be considering the procedure. It is only a few seconds of discomfort. For me breast screening provides reassurance that everything is ok. And if any abnormality is found, it can be treated early.

## Process – negative experience

- Was a mobile unit, felt clinical and rushed.
- I have had breast cancer, and I was told this would be known by the staff doing the screening. They didn't have a clue; this information should be passed on to them.
- The care and professionalism can vary which might impact on people's decision to attend again.
- A friend told me she doesn't attend because she doesn't want her breasts manhandled and to feel like a piece of meat (despite the risks to her health of not knowing if she has Breast Cancer).
- A bit hard to find the mobile unit.

## Comments as to why they do not attend when invited

- I believe some women don't go out of fear of a negative result and the consequences of hair loss, chemo, breast removal etc. My mother had breast cancer and the treatment was horrible.
- The machine was not working the last time I had a screening at the mobile unit at St. Richards Hospital, and I had to be recalled to another screening, I was really nervous about having two lots of radiation going through my body, but I did attend.

After much hesitation, I did attend the screening, however, the staff were helpful, but I was particularly concerned to read the secure code for the entrance door on public display on the staff whiteboard.

## Administration and information

Additional procedural information would be helpful, especially when attending for the first screening.

- Please may I have a breast screening appointment?
- Am currently working away in Scotland and would be glad if signposted to a clinic near me in Elgin.
- I have chased two or three times for an appointment I'm 51 but told there's a waiting list. My cousin who lives in Surrey had her first check up when she had just turned 50.
- As it is almost impossible to see a doctor how does one book an appointment for a screening. Can they be booked on line?
- I attend the Park Centre clinic in Brighton, which is East Sussex, but I'm based in Chichester, West Sussex. Ideally, I'd prefer not to go to Brighton but I'm just grateful to be on the screening programme.

I received a letter asking me to phone to book my appointment, when I rang, I was told there were no appointments in my area and that I need to call back in a few weeks. This is very poor patient experience and puts the onus on the patient to keep calling until there are slots in their area.

If wanted to alter appointment people on phone line very obliging.

I live a 2-minute walk from the breast clinic in Worthing but have to go all the way to Preston Park for screening which led to me having to take time off work and travel miles. I was told I couldn't be transferred to Worthing. There is no parking available at Preston Park which makes it difficult.

## Comments about Staff

- The staff were lovely; for something that felt quite undignified, they made it feel normal.
- Lovely lady who explained everything.
- Nice to have female clinicians.
- The nurse was rude to me when I told her I believed in preventative medicine and had breast screening privately for years and this was my first NHS. I had taken my stuff with me. I was so shocked.
- Professional staff. Empathy, support, and kindness. Felt at ease.
- Staff were very friendly and helpful and reassured me throughout.
- My latest experience this year, I felt part of a production line in how the test was carried out.

I found the staff very helpful, and the surroundings are brilliant. However, it is a **terrifying experience** and one that could be life altering. I do not know if I would have attended if I did not have support.

The screening went very well, and the staff were absolutely lovely.

## Not invited for the screening as over 70 years

- I always attended my appointments; I am now 78 years of age, well past the qualifying age group.
- I haven't been invited because I am over 71.
- I attend even though I am above the age you are sent for.
- As I am over 70, I have to remember to request this.
- I am 79 and have opted to continue screening as I was on HRT for a number of years.
- I don't think breast screening should stop at 71.
- I'm over 73 and no longer get invitations but still think it is important to have breast screening. Therefore, I make the effort to contact the breast screening service and have attended when an appointment has been made.

It would be a better idea, if we were asked at a certain age if we wanted to continue to be called for screening if it is not to be carried on after that age. Don't just abandon us. I know ladies who have had breast cancer after the age of 71. It is not a given that you are too old to get it.

I am 76 years old, so I now have to request a mammogram appointment which I think is a great pity. If catching breast cancer in the early stages is vital the NHS must be proactive and recall older women automatically every three years, not leave it to the individual. There is even a poster in my GP's surgery saying that breast cancer doesn't only affect the young so why penalise older women. They should have regular appointments too. If they then decide not to have a mammogram, then that is up to them. The appointment should be offered not asked for.

## Not invited for screening as under 53 years

- Not old enough, but service should be available, starting younger even if offered every 5 years to allow for it.
- I'm 51 and will definitely be attending when I'm invited for my first one and subsequent follow ups.
- I haven't had a breast screening appointment, I was diagnosed with breast cancer at age 46, below the screening age. I thought screening was supposed to start earlier than 50 these days.
- I am shocked I haven't had an offer.
- I have not been offered an appointment.

I have not been invited. I am under 50 and have recently been diagnosed with breast cancer. A cancer that could have been diagnosed earlier with breast screening, for which the age should be lowered. Early stages of cancer give you more chance to fight the illness. Targeting women at an earlier age would increase awareness. If there has not been enough uptake from over 50s, why not relax the rules and lower the age - at least during the awareness month.

I was diagnosed with breast cancer from my first mammogram at the age of 50. If I had not gone, I wouldn't have been so lucky as I had no lump and no symptoms.

I have just today been to the breast clinic expecting to get a mammogram which was not done because I am not 50 and do not meet the criteria of being ILL!!!!!!

## Transport and parking

- I had to travel from Horsham to my appointment at Worthing hospital. I would have preferred a location nearer home.
- I really dislike having to attend a van parked in a car park of a Tesco's superstore. It is not discrete and the whole area is usually busy. I get there is parking, but it isn't exactly private. Last time some of the teenage boys I teach were hanging around the area.
- Had to travel 15 miles to the local hospital.
- It was far easier to have locally as no travel or Parkin cost and saves time and no need to take time off work.
- It was fine, however I had to go to Worthing which I imagine would deter many people from attending, through cost, time, and similar concerns.

I found it difficult to get parked at Princess Royal Hospital, I was 5 minutes late for my appointment and they refused to screen me, saying they had already switched the machine off for the day. I had to re book. There was a complete lack of flexibility. I re booked, as I prioritise this screening, but I can well imagine that many women would not have bothered.

## Dignity

- Lack of privacy when undressing before screening.
- A good experience. Well organised and the staff kept my dignity.
- It's just uncomfortable and lacking dignity.
- I find the occasion demeaning and physically uncomfortable.

## Pain and discomfort

- Very quick and pain free – just a small amount of discomfort.
- No problem for me but I do understand that many ladies experience severe pain which puts them off going.
- Usually, they hurt like hell and most of the nurses have been abrupt, impatient, and uncaring. No wonder a lot of women don't take up the offer.

Personally, I don't feel any changes need to be made – it is women's perception of the experience especially when on occasions friends say the clamps on the breast's hurts. To my way of thinking better to have 5 seconds feeling uncomfortable than what I could go through during chemo or other treatment when left too late.

It is an uncomfortable experience and can be quite painful! I hear many comments from other women that they won't attend because it is such an unpleasant experience!!

It is very painful, and I worry that it might cause damage – surely a kinder method could be used?

## Disability

- My experience of Breast Screening is usually good, especially my last one where the radiologist suggested, I could sit down for the screening as I have a bad back, and so it was more tolerable.
- I am elderly and have had a stroke. The appointment made for me was out of my town (Crawley) and I could not attend as it is not accessible for me.

I recently took a friend who suffers from severe agoraphobia and the staff were so kind and understanding. Helping to make my friend feel as comfortable as she could, allowing me to stay close by and providing reassurance. Again, I have nothing but positive things to say about the two members of staff on duty on the day we attended – 10/10.

## Working age

- Very quick and pain free – just a small amount of discomfort.
- No problem for me but I do understand that many ladies experience severe pain which puts them off going.
- Usually, they hurt like hell and most of the nurses have been abrupt, impatient, and uncaring. No wonder a lot of women don't take up the offer.
- Very easy to get to – be good to have time off work for this and not use annual leave as appointments are often work times and that is then awkward and embarrassing.

I have never attended a breast screening appointment. In my early 50's, appointments were made at inconvenient times for working people in places where parking was too far from the venue or too far from the workplace to make it possible to attend.

Needed to take time off work to do so, no parking available, little explanation as to what was happening (poor communication).

## Personal choice

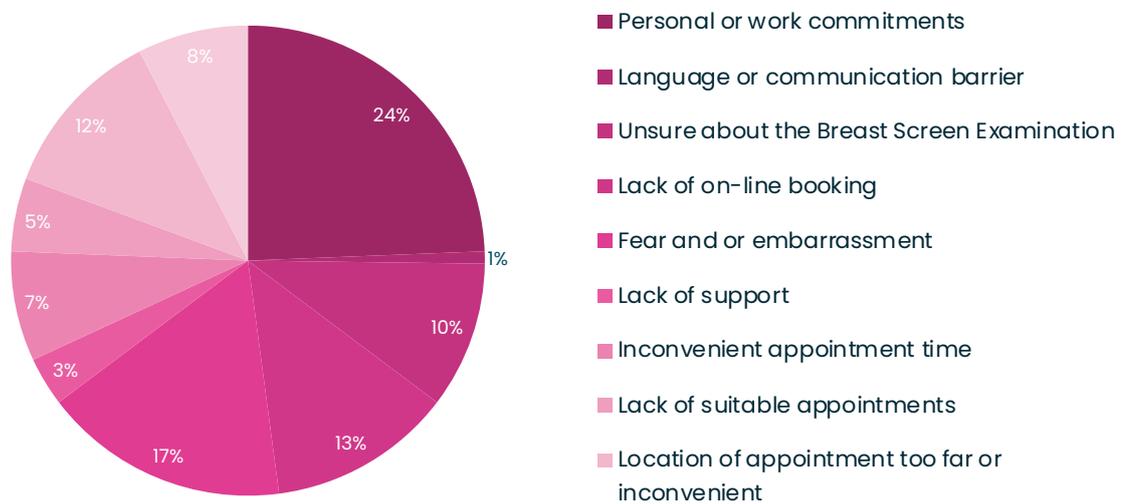
- I attended for a few years but have decided to stop.
- I know how to check myself.
- I don't look for trouble if I'm feeling great!!
- I'm feeling great!!

More recent literature stresses that the results may not be accurate suggesting the NHS is covering itself for these inaccurate diagnosis. Hence, I have no confidence in this screening process if you have no symptoms.

## Q2. Not attended Breast Screening appointment

The reasons stated as to why the Breast Screening invitation (n119) has not been accepted was due to personal or work commitments, fear and embarrassment, lack of on-line booking, location of appointment, unsure about the breast screening examination, inconvenient appointment, forgot appointment, lack of suitable appointments, and lack of support.

### I have not attended my Breast Cancer Screening appointment



### Personal decision

- I don't want it.
- I'm 69. I work hard looking after my home, my garden and myself.
- Have history of multiple breast cysts and very painful.
- I check my breast daily but don't wish to have the screening done.
- I have looked at the evidence for screening and decided not to attend.

I don't intend to go unless I have a concern. I have heard they are very painful and I'm not sure how reliable the screening is.

## Work commitments

- My surgery at the time was Langley Corner and the appointments that were offered were very limited and did not fit around my work and family commitments.
- Unable to take time of work to go when invited. Tried to arrange several times but then taken off the list.
- No option to book an appointment outside of work hours or days.
- No local facility to attend my breast cancer screening appointment. I am able to do so during my annual leave when I am off, I am not completely putting this off.

I don't wish to travel to Worthing for the screening. If it were at St Richards Hospital in Chichester, where I have had a breast screening before, I'd attend. Worthing is too far, inconvenient, and costly. I'd have to take time off work to attend and pay for petrol and parking. In Chichester I can walk during my lunch break.

The screening times offered were quite restrictive 10 - 3. I work full time and the screening unit is a 20 min drive from my work. I want attend but will have to take unpaid time off to do so. My last screening was in London and had much more flexible timings.

## Location

- The appointment made for me is not in my town and I am elderly and have had a stroke.
- Parking is very tight at the hospital, which means that everything takes longer.
- No transport.
- As a carer even if the screening is done locally the results mean a trip to Worthing, this is difficult as it means hours away from home.
- My doctor has wanted me to book an appointment because I'm high risk, but I've been trying for 4 months to find one in my area Crawley and the nearest one is 20 miles away. I am a carer for my disabled daughter and parent which makes travelling and time very difficult.

I normally attend breast screening. Unfortunately for personal reasons I missed my last appointment. Today I heard that the mobile screening unit will not be at Bognor hospital but at Worthing instead. Why? This will make it inconvenient and harder for anyone in the Bognor area to attend. Madness.

## Lack of on-line booking

- I forgot, but I do have the NHS app so it would be good if it were in there as a notification.
- I have received letters with a pre-set appointment time when I've been away and unable to attend. It would be easier with a busy life to be able to book online.
- Lack of on-line booking: this would be very helpful but not a must.

## Unsure of process

- No information regarding what to expect.
- I'm concerned about the exam.
- The last screening was very painful.

I am very funny about breast examinations, and it took me ages to pluck up the courage.

## Lack of suitable appointment

- I am waiting to be called.
- The appointment wasn't actually inconvenient. Goodwood Festival of Speed meant roads at a complete standstill and couldn't get there. Will re-book.
- My appointment was cancelled.
- Since I registered with the GP, I haven't been contacted about booking an appointment for it.
- Outside, of age bracket

How easy is it to get an appointment after the age of 71 and how long is the wait? I would appreciate taking the breast screening

They usually come up in January, which is when I am extremely busy at work. It would be great if I could reschedule for the spring or summer time.

## Lack of support

- I am disabled.
- I find the main method of breast screening very intrusive and painful; I have fibromyalgia and chronic knee problems. I am also autistic, and the anticipation of the physical pain caused by the equipment causes me a great deal of anxiety.
- Unsure of accessibility as I'm now in a wheelchair.
- I am bedridden and housebound.
- Physical problems.

Suffer with anxiety so didn't attend last appointments I would like one now.

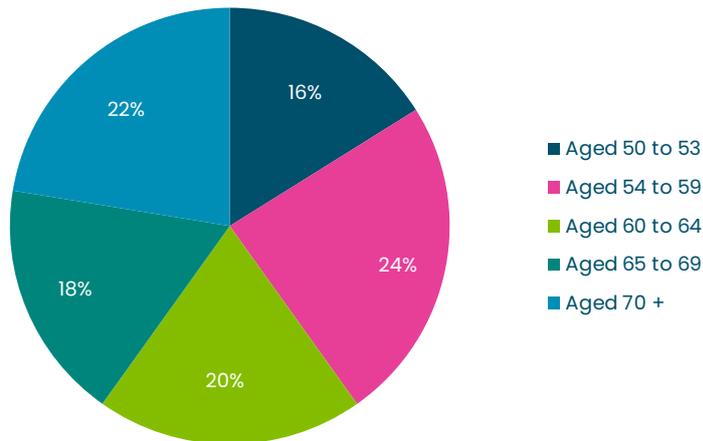
## Other comments

- I didn't know that over a certain age a breast screening appointment could be made.
- Check my breasts regularly myself.
- Don't know who to contact.
- 52 and not invited yet - have chased but was told to wait until they are back in my area which was supposed to have been earlier this year. No way to get booked in out of area.
- Doctor said I have to wait!!

Perhaps because I perceive myself as low risk, I don't make this appointment the priority it should be.

### Q3. Age of responders

Age of responders

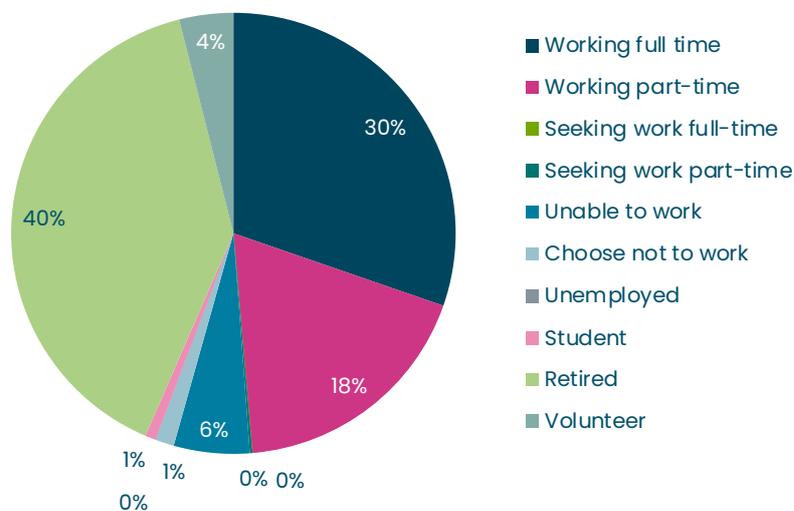


### Q4. West Sussex area responder live

Adur	n15	Arun	n63
Crawley	n90	Chichester	n119
Horsham	n50	Mid Sussex	n40
Worthing	n91	West Sussex	n4

### Q5. Employment and other status

Employment and other status



## Q6. Ethnic characteristics of responders

White British, Irish, other?	n448		
Asian or Asian British <ul style="list-style-type: none"> <li>• Indian</li> <li>• Pakistani</li> <li>• Bangladeshi</li> <li>• Any other Asian background</li> </ul>	n8	Black or Black British <ul style="list-style-type: none"> <li>• Caribbean</li> <li>• African</li> </ul>	n6
Mixed <ul style="list-style-type: none"> <li>• White and Black Caribbean</li> <li>• White and Black African</li> <li>• White and Asian</li> </ul>	n3	Any other Ethnic Group <ul style="list-style-type: none"> <li>• Chinese</li> <li>• Any other Ethnic Group</li> <li>• Prefer not to say</li> </ul>	n2  n2

## Q7. Views from carers

20% (n98) people answered that they are a carer, and 4.5% (n22) stated that this would affect their ability to attend an appointment.

I consider myself to be a carer	Yes	n98
Would this affect you attending a	Yes	n22

A further 55 responses were received which covered the topics of: time (9%), transport (11%), self-care (5%), flexible appointments (23%), work (7%), and other comments.

My health as a carer is very important, I'd be of no use if I got ill.

## Time

- I would need to have an appointment at a time that I could arrange cover for my caring role.
- If I were a carer, I know that I would not be able to take 4 hours to travel to and from an appointment.
- It limits my time and energy. There are times when I have to drop everything to prioritise my caring role.
- My son is in hospital in London and my spare time is usually taken up visiting him.
- I have limited available hours when I could attend.

## Transport

- Need help as disabled, and transport is required.
- I don't drive, I have to use public transport - it is a 20-minute walk along a very muddy footpath to the station in winter.
- I'm a carer for my disabled daughter and parents so time is very limited, and I just can't travel a 40-mile round trip.
- Worthing too far away even if screening is local.

Self-care is important to facilitate the caring role, so I would not miss a breast screening appointment based on this principle. However, I am lucky to be able to call on the aid of others, and also that my work place has flexible working in place to help accommodate cancer screening.

## Appointments

- I care 24/7 for my disabled husband and have done so for the past 10 years. Maintaining my own health so that I can continue to care for him is extremely important to me.
- I am no longer a carer but when my husband was ill with lymphoma, I was nursing him. I couldn't go anywhere at that time because of risk of infection. Sadly, he has passed so this no longer applies but I understand why a carer may not be able to attend.

## Other comments

I am 51 and haven't been offered an appointment.

I always attend when called to a screening as a few years ago found a pre cancer that was removed.

It would have detected my partners invasive breast cancer if the screening started at 40 like our European neighbours.

## Work and appointments

- I work as a support worker and as long as I have enough notice, I can arrange time off.
- No. More a difficulty of arranging around work.
- Sometimes my work commitments can affect whether I can attend the appointment.

## Why a flexible approach for appointments is needed.

- I would have to prioritise my Mum around any appointment. So, if she were acutely unwell on the date of the appointment, I would need to reschedule.
- My husband is bed and house bound. If he is poorly, he likes me to be with him, doesn't like to be left alone.
- I would bring my cared for age 17 daughter or ask for the appointment to be when she is in college if she is in college. If not, she'll just have to come and sit in the waiting area. She is well behaved so this would be fine.
- Elderly mother, but sisters help too so fit around necessary appointments between us.
- Care for grandchildren as well as working part time. May therefore need to re book. Also, on zero hours contract.

If my appointment were on one of my caring days, I would need to reschedule but, I would still try to attend.

### Q8: Disability or a long-term health condition

16% (n79) stated they have a disability, 33% (n160) stated they have a long-term condition. 5.7% (n28) stated that their health condition would affect them attending a screening.

Yes, I consider myself to have a disability	n79
Yes, I consider myself to have a long-term condition	n160
Would this affect you attending a Breast Screening appointment	n28

A further 109 responses were received covering the following topics:

impact of health condition (19%), difficulties accessing screening (1%), and appointments (16%).

### Impact of health condition.

- I cannot stand for long periods.
- Mental health can prevent appointments.
- Cannot stand up still for long and use wheelchair.
- PTSD prevents me doing a lot of things especially medical.
- Would need accessible access.
- I often forget appointments as I have short term memory. I sometimes set off for appointment then end up somewhere else.

## Difficulties accessing screening.

- Ability to access screening vehicle.
- I am disabled and housebound, so it is very difficult for me to go anywhere. It is difficult for me to manoeuvre or stand and most chairs are unsuitable.
- I find steps difficult to go up and down, as I need to walk with a 4 wheeled walker.
- Access may be an issue and availability of nearby parking.
- Driving over bumpy rural roads is not helpful.

At the moment I can get to appointments, and get up the steps into the mobile units, but having Osteoporosis and hip issues. This may cause me issues in the future.

Family member cares for me and is able to take me to any appointments.

## Appointments

- Give me an appointment and I will be there on the dot.
- Help would be needed to get me to an appointment.
- I would always attend a medical appointment.
- Never a problem and you can always change your appointment if the one they sent you is not suitable.
- Because of my age I now have a number of long-term conditions. They would NOT, prevent me from attending screening tests.
- Potentially, if unwell I would cancel and then ring up and rebook for when I was feeling better.
- As long as it has parking.
- I think females should try all avenues to attend their screening.

I have degeneration of the spine and bulging discs as well as a malformation in my neck, which makes it very uncomfortable and somewhat painful to stand in the required position, and to turn my head to one side, which is why it was so much better last time, when I was allowed to sit by the X-ray equipment for my breast screening.

I was diagnosed with Breast Cancer in August 2019 and the whole process was dealt with brilliantly. I always promote to people to attend their breast screening appointments. I do have a lot of pain, but it would never prevent me from attending a screening.





## Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email [cheryl.berry@healthwatchwestsussex.co.uk](mailto:cheryl.berry@healthwatchwestsussex.co.uk)

## How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future.

### For help, advice, and information or to share your experience

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

Here to help you on the next step of your health and social care journey



You can review how we performed and how we report on what we have done by visiting our website [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

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Healthwatch West Sussex works with **Help & Care** to provide its statutory activities.



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