Section 3

Symptoms and diagnosis

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Symptoms leading to diagnosis

The most common symptom leading to diagnosis was having a lump or lumps in their breast (n=26, 50.00%), this was followed by being vigilant about having breast check-ups due to their family or personal medical history (n=7, 13.46%), breast pain (n=5,9.62%), and breast skin changes such as puckering, dimpling, a rash or redness of skin (n=5, 9.62%).

Symptoms leading to diagnosis: Seeking medical attention

There were 25 participants (48.08%) that described having symptoms and seeking medical attention relatively soon. There were 14 participants (26.92%) that described being diagnosed through screening without experiencing symptoms, and 13 participants (25.00%) described having symptoms and not seeking medical attention initially.

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly diagnosed through a population screening program (n=19, 36.54%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=17, 32.69%), and being referred directly to a specialist from their general practitioner which led to their diagnosis (n=16, 30.77%).

Time from symptoms to diagnosis

Duration was calculated for 22 participants (30 participants had no symptoms before diagnosis), there were three participants (13.64%) that were diagnosed less than 1 month of noticing symptoms, six participants (27.27%) diagnosed 1 to 2 months from noticing symptoms, four participants (18.18%) that were diagnosed 3 to 6 months of noticing symptoms, and five participants (22.73%) that were diagnosed more than 6 months of noticing symptoms

Time from diagnostic test to receiving a diagnosis

Participants were most commonly diagnosed less than one week after diagnostic tests (n=21, 40.38%), followed by being diagnosed between 1 and 2 weeks (n=16, 30.77%)

Diagnostic tests

Participants reported between 1 and 5 diagnostic tests (median = 3.00 , IQR = 1.00). The most common tests were mammogram (n = 47, 90.38%), breast ultrasound (n = 47, 90.38%), fine needle aspiration (n = 25, 48.08%), and core biopsy (n = 40, 76.92%)

Diagnosis provider and location

More than half of the participants were given their diagnosis by a specialist doctor (n=31, 59.62%), and there were 21 participants (40.38%) given the diagnosis by a general practitioner (GP)

Participants were most commonly given their diagnosis in the general practice (GP) (n = 17, 32.69%), this was followed by the specialist clinic (n = 14, 26.92%), and the hospital (n = 8, 15.38%)

Breast cancer diagnosis

The majority of participants were diagnosed with invasive breast cancer (n = 30, 57.69%), followed by invasive lobular breast cancer (n = 10, 19.23%) and ductal carcinoma in situ (DCIS) (n=7, 13.46%)

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV.

Understanding of disease at diagnosis

Most participants described having limited knowledge about the condition at diagnosis (n=30, 57.69%), this was followed by having no knowledge (n=11, 21.15%), and having had a good knowledge (n=9, 17.31%). The most common reasons for having limited knowledge was from having a family history of the condition (n=9, 17.31%), having a friend or acquaintance with the condition (n=8, 15.38%), having a medical, research or relevant professional background (n=8, 15.38%), and researching the condition during the diagnostic process (n=5, 9.62%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background (n=9, 9.62%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis. There were 29 participants (55.77%) who had enough information, 21 participants (40.38%) that had some information but it wasn't enough, and two participants (3.85%) had no information.

Costs at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. There were 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000.

Burden of diagnostic costs

For 13 participants (39.39%) the cost was slightly or not at all significant. For 12 participants (36.36%) the out-of-pocket expenses were somewhat significant, and for eight participants (24.24%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n = 16, 30.77%). There were 14 participants (26.92%) who brought up the topic with their doctor, and 22 participants (42.31%) whose doctor brought up the topic with them.

Half of the participants did not have any genetic or biomarker tests but would like to (n = 26, 50.00%). There were five participants (9.62%) who did not have these tests and were not interested in them, and a total of seven participants (13.46%) that had biomarker tests

Biomarker status

All participants knew the status for at least one biomarker (n = 52, 100%). All participants knew their ER status (n=52, 100%), and most participants knew their PR status (n = 42, 80.77%). There were 15 participants (28.85%) that knew their HER2 status and seven participants (13.46%) that knew their BRCA status.

Current symptoms

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 24, 46.15%). Participants had between four and 13 symptoms (mean = 4.10, SD = 4.69).

The most common current symptoms, and those where more than 40% of the participants experienced the symptom were; sleep problems (n = 23, 44.23%), weight and muscle changes (n = 23, 44.23%), thinking and memory problems (n = 22, 42.31%), anxiety/anxious mood (n=21, 40.38%), fatigue (n = 23, 44.23%), and pain(n = 23, 44.23%).

The median quality of life was between 2.00 and 3.00, for all of the symptoms listed in the questionnaire, this is in the "Life was distressing" to "Life was a little distressing" range.

Understanding of prognosis

Participants most commonly described their prognosis in relation to no evidence of disease or that they are in remission (n=23, 44.23%). There were 22 participants (42.31%) that described a positive prognosis in relation managing their condition with treatment. Other participants described prognosis in relation to statistics such as five year survival rates (n=19, 36.54%), in relation to probable recurrence/cycle of recurrence (n=16, 30.77), and in relation to monitoring their condition without treatment until there is an exacerbation or progression (n=6, 11.54%).

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

The majority participants described symptoms leading to a diagnosis in a clear way (n=38, 73.08%). All other participants (n=14, 26.92%) described having no symptoms.

The most common symptom leading to diagnosis was having a lump or lumps in their breast (n=26, 50.00%), this was followed by being vigilant about having breast check-ups due to their family or personal medical history (n=7, 13.46%), breast pain (n=5, 9.62%), and breast skin changes such as puckering, dimpling, a rash or redness of skin (n=5, 9.62%).

Participant describes having lump(s) in the breast, which led to their diagnosis

I didn't really have anything like that. I just found a lump and went to the doctor a couple days later. So I found a lump. In my left breast, I have been working in a job for SHOP so I thought maybe I just had a box hit me in the chest or something. So I waited a day or so. When it didn't go away or didn't bruise or anything. I made a doctor's appointment. I went to the doctor about two days after that. Participant 020_2021AUHRP

I went to the GP because of my lump. She sent me for a mammogram. Participant 012_2021AUHRP

Yeah, look, I don't recall any symptoms at all. It's simply a purely sound the lump by chance. I, it was winter, and I had a really hot shower before going to bed, went to bed, and then kind of cooked myself a little bit, I was quite hot, and then put my hand under my top and just scratched and just scratched my left breast, and then that's when I because it was sort of itchy. And then that's when I found the lump. Participant 013_2021AUHRP

Participant describes having no symptoms, and being diagnosed through screening

Yes, so the BreastScreen van was in our town and I just had turned 50 the month before I went. I made an appointment and went down only because it was here. Otherwise, I probably wouldn't have. Participant 006_2021AUHRP

PARTICIPANT: No, none.
INTERVIEWER: None, okay.
PARTICIPANT: None. I had absolutely no idea because my cancer wasn't a lump. It's a spreader. Participant 026_2021AUHRP

Okay. I used to get my two-yearly breast mammogram. I'm pretty body aware, and I didn't notice anything. There was no lump as such. I just went off to my BreastScreen LOCATION screening, but because of COVID, my screen was put off almost one year to the day. Participant 032_2021AUHRP

I just went for a routine mammogram. Then got recalled when they noticed some changes on that one. Went then to Breast Screen in town and had a repeat mammogram and then a biopsy, ultrasound. When they then discovered yes, I had a tumor. Then I went to see the surgeon, and he on looking at the mammogram, then sent me for an MRI, and they subsequently found a second tumor. Participant 050_2021AUHRP

Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis

I didn't have any actually I've been part of the breast screen for clinic for about eight years prior because my mum passed away. She was diagnosed at 41. So I really fought for my doctor to give me that referral because I was like, I had it in my head doesn't get breast cancer around the same time. So it was a bit of a fight. But I think I got there a couple of years later with her and she referred me on so yeah, it was just a routine. I was having routine MRIs that they found it. Participant 048_2021AUHRP

My sister had breast cancer at a young age as well, so I was getting a mammogram, that was one thing. In terms of the diagnosis for this one, because it was in inflammatory breast cancer, it came up like an infection, so it was really red and hot and swollen and all that sort of thing. I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. 052_2021AUHRP

Yeah, I was just having a usual yearly mammogram because my mum had breast cancer and I've had implants that 14 years ago.
041_2021AUHRP

Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin)

I hesitate to even call it a rash. I had a patch of dry skin on one side of my breast that I thought was dry skin or maybe a fungal infection. It seemed to come and go a bit, so I didn't think a lot of it. I had a skin check with my GP and so I got her to have a look and she didn't really think it was anything either, but gave me some forms to go off and get scanned and I didn't get around to doing that.
INTERVIEWER: Was that the only sign? Sorry.
PARTICIPANT: That was the only sign and everyone all the way through has said it never looks like any of the typical breast cancer rashes that we're told about, there was no nipple change, there wasn't the orange pill. There was none of that. There was a real question around whether it was ever actually related or not, but I had the lumpectomy it's gone away. I think it probably was. I should have taken some pictures and written it up. [chuckles] Participant 011_2021AUHRP

For me, it was orange peel appearance on the breast and my nipple started to invert, but it was actually only after a friend posted something on Facebook while I was working overseas. I looked and went, ah, because I lost a lot of weight in the previous 12 months. I put it down to wrinkly bits and changes because of that. Then I had a look and went, okay, probably not. That was my first indication. Although the few years previously I had had multiple mammograms because I have a family history, unfortunately. Participant 018_2021AUHRP

Yes, sure. I was diagnosed in August of 2019, but I had felt a lump back in May. I noticed dimpling of that breast, which though I wasn't particularly alarmed, I had my suspicions as to what that might indicate. They were the signs that sparked my wish to go to the doctors to get ultrasound or whatever, a mammogram. At the same time I was having back pain, by late July I was getting back pain, but at the time I didn't realize that the two were linked. I was literally at the same doctor's appointment, I was flagging with him the lump and the need to probably not go and get an x-ray, but to go and get some physio. The lump, first initially I was aware of it by that mid to late May. Participant 051_2021AUHRP

Table 3.1: Symptom recall

Symptom recall	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	38	73.08	13	68.42	15	71.43	10	83.33	20	68.97	18	78.26	14	73.68	24	72.73
Participant describes having no symptoms	14	26.92	6	31.58	6	28.57	2	16.67	9	31.03	5	21.74	5	26.32	9	27.27

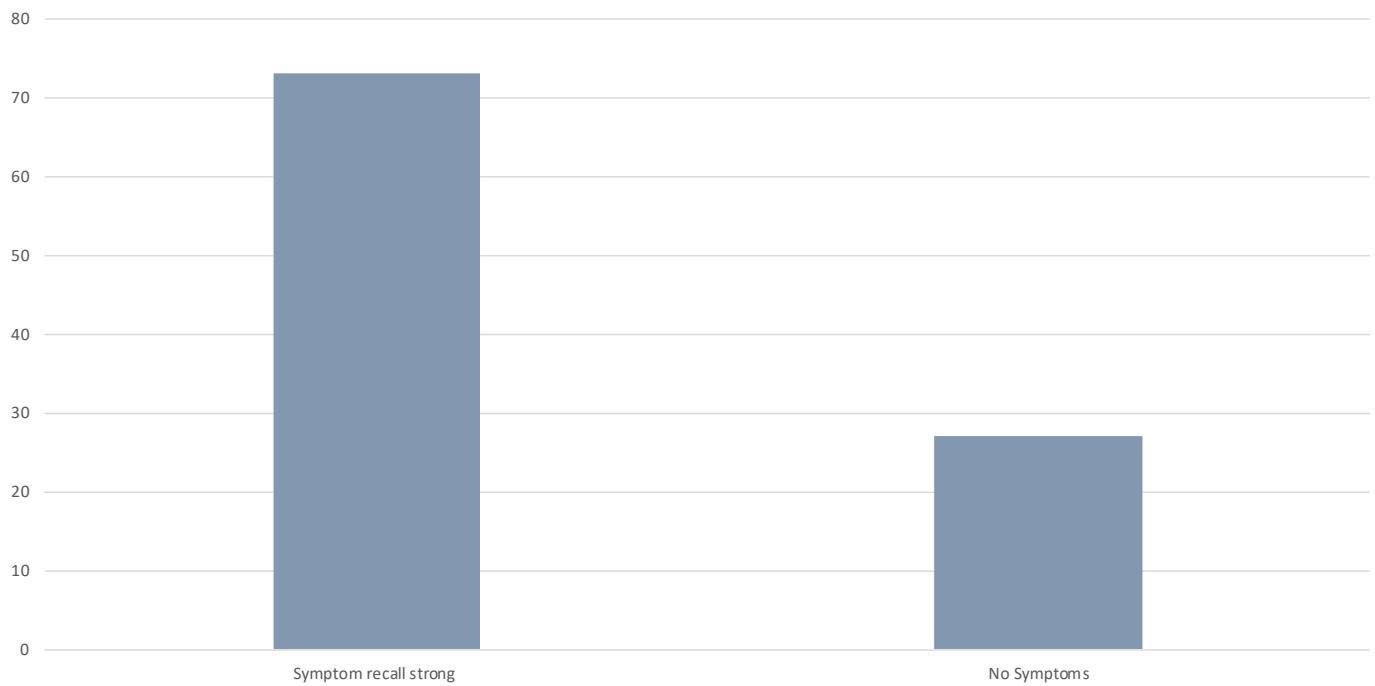| Symptom recall	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	38	73.08	4	40.00	12	75.00	22	84.62	8	72.73	30	73.17	15	83.33	23	67.65
Participant describes having no symptoms	14	26.92	6	60.00	4	25.00	4	15.38	3	27.27	11	26.83	3	16.67	11	32.35

Figure 3.1: Symptom recall (percent of all participants)

Table 3.2: Symptom recall -subgroup variations

Symptom recall	Reported less frequently	Reported more frequently
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	Diagnosed in 2016 or before	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status
Participant describes having no symptoms	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status	Diagnosed in 2016 or before

Table 3.3: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes having lump(s) in the breast, which led to their diagnosis	26	50.00	10	52.63	10	47.62	6	50.00	15	51.72	11	47.83	10	52.63	16	48.48
Participant describes having no symptoms, and being diagnosed through screening	14	26.92	6	31.58	6	28.57	2	16.67	9	31.03	5	21.74	5	26.32	9	27.27
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	7	13.46	4	21.05	2	9.52	1	8.33	2	6.90	5	21.74	3	15.79	4	12.12
Participant describes having breast pain), which lead to their diagnosis	5	9.62	1	5.26	2	9.52	2	16.67	3	10.34	2	8.70	3	15.79	2	6.06
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin), which lead to their diagnosis	5	9.62	3	15.79	0	0.00	2	16.67	3	10.34	2	8.70	2	10.53	3	9.09

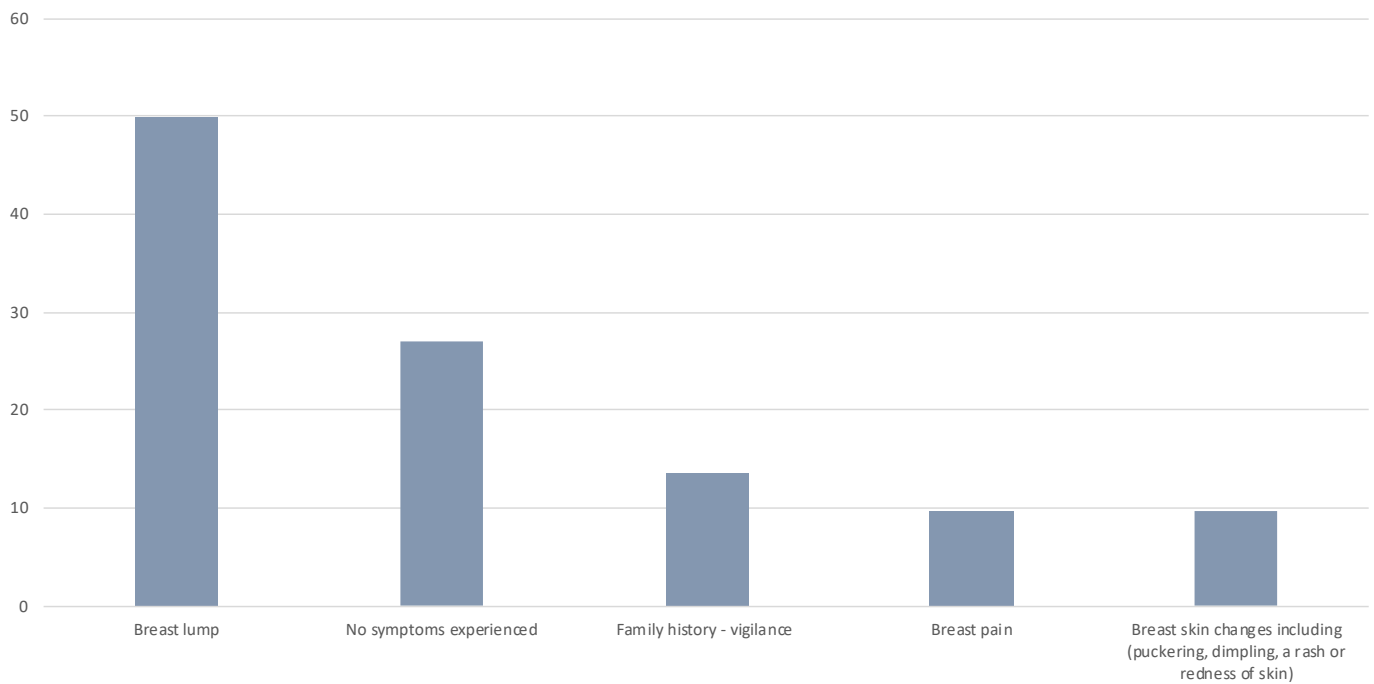| Symptoms leading to diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes having lump(s) in the breast, which led to their diagnosis	26	50.00	4	40.00	8	50.00	14	53.85	4	36.36	22	53.66	9	50.00	17	50.00
Participant describes having no symptoms, and being diagnosed through screening	14	26.92	6	60.00	4	25.00	4	15.38	3	27.27	11	26.83	3	16.67	11	32.35
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	7	13.46	3	30.00	1	6.25	3	11.54	2	18.18	5	12.20	3	16.67	4	11.76
Participant describes having breast pain), which lead to their diagnosis	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin), which lead to their diagnosis	5	9.62	0	0.00	1	6.25	4	15.38	1	9.09	4	9.76	1	5.56	4	11.76

Figure 3.2: Symptoms leading to diagnosis (percent of all participants)

Table 3.4: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having lump(s) in the breast, which led to their diagnosis	Regional or remote	-
Participant describes having no symptoms, and being diagnosed through screening	Stage III and IV	Stage II Diagnosed in 2016 or before
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	-	Trade or high school

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 25 participants (48.08%) that described having symptoms and seeking medical attention relatively soon. There were 14 participants (26.92%) that described being diagnosed through screening without experiencing symptoms, and 13 participants (25.00%) described having symptoms and not seeking medical attention initially.

Participant describes having symptoms and seeking medical attention relatively soon

Yes, so then. So it was pretty scary, because the lump was quite big. So I went straight into a GP, a medical practice the next morning and saw a GP just got their first thing for when they opened for a GP. And he then was it gave me a referral to the hospital to get some scans done. Participant 013_2021AUHRP

I didn't really have anything like that. I just found a lump and went to the doctor a couple days later. So I found a lump. In my left breast, I have been working in a job for COMPANY so I thought maybe I just had a

box hit me in the chest or something. So I waited a day or so. When it didn't go away or didn't bruise or anything. I made a doctor's appointment. I went to the doctor about two days after that. Participant 020_2021AUHRP

Okay, so I, I found the lump in my breast. When I was having a shower went to the GP, I'd never had a mammogram in the past I was 44. Participant 034_2021AUHRP

Participant describes having no symptoms or not noticing any symptoms before diagnosis

Well, that's not how it happened. And for me, I was just having a routine mammogram. I had no symptoms. Participant 001_2021AUHRP

I didn't have any. It was just a mammogram. Participant 024_2021AUHRP

No signs or symptoms whatsoever. I was booked in for a two-yearly mammogram and they recalled me because I wanted to have a better look to make sure everything was fine. Ha-ha-ha. Participant 039_2021AUHRP

Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight

With me, it was quite a large lump that had been there for probably 20 years or more and had been investigated many times, and was always found just to be breast tissue. When I was in the shower, it was sore, which was just before Christmas last year. I thought, "Oh, I wonder why that's sore, I must have bumped it." Didn't think too much more about it. It still continued to be sore, so probably about a few weeks later, I decided I better go and see the doctor. By the time I got into the doctor, I'd canceled a couple of appointments. It's very hard to get into a doctor when you're in a rural area with limited doctors. Participant 017_2021AUHRP

Yes, I did feel a lump. I felt a lump but I'm not obese and I'm probably quite-- I eat healthy and I exercise. I didn't think much of it. I just thought, "Oh, I'll get that checked out," but my parents were sick and I put them first. Participant 021_2021AUHRP

One day, I was sitting on a couch with like, I was just a bit premenstrual and my boobs are a bit sore. And I just thought, you know, that's a usual thing. But I had taken my bra off, and I just pushed my left hand across my right breast, just to sort of give them a bit of support when I was sitting there, and I'm pajamas, and I found a lump. But it felt like the mastitis, like it felt like the same way my breasts had felt when I got mastitis, but just without the infective, like bits going on. So I sort of didn't think anything of it because I was 32. And, you know, it was just before my period, and maybe it was just lumpy, you know, premenstral breast, that kind of thing. So I didn't really think anything of it. And then the next month, I felt it again. Same, same still trying for a baby bit premenstrual, we're just like, whatever. And then the following months, I felt it earlier in the month. So I was like, Okay, well, we'll go and get that investigated. Participant 033_2021AUHRP

Table 3.5: Seeking medical attention

Seeking medical attention	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes having symptoms and seeking medical attention relatively soon	25	48.08	10	52.63	7	33.33	8	66.67	13	44.83	12	52.17	7	36.84	18	54.55
Participant describes having no symptoms or not noticing any symptoms before diagnosis	14	26.92	6	31.58	6	28.57	2	16.67	9	31.03	5	21.74	5	26.32	9	27.27
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	13	25.00	3	15.79	8	38.10	2	16.67	7	24.14	6	26.09	7	36.84	6	18.18

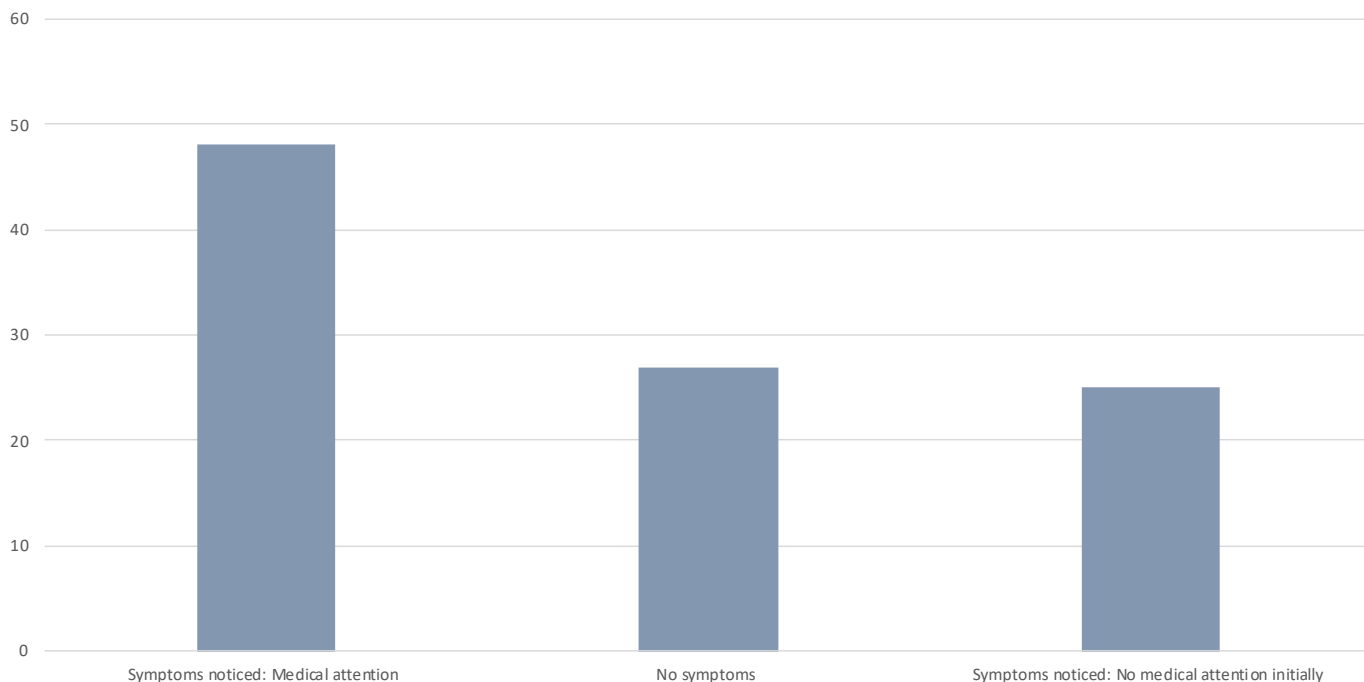| Seeking medical attention	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes having symptoms and seeking medical attention relatively soon	25	48.08	4	40.00	8	50.00	13	50.00	4	36.36	21	51.22	10	55.56	15	44.12
Participant describes having no symptoms or not noticing any symptoms before diagnosis	14	26.92	6	60.00	4	25.00	4	15.38	3	27.27	11	26.83	3	16.67	11	32.35
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	13	25.00	0	0.00	4	25.00	9	34.62	4	36.36	9	21.95	5	27.78	8	23.53

Figure 3.3: Seeking medical attention (percent of all participants)

Table 3.6: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Stage II Trade or high school Regional or remote	Stage III and IV
Participant describes having no symptoms or not noticing any symptoms before diagnosis	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status	Diagnosed in 2016 or before
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	Diagnosed in 2016 or before	Stage II Trade or high school Regional or remote

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly diagnosed through a population screening program (n=19, 36.54%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=17, 32.69%), and being referred directly to a specialist from their general practitioner which led to their diagnosis (n=16, 30.77%).

Participant describes being diagnosed through a population screening program

Well, that's not how it happened. And for me, I was just having a routine mammogram. I had no symptoms. Because it was my routine, biannual mammogram, so I booked it. My GP is fairly proactive here. He will, he will remind me when I'm due. Participant 001_2021AUHRP

PARTICIPANT: On my two-yearly mammogram.
INTERVIEWER: Who organized that for you?
PARTICIPANT: You get a reminder to say that you're due for your two-yearly mammogram and then it's up to you to ring up and make an appointment. It was when I first got the letter, it was maybe August or something of last year when we were going through that first crappy lockdown COVID crap. I thought, "Oh, no, I'm not going anywhere yet. I'm not going to a breast screen place to get tested yet. I'll put it off." I mentally put it off and then I did make the appointment when I felt safer to do so. I think the breast screen places were pretty much shut down anyway. Participant 010_2021AUHRP

Okay. I was having regular mammograms every two years because I'm-- How old am I now? I'm 52 and I have them in, I think the odd years. Anyway, it doesn't matter. I don't have routine mammograms anymore. Anyway, it was a routine mammogram. I did that because that's what you do and I'd always go along and you'd get a letter a few weeks later saying, "Yes, it's all good". This time I got a phone call. That was, the phone call was here. "We just want to have a bit of a look at your right breast again". They did, and they also have a look at my left breast. They did a mammogram, they did an ultrasound and they did a pine needle aspiration, I think it's called. Great big, long thing they stick in and they might've done something with the lymph nodes as well.

…So the outcome of that was I have a day at the breast screen, lots of nice people who were basically preparing me for a diagnosis of breast cancer. They didn't say, "You have breast cancer", but it was all, "This looks very suspicious". They did it nicely, but by the time I left, I was fairly confident I had breast cancer. I had to wait for a week for an appointment with them, which with hindsight was something that was wrong. The pathology reports were all date of the day after the test. I was told "Come back in a week", which I did and by the time I come back in a week, they had made a series of appointments with me. My GP knew about it. It was looked after well, but that delay was not good for my mental health. Participant 039_2021AUHRP

Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)

Okay. I just went to my normal GP and they felt the lump. She didn't think too much of it, but she sent me to a women's imaging center to have more invas-- which I've had before but a more invasive, like a mammogram and a ultrasound. I did that one week and then they called me and I had to go back from the ultrasound and have a fine needle aspiration.
Then while I had the fine needle, they went out of the room and checked the cells that they'd taken while I still was there. They warned me that might happen. They came back and did like a core biopsy where they dug a little bit deeper. From that, I went back to the GP and she diagnosed me. Participant 009_2021AUHRP

Okay, because it was a Saturday, that I found that. I didn't think it was worth trying to turn up at a public hospital to get a mammogram that day. I reckon they just would've turned us away. I waited until Monday

morning and I rang my GP. I had a bit of trouble with the receptionist because it was still COVID and they were still mostly only doing telehealth. I said to the receptionist, she's saying, "She's not going to want you to come in." I said, "I am coming in. You tell her I have found a lump in my right breast on Saturday and I need it checked." Anyway, went into the GP and she went. "Yes, you need an mammogram and an ultrasound." She walked straight back out to the receptionist with me and she said to me, "Just sit down there for a minute." She said, "You're not leaving until I find someone who'll do a mammogram today because," she said, "if I send you with a referral, they'll just laugh it off and you won't get one for three months." She said it's just too important. Participant 030_2021AUHRP

I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. While I was still on my antibiotics, I went for a mammogram first off, and in the mammogram, she said, "Oh, it's just a bit of mastitis and some fibroids, because I already have fibroids in the other breast. When I had the ultrasound I think that's when she found it. She didn't say anything to me during that, but she was a bit quiet. I was called in the next day, to my GP, and she said that since she told me that it's highly likely that it is breast cancer. Participant 052_2021AUHRP

Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis

Yep, so my GP just did a breast exam. And she felt the lump as well. I was then referred to get an ultrasound. And then, when the results of that came back, I was referred to HOSPITAL, which was two and a half hours away from where I lived for a biopsy. And I had that at around 11:30 one day by 12:30. Lunchtime the next day, the doctor had rung me and given me the results. Participant 020_2021AUHRP

Then I went to my local doctor. This is a different doctor. I went to a new doctor,, and as soon he felt it, because he was a surgeon for seven, eight years, he said, "I'll say why didn't you come sooner?" I was just devastated. He sent me straight away for ultrasound, mammograms, and biopsies, and he said to me that if "They deny of those-- Because sometimes they'll say, 'We don't want to do the biopsies.' you ring me there and then." because he said "I wanted to have all of them. The three options, and if you don't have all of those--" because he said, "I really want to sure to make sure." because he said, "They might not be cancer, but it might be." That's when I went had all my scans done. Participant 029_2021AUHRP

The doctor, I saw the same GP that I'd seen for the original lump, same lump, two months earlier. I think he and I both agreed that the lumps were of concern. He sent me off for an ultrasound, and he also suggested that maybe it'd be worth looking in to see a breast specialist surgeon. Because if again we didn't see anything on the investigations, then at least she could explain why this kept on happening. In *hindsight, I think he knew better. He knew more than he was giving away. The ultrasound definitely showed breast cancer or very suspicious stuff. I saw the breast specialist literally within a day after getting the ultrasound. She pretty much diagnosed me on the spot, seeing the ultrasound and examining me. Participant 051_2021AUHRP*

Table 3.7: Diagnostic pathway

Diagnostic pathway	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being diagnosed through a population screening program	19	36.54	6	31.58	7	33.33	6	50.00	11	37.93	8	34.78	9	47.37	10	30.30
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	17	32.69	6	31.58	7	33.33	4	33.33	8	27.59	9	39.13	5	26.32	12	36.36
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	16	30.77	7	36.84	7	33.33	2	16.67	10	34.48	6	26.09	5	26.32	11	33.33

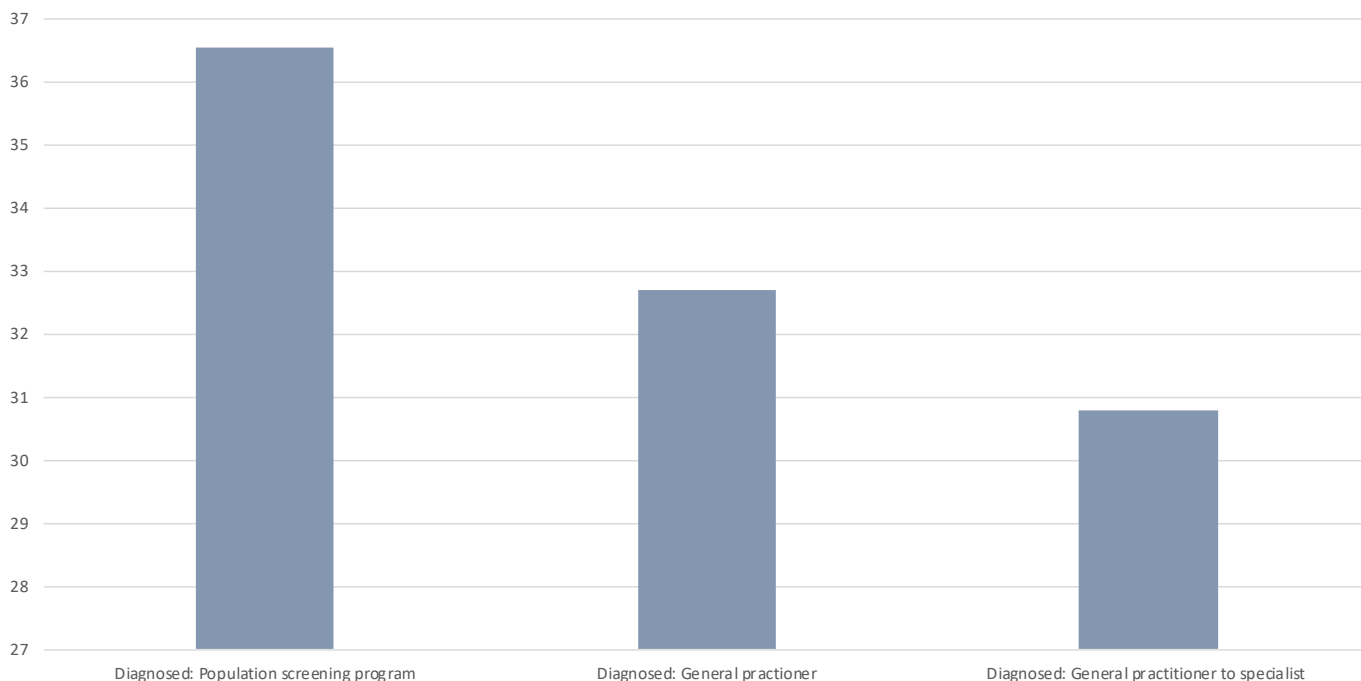| Diagnostic pathway	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being diagnosed through a population screening program	19	36.54	6	60.00	5	31.25	8	30.77	5	45.45	14	34.15	7	38.89	12	35.29
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	17	32.69	3	30.00	6	37.50	8	30.77	5	45.45	12	29.27	5	27.78	12	35.29
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	16	30.77	1	10.00	5	31.25	10	38.46	1	9.09	15	36.59	6	33.33	10	29.41

Figure 3.4: Diagnostic pathway (percent of all participants)

Table 3.8: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed through a population screening program	-	Stage III and IV Trade or high school Diagnosed in 2016 or before
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	-	Regional or remote
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Stage III and IV Diagnosed in 2016 or before Regional or remote	-

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of condition and the approximate date of diagnosis with condition. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 22 participants (30 participants had no symptoms before diagnosis), there were three participants (13.64%) that were diagnosed less than 1 month of noticing symptoms, six participants (27.27%) diagnosed 1 to 2 months from noticing symptoms, four participants (18.18%) that were diagnosed 3 to 6 months of noticing symptoms, and five participants (22.73%) that were diagnosed more than 6 months of noticing symptoms (Table 3.9, Figure 3.5).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed less than one week after diagnostic tests (n=21, 40.38%), followed by being diagnosed between 1 and 2 weeks (n=16, 30.77%) (Table 3.10, Figure 3.6).

Table 3.9: Time from symptoms to diagnosis

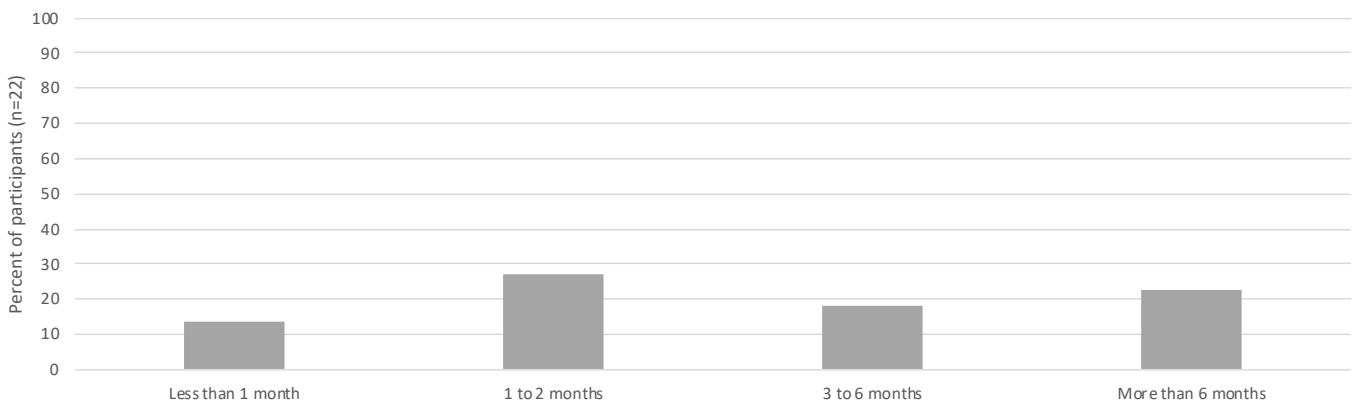| Time from symptoms to diagnosis	n=22 (with symptoms before diagnosis)	Percent
Less than 1 month	3	13.64
1 to 2 months	6	27.27
3 to 6 months	4	18.18
More than 6 months	5	22.73
Incomplete data	4	18.18

Figure 3.5: Time from symptoms to diagnosis

Table 3.10: Time from diagnostic test to diagnosis

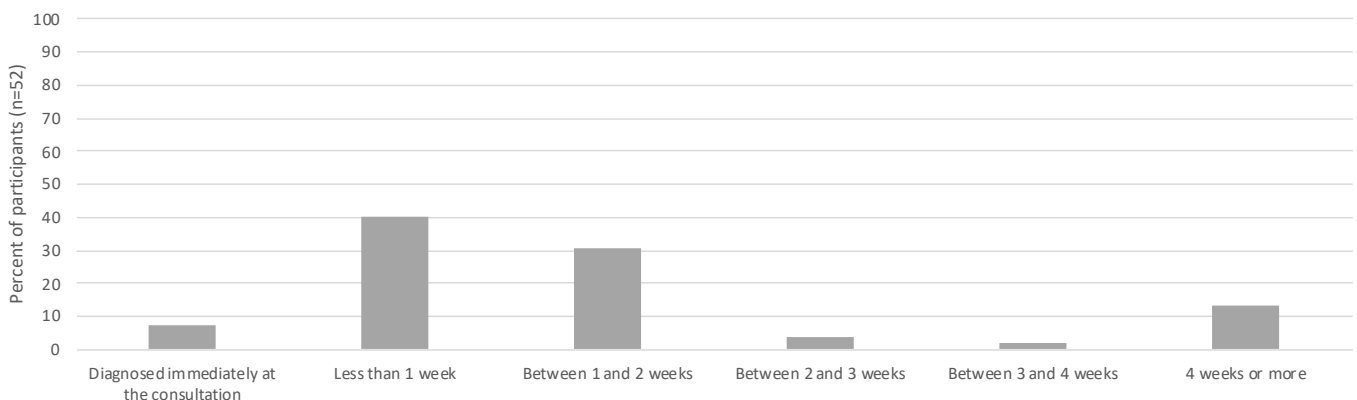| Time from diagnosis test to diagnosis	Number (n=52)	Percent
Diagnosed immediately at the consultation	4	7.69
Less than 1 week	21	40.38
Between 1 and 2 weeks	16	30.77
Between 2 and 3 weeks	2	3.85
Between 3 and 4 weeks	1	1.92
4 weeks or more	7	13.46
Not specified	1	1.92

Figure 3.6: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with condition. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 5 diagnostic tests (median = 3.00 , IQR = 1.00) (Table 3.11, Figure 3.7). The most common tests were mammogram (n = 47, 90.38%), breast ultrasound (n = 47, 90.38%), fine needle aspiration (n = 25, 48.08%), and core biopsy (n = 40, 76.92%) (Table 3.12, Figure 3.8).

Table 3.11: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=52)	Percent
1 to 2	7	13.46
3	29	55.77
4 to 5	16	30.77
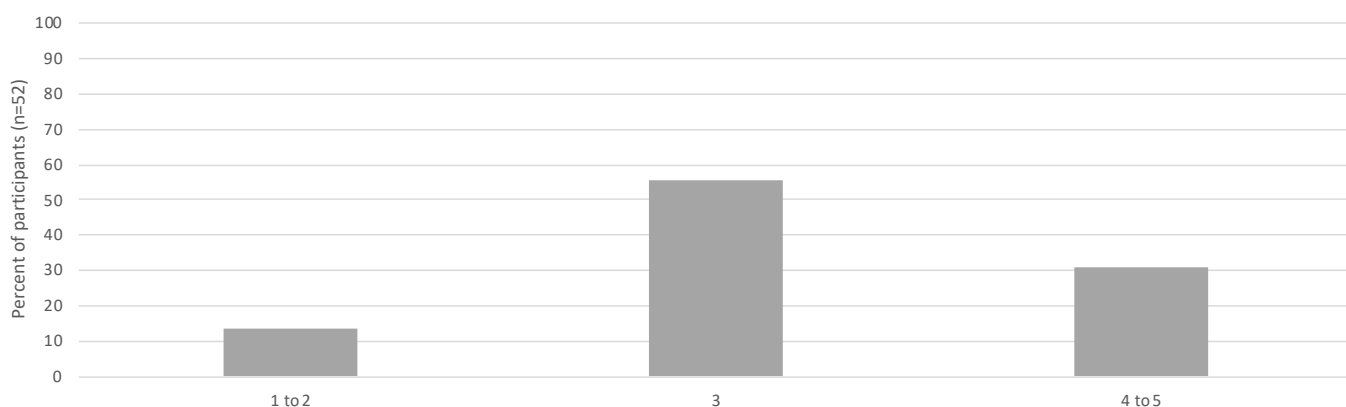
Figure 3.7: Number of diagnostic tests

Table 3.12: Diagnostic tests

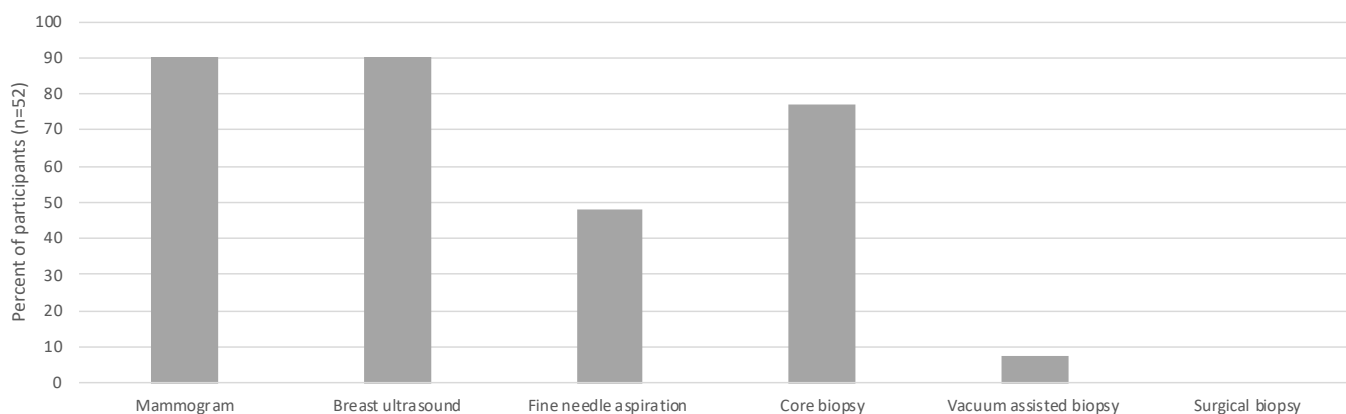| Diagnostic tests	Number (n=52)	Percent
Mammogram	47	90.38
Breast ultrasound	47	90.38
Fine needle aspiration (A thin needle is used to take tissue from the breast lump)	25	48.08
Core biopsy (A wider needle is used to remove a piece of tissue)	40	76.92
Other	4	7.69

Figure 3.8: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

More than half of the participants were given their diagnosis by a specialist doctor (n=31, 59.62%), and there were 21 participants (40.38%) given the diagnosis by a general practitioner (GP) (Table 3.13, Figure 3.9).

Participants were most commonly given their diagnosis in the general practice (GP) (n = 17, 32.69%), this was followed by the specialist clinic (n = 14, 26.92%), and the hospital (n = 8, 15.38%) (Table 3.14, Figure 3.10).

Table 3.13: Diagnosis provider

Health professional gave diagnosis	Number (n=52)	Percent
General practitioner (GP)	21	40.38
Specialist doctor	31	59.62
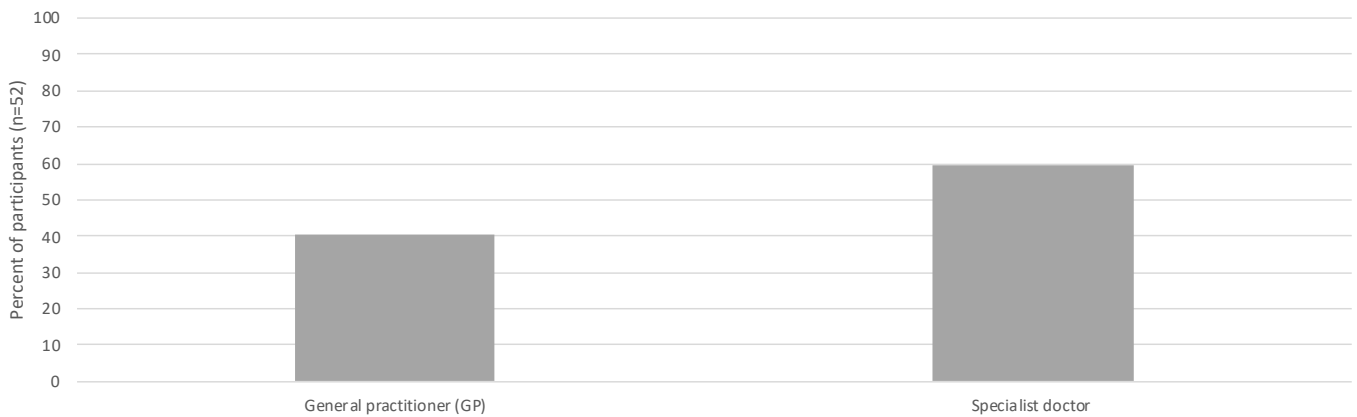
Figure 3.9: Diagnosis provider

Table 3.14: Diagnosis location

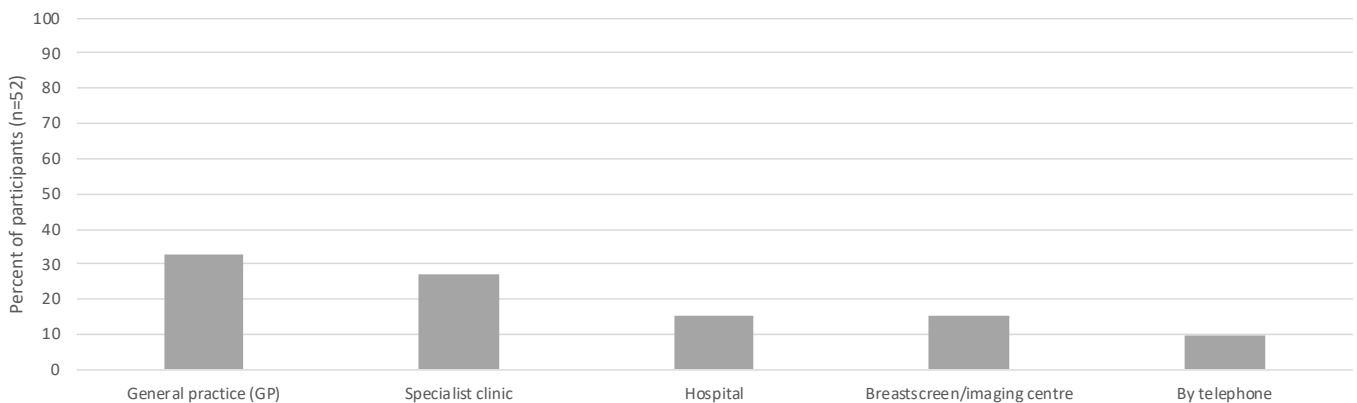| Location of diagnosis	Number (n=52)	Percent
General practice (GP)	17	32.69
Specialist clinic	14	26.92
Hospital	8	15.38
Breastscreen/imaging centre	8	15.38
By telephone	5	9.62

Figure 3.10: Diagnosis location

Breast cancer diagnosis, and stage

Breast cancer diagnosis

The majority of participants were diagnosed with invasive breast cancer (n = 30, 57.69%), followed by invasive lobular breast cancer (n = 10, 19.23%) and ductal carcinoma in situ (DCIS) (n=7, 13.46%) (Table 3.15, Figure 3.11).

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV (Table 3.16, Figure 3.12).

Table 3.15: Type of breast cancer

Diagnosis	Number (n=52)	Percent
Invasive breast cancer	30	57.69
Invasive lobular breast cancer	10	19.23
Ductal carcinoma in situ(DCIS)	7	13.46
Other	5	9.62
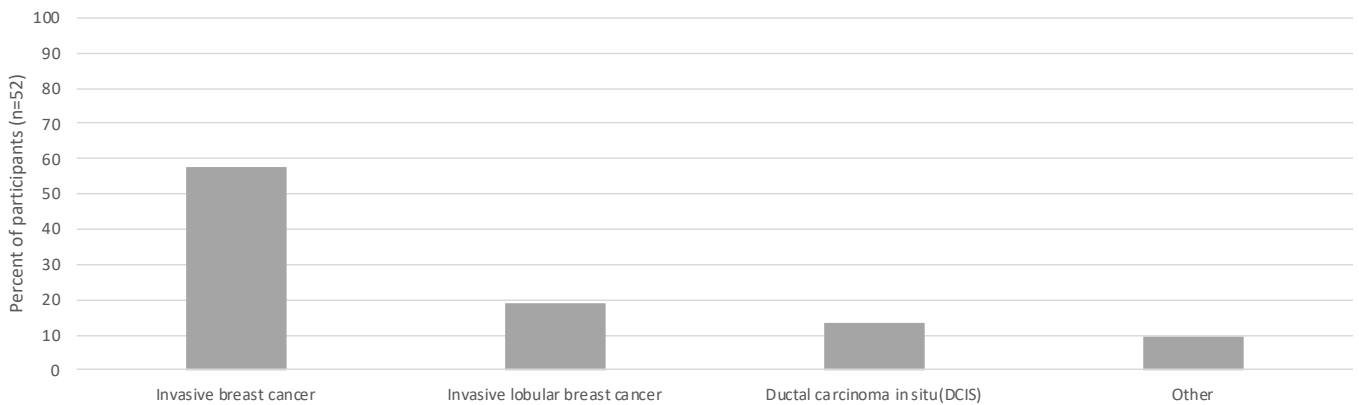
Figure 3.11: Type of breast cancer

Table 3.16: Breast cancer stage

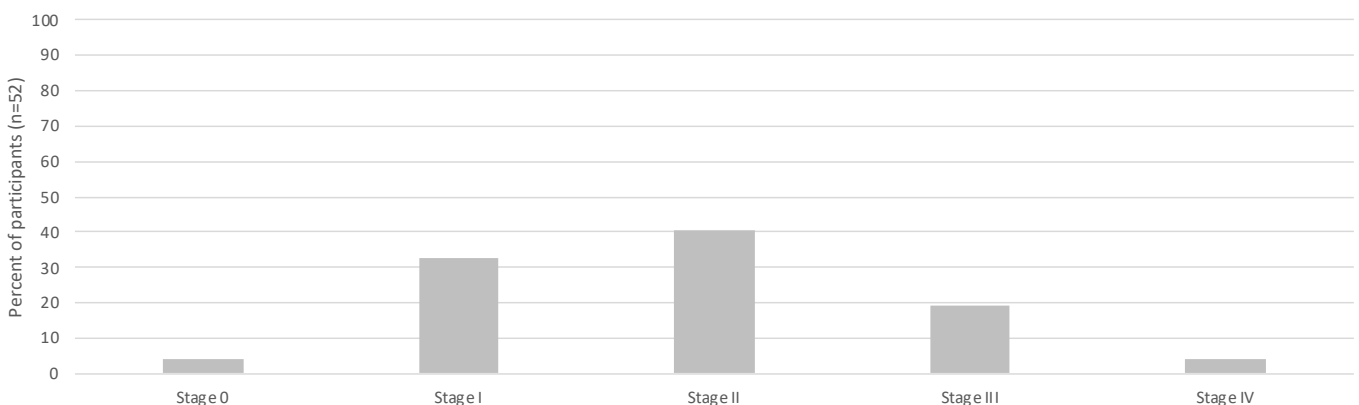| Participants and diagnosis	Number (n=52)	Percent
Stage 0	2	3.85
Stage I	17	32.69
Stage II	21	40.38
Stage III	10	19.23
Stage IV	2	3.85

Figure 3.12: Breast cancer stage

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having limited knowledge about the condition at diagnosis (n=30, 57.69%), this was followed by having no knowledge (n=11, 21.15%), and having had a good knowledge (n=9, 17.31%). The most common reasons for having limited knowledge was from having a family history of the condition (n=9, 17.31%), having a friend or acquaintance with the condition (n=8, 15.38%), having a medical, research or relevant professional background (n=8, 15.38%), and researching the condition during the diagnostic process (n=5, 9.62%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background (n=9, 9.62%).

Participant describes having limited knowledge from research through diagnostic process

They told me when I went back to see the breast surgeon that I had invasive ductal cancer. That's what the needle biopsy showed. I was given the impression that I had invasive ductal carcinoma. It was very, very small, very treatable. I would only need a lumpectomy. It was 7 mm. That's very tiny. Definitely did not need a mastectomy. She said definitely did not need a mastectomy. I would only require a lumpectomy. She was pretty positive that it wasn't in any lymph nodes. They gave me a lot of information. Asked me if I had questions. I was in shock aura. I didn't know what to ask. I really didn't know what to ask. She was just giving me information. Participant 010_2021AUHRP

Not a lot because I was in shock, to start off with because it was only about a week later I was in and I had surgery. It was quick bang, bang, bang in the hospital had the surgery and I had a lumpectomy. Participant 015_2021AUHRP

Not much, really, when I think about it. I didn't know that there were so many different varieties of breast cancer. I had no idea. Participant 032_2021AUHRP

Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment

A moderate amount. I'm medical, I'm a PROFESSION so I knew medical student level information about breast cancer from about 15 years ago. [chuckles]

Relatively literate but not really up to date, that would be my summary. Obviously it's not something I'd done a lot of reading about in the last 10 years because it really hadn't been on my radar, but I had a reasonable understanding of most of the basics. Participant 005_2021AUHRP

Quite a bit, really, because I'm a registered nurse. I knew a reasonable amount. I knew the lumpectomies and mastectomies because I've worked on surgical wards for many years, and have looked after a lot of people who had mastectomies and lumpectomies. Is that what you mean? Participant 017_2021AUHRP

I'm actually a nurse. So I knew a fair bit and one of the wards I worked on, one of the surgeries they did was mastectomy. So I pretty much knew a fair bit about, like the early stages, as far as you know, the difference between lumpectomy and mastectomy. And I knew that basically, due to my age that they were going to do is really radical treatment rather than like, let's just wait and see. So I had that bit of bit of knowledge. But obviously, I've never haven't ever done any oncological nursing so that when we got to the next part, so the chemo, I didn't really know much about that. But I from the surgical point of view, I knew more than the average Joe Blow. Participant 033_2021AUHRP

Participant describes knowing nothing about the condition at diagnosis

Before diagnosis, I didn't know anything about a DCIS. I didn't know about breast cancer. But I didn't know about pre cancer. Participant 001_2021AUHRP

I didn't know anything about my condition at all. Not a thing. Participant 004_2021AUHRP

Not a lot, to be honest with you. For me, because of my age, not many people had spoken about it before. I've never really been educated on it, so nothing. Now I know everything about it, but yes, nothing at all really. Participant 008_2021AUHRP

Nothing really, I was pretty much in denial. The GP who wasn't my GP was just filling in got the report and just rang me and said, You need to come in today and I was like what? What for and I was thinking why I haven't been to the doctors, and then I remembered three weeks ago and he said, Now you need to come in. I said this to me and he goes, I can't you need to come in. I went about a week later. Okay. Participant 041_2021AUHRP

Table 3.17: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes knowing very little about the condition at diagnosis	30	57.69	12	63.16	11	52.38	7	58.33	17	58.62	13	56.52	13	68.42	17	51.52
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	9	17.31	6	31.58	3	14.29	0	0.00	2	6.90	7	30.43	6	31.58	3	9.09
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	8	15.38	4	21.05	0	0.00	4	33.33	4	13.79	4	17.39	1	5.26	7	21.21
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	8	15.38	1	5.26	5	23.81	2	16.67	6	20.69	2	8.70	3	15.79	5	15.15
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding	8	15.38	3	15.79	3	14.29	2	16.67	5	17.24	3	13.04	5	26.32	3	9.09
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	3	15.79	2	6.06
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	9	17.31	4	21.05	3	14.29	2	16.67	3	10.34	6	26.09	3	15.79	6	18.18
Participant describes knowing about the condition as they have a medical, research or relevant professional background	5	9.62	4	21.05	1	4.76	0	0.00	2	6.90	3	13.04	2	10.53	3	9.09
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09
Participant describes knowing nothing about the condition at diagnosis	11	21.15	3	15.79	6	28.57	2	16.67	8	27.59	3	13.04	2	10.53	9	27.27

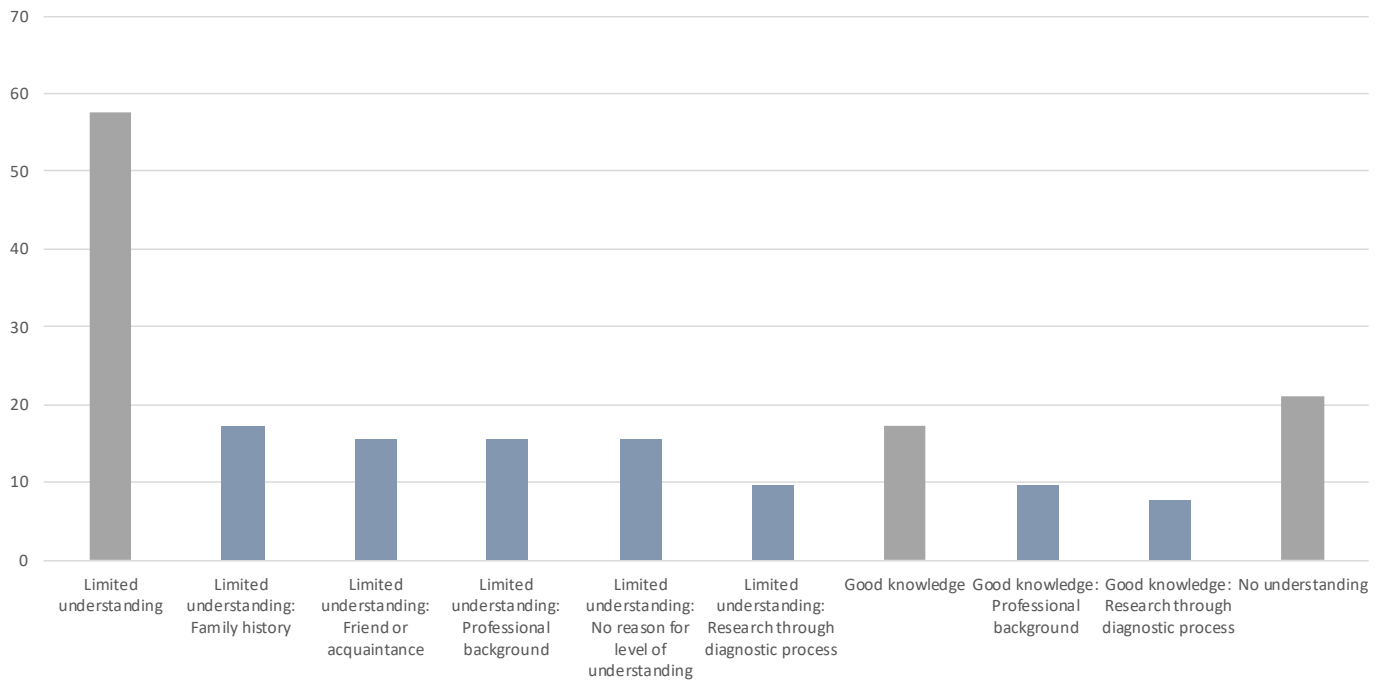| Understanding of disease at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes knowing very little about the condition at diagnosis	30	57.69	5	50.00	8	50.00	17	65.38	6	54.55	24	58.54	12	66.67	18	52.94
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	9	17.31	2	20.00	3	18.75	4	15.38	3	27.27	6	14.63	5	27.78	4	11.76
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	8	15.38	1	10.00	3	18.75	4	15.38	0	0.00	8	19.51	5	27.78	3	8.82
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	8	15.38	1	10.00	1	6.25	6	23.08	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding	8	15.38	2	20.00	2	12.50	4	15.38	3	27.27	5	12.20	1	5.56	7	20.59
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	5	9.62	2	20.00	1	6.25	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	9	17.31	1	10.00	3	18.75	5	19.23	3	27.27	6	14.63	2	11.11	7	20.59
Participant describes knowing about the condition as they have a medical, research or relevant professional background	5	9.62	0	0.00	2	12.50	3	11.54	2	18.18	3	7.32	1	5.56	4	11.76
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	2	11.11	2	5.88
Participant describes knowing nothing about the condition at diagnosis	11	21.15	4	40.00	4	25.00	3	11.54	1	9.09	10	24.39	3	16.67	8	23.53

Figure 3.13 Understanding of disease at diagnosis (percent of all participants)

Table 3.18: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing very little about the condition at diagnosis	-	Trade or high school
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	Stage III and IV Aged 25 to 54	Stage 0 and I Aged 55 to 74 Trade or high school Mid to low status
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	Stage II Trade or high school Regional or remote	Stage III and IV Mid to low status
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	Stage 0 and I	-
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding		Trade or high school Regional or remote
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process		Diagnosed in 2016 or before
Participant describes knowing about the condition as they have a medical, research or relevant professional background		Stage 0 and I
Participant describes knowing nothing about the condition at diagnosis	Trade or high school Regional or remote	Diagnosed in 2016 or before

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support (Table 3.19, Figure 3.14).

Subgroup variations of more than 10% are listed in Table 3.20

Table 3.19: Emotional support at diagnosis

Emotional support at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Enough support	15	28.85	5	26.32	6	28.57	4	33.33	9	31.03	6	26.09	6	31.58	9	27.27
Some support but it wasn't enough	11	21.15	4	21.05	5	23.81	2	16.67	6	20.69	5	21.74	5	26.32	6	18.18
No support	26	50.00	10	52.63	10	47.62	6	50.00	14	48.28	12	52.17	8	42.11	18	54.55

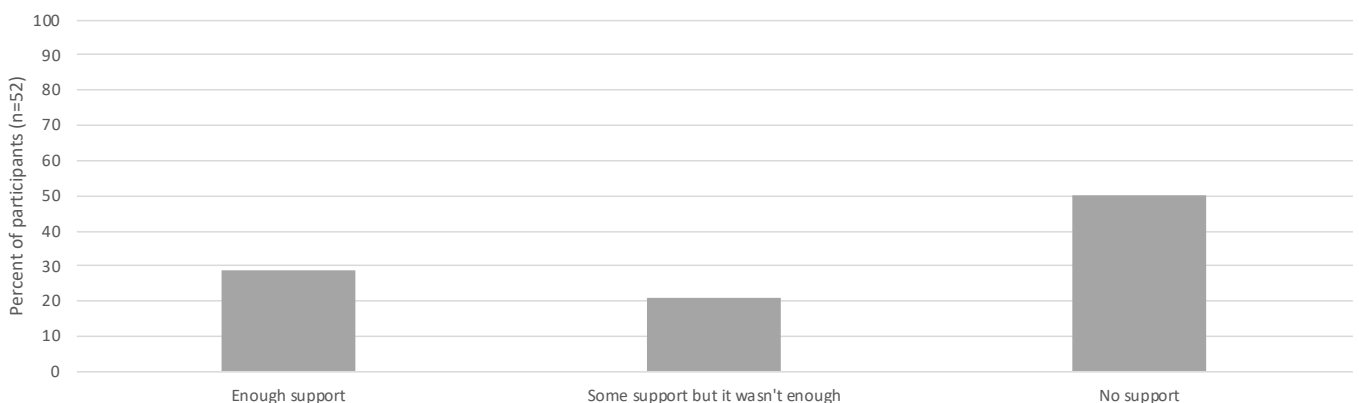| Emotional support at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Enough support	15	28.85	2	20.00	5	31.25	8	30.77	4	36.36	11	26.83	7	38.89	8	23.53
Some support but it wasn't enough	11	21.15	3	30.00	1	6.25	7	26.92	4	36.36	7	17.07	3	16.67	8	23.53
No support	26	50.00	5	50.00	10	62.50	11	42.31	3	27.27	23	56.10	8	44.44	18	52.94

Figure 3.14: Emotional support at diagnosis

Table 3.20: Emotional support at diagnosis – subgroup variations

Emotional support at diagnosis	Less frequently	More frequently
Enough support	-	Mid to low status
Some support but it wasn't enough	Diagnosed in 2017 to 2019	Regional or remote
No support	Regional or remote	Diagnosed in 2017 to 2019

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 29 participants (55.77%) who had enough information, 21 participants (40.38%) that had some information but it wasn't enough, and two participants (3.85%) had no information (Table 3.21, Figure 3.15).

Subgroup variations of more than 10% are listed in Table 3.24

Table 3.21: Information at diagnosis

Information at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Enough information	29	55.77	7	36.84	13	61.90	9	75.00	18	62.07	11	47.83	11	57.89	18	54.55
Some information but it wasn't enough	21	40.38	11	57.89	7	33.33	3	25.00	11	37.93	10	43.48	7	36.84	14	42.42
No information	2	3.85	1	5.26	1	4.76	0	0.00	0	0.00	2	8.70	1	5.26	1	3.03

| Information at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Enough information	29	55.77	5	50.00	9	56.25	15	57.69	5	45.45	24	58.54	10	55.56	19	55.88
Some information but it wasn't enough	21	40.38	5	50.00	6	37.50	10	38.46	5	45.45	16	39.02	6	33.33	15	44.12
No information	2	3.85	0	0.00	1	6.25	1	3.85	1	9.09	1	2.44	2	11.11	0	0.00
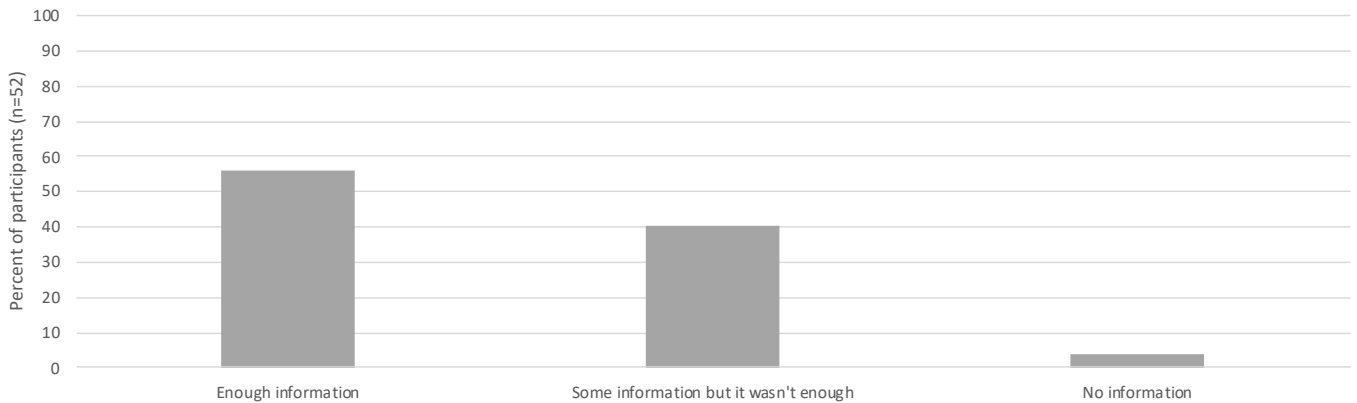
Figure 3.15: Information at diagnosis

Table 3.22: Information at diagnosis – subgroup variations

Information at diagnosis	Less frequently	More frequently
Enough information	Stage 0 and I	Stage III and IV
Some information but it wasn't enough	Regional or remote Stage III and IV	Stage 0 and I

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000 (Table 3.23, Figure 3.16).

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 13 participants (39.39%) the cost was slightly or not at all significant. For 12 participants (36.36%) the out-of-pocket expenses were somewhat significant, and for eight participants (24.24%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.24, Figure 3.17).)

Table 3.23: Out of pocket expenses at diagnosis

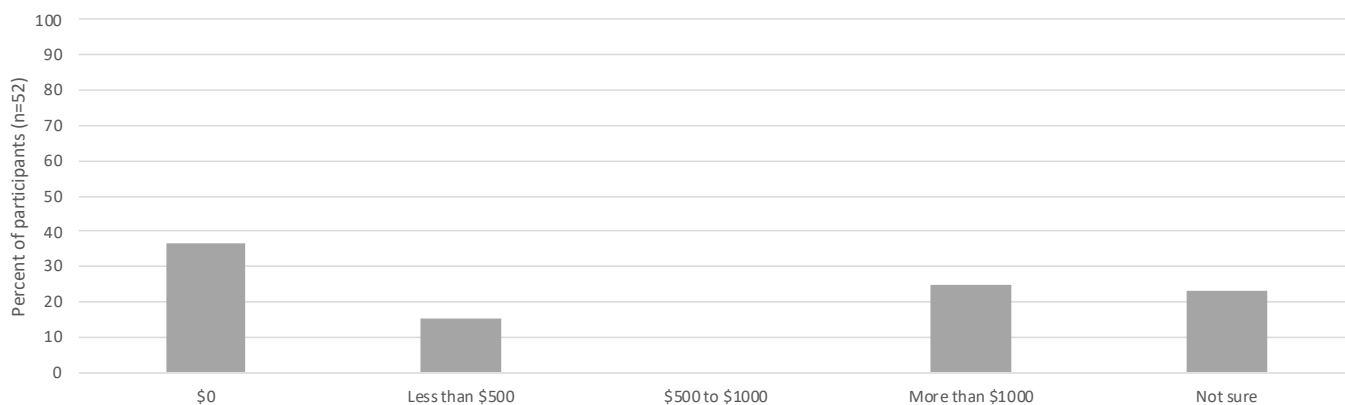| Out of pocket expenses for diagnostic tests	Number (n=52)	Percent
$0	19	36.54
Less than $500	8	15.38
$500 to $1000	0	0.00
More than $1000	13	25.00
Not sure	12	23.08

Figure 3.16: Out of pocket expenses at diagnosis

Table 3.24: Burden of diagnostic costs

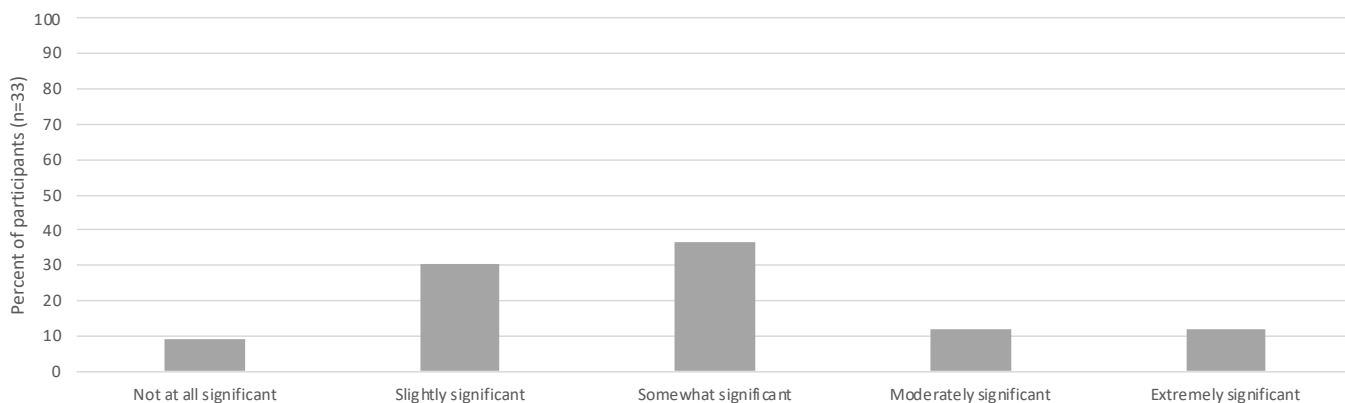| Burden of diagnostic costs	Number (n=33)	Percent
Not at all significant	3	9.09
Slightly significant	10	30.30
Somewhat significant	12	36.36
Moderately significant	4	12.12
Extremely significant	4	12.12

Figure 3.17: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n = 16, 30.77%). There were 14 participants (26.92%) who brought up the topic with their doctor, and 22 participants (42.31%) whose doctor brought up the topic with them (Table 3.25, Figure 3.18).

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Half of the participants did not have any genetic or biomarker tests but would like to (n = 26, 50.00%). There were five participants (9.62%) who did not have these tests and were not interested in them, and a total of seven participants (13.46%) that had biomarker tests (Table 3.26, Figure 3.19).

Table 3.25: Discussions about biomarkers

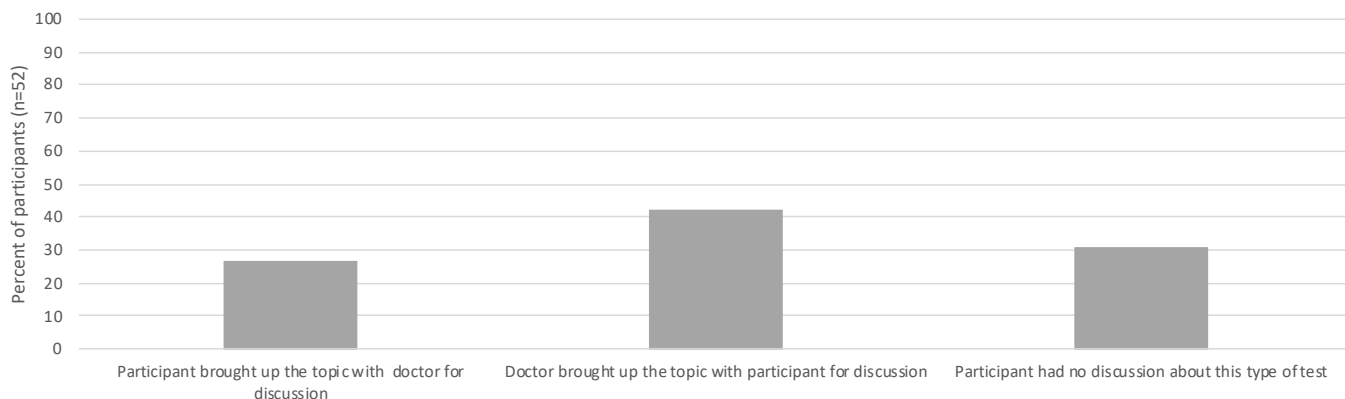| Discussions about biomarkers	Number (n=52)	Percent
Participant brought up the topic with doctor for discussion	14	26.92
Doctor brought up the topic with participant for discussion	22	42.31
Participant had no discussion about this type of test	16	30.77

Figure 3.18: Discussions about biomarkers

Table 3.26: Experience of genetic tests and biomarkers

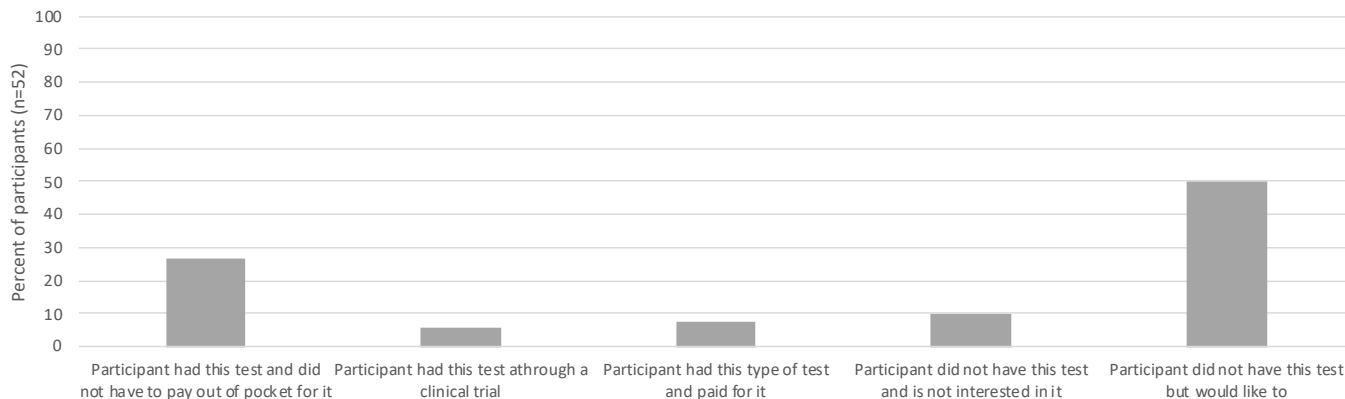| Experience of genetic tests and biomarkers	Number (n=52)	Percent
Participant had this test and did not have to pay out of pocket for it	14	26.92
Participant had this test athrough a clinical trial	3	5.77
Participant had this type of test and paid for it	4	7.69
Participant did not have this test and is not interested in it	5	9.62
Participant did not have this test but would like to	26	50.00

Figure 3.19: Experience of genetic tests and biomarkers

Biomarker status

All participants knew the status for at least one biomarker (n = 52, 100%). All participants knew their ER status (n=52, 100%), and most participants knew their PR status (n = 42, 80.77%). There were 15 participants (28.85%) that knew their HER2 status and seven participants (13.46%) that knew their BRCA status (Table 3.27, Figure 3.20).

Table 3.27: Biomarker status

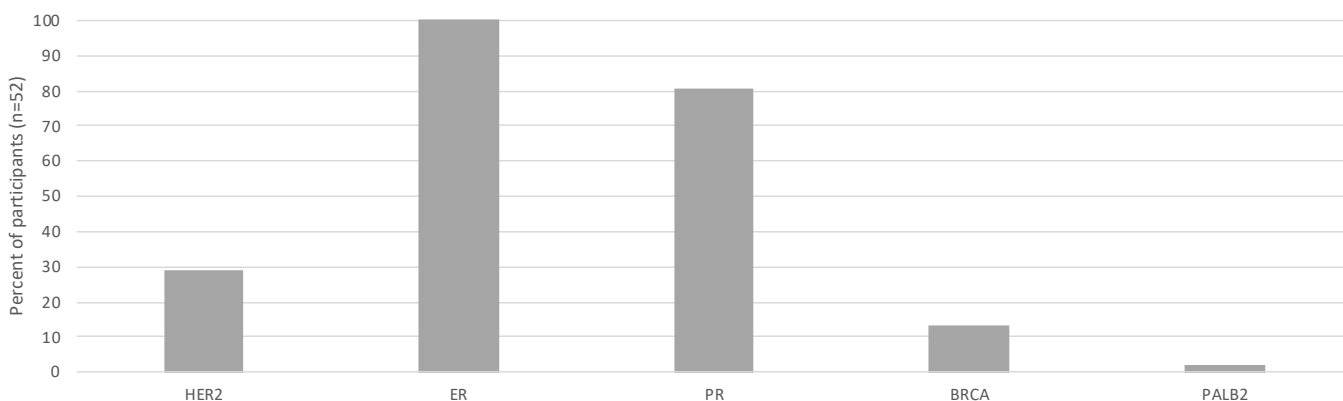| Biomarkers status known	Number (n=52)	Percent
HER2	15	28.85
ER	52	100.00
PR	42	80.77
BRCA	7	13.46
PALB2	1	1.92

Figure 3.20: Biomarker status

Current symptoms

Number of current symptoms

Participants were asked in the questionnaire what symptoms they are currently dealing with, they could choose from a set lit of symptoms and could then specify other symptoms not listed.

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 24, 46.15%). Participants had between four and 13 symptoms (mean = 4.10, SD = 4.69) (Table 3.28, Figure 3.21).

Type of current symptoms

The most common current symptoms, and those where more than 40% of the participants experienced the symptom were; sleep problems (n = 23, 44.23%), weight and muscle changes (n = 23, 44.23%), thinking and memory problems (n = 22, 42.31%), anxiety/anxious mood (n=21, 40.38%), fatigue (n = 23, 44.23%), and pain(n = 23, 44.23%) (Table 3.29, Figure 3.21).

Quality of life from current symptoms

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great" (Figure 3.26). The median quality of life was between 2.00 and 3.00, for all of the symptoms listed in the questionnaire, this is in the "Life was distressing" to "Life was a little distressing" range.

The symptoms with the lowest quality of life were sleep problem, weight and muscle changes, and fatigue.

Table 3.28: Number of current symptoms

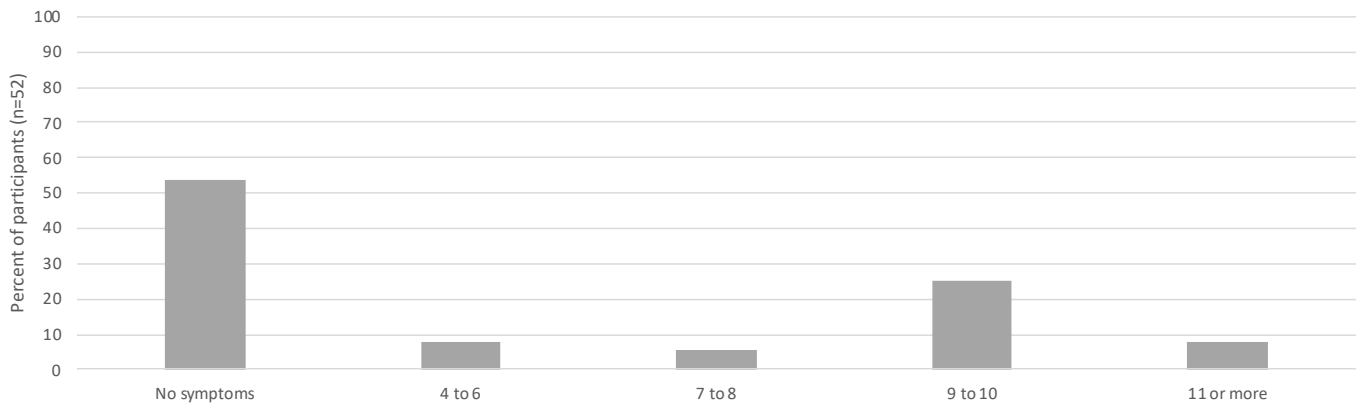| Number of symptoms before diagnosis	Number (n=52)	Percent
No symptoms	28	53.85
4 to 6	4	7.69
7 to 8	3	5.77
9 to 10	13	25.00
11 or more	4	7.69

Figure 3.21: Number of current symptoms

Table 3.29: Type of current symptoms

| Symptom	Number (n=52)	Percent	Quality of life	
			Mean	SD
No symptoms	28	53.85	NA	NA
Bladder problems	6	11.54	3.00	2.75
Sexual function/ability to have inimate relationships	20	38.46	2.00	2.00
Sleep problems	23	44.23	3.00	1.50
Weight and muscle changes	23	44.23	2.00	2.00
Thinking and memory problems	22	42.31	3.00	2.75
Bone problems	18	34.62	3.00	2.00
Depression/depressed mood	19	36.54	3.00	2.00
Anxiety/anxious mood	21	40.38	3.00	1.00
Fatigue	23	44.23	3.00	1.00
Pain	23	44.23	3.00	1.50
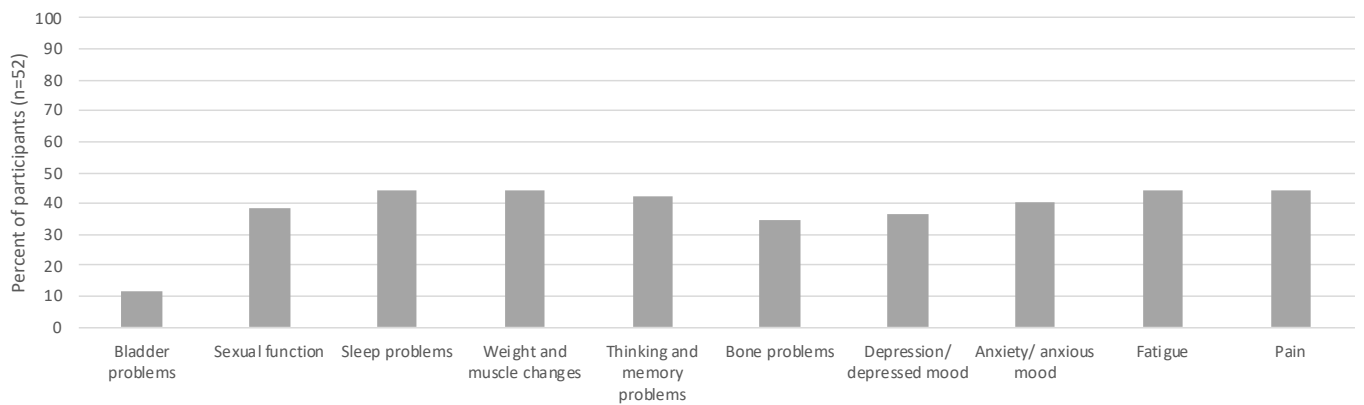
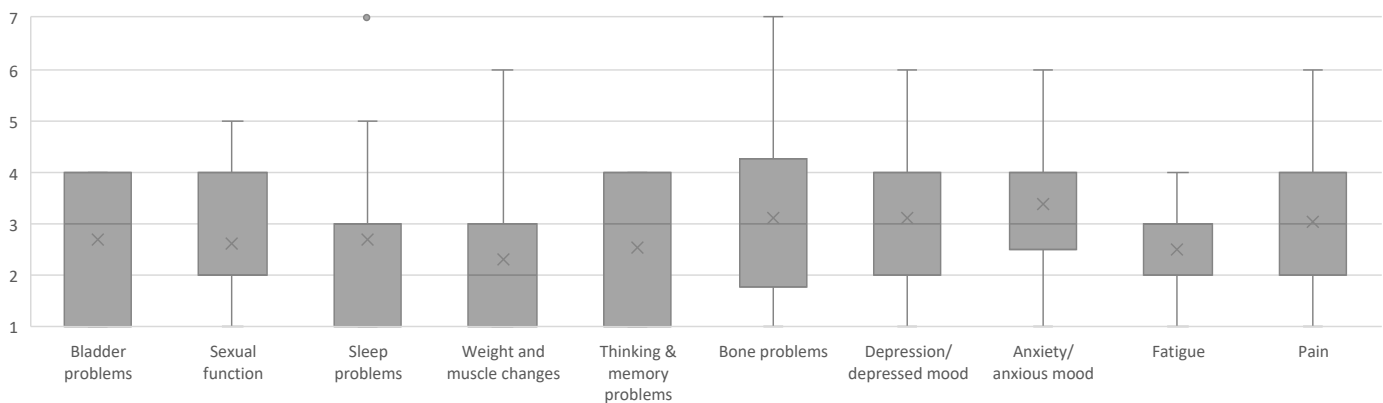**Figure 3.22: Type of current symptoms**

Figure 3.23: Quality of life from current symptoms

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to no evidence of disease or that they are in remission (n=23, 44.23%). There were 22 participants (42.31%) that described a positive prognosis in relation managing their condition with treatment. Other participants described prognosis in relation to statistics such as five year survival rates (n=19, 36.54%), in relation to probable recurrence/cycle of recurrence (n=16, 30.77), and in relation to monitoring their condition without treatment until there is an exacerbation or progression (n=6, 11.54%).

Participant describes prognosis in relation to no evidence of disease or that they are in remission

Yes, so I am technically free of cancer now, thankfully. I have finished my treatments six weeks ago now, end of radiation. Now it's just all the follow-ups. I've just literally started my hormone blockers yesterday. Participant 008_2021AUHRP

When I was having the radiation treatment, I saw a radiation oncologist, and she said, "Oh, you've got no cancer now." I thought that was a bit swift because it was only after my second day of the radiation treatment. No one's really said anything other than that. Participant 012_2021AUHRP

I'm four years clear in August. I've just had tissue expanders in March. All clear at the moment. Participant 024_2021AUHRP

I've never asked and they don't tell you. I'm not stage four. I guess what you'd say is that I've no evidence of disease, prognosis isn't anything that my specialists talked to me about. Participant 043_2021AUHRP

Participant describes prognosis in relation to it being positive: Manageable with treatment

Good question. I'm ERPR positive and I'm on hormone blockers for the next six years, I think. I've been on them already four or five. They don't really say a lot but they did tell me that if I didn't follow the protocols that I probably wouldn't be around in a couple of years. We tend to just do what you're told. Not that that always works because I'm sorry, the flow-on effects really don't make for a fun life, I can assure you. Participant 018_2021AUHRP

My surgeon contacted my oncologist and they did test, a whole heap of bloods and there was nothing. They were thinking that it might be, shall I say, fatty tissue? [laughs]. At this stage, I'm on tamoxifen for 10 years and I have six-monthly checkups with the oncologist and 12-monthly checkups with my surgeon. Participant 031_2021AUHRP

Yes. Again, I am one of these people, I actually feel guilty even telling people I have breast cancer because my journey has been so easy and simple compared to so many other people I've seen around me. I am reradiation. I have just started the tamoxifen, which I have not had very bad side effects. A little bit of lesions, but no other side effects. I've come through all the physical therapy. I'm swimming and running, so I would say it was more of a wake up call to a healthier lifestyle, than anything else. Participant 007_2021AUHRP

My prognosis should be good, but I'm taking Arimidex. Hopefully, because mine's hormone positive, so it's a receptor blocker. Participant 032_2021AUHRP

Participant describes prognosis in relation to statistics such as five year survival rates

I would say it's pretty good. Mine was a low stage tumor so it's only a 1A but it was high grade, grade three, and it was treated with wide local excision and radiotherapy which means the risk of recurrence in the same site at five years is about 10%. Because it's a hormone-positive tumor, total risk of recurrence per year is 2%, and that doesn't seem to diminish after 20 years, which is the longest trial that's been done so far. Participant 005_2021AUHRP

Nobody can tell you categorically that you're in the clear. I don't know what my outlook is. The guy that did my radiology on oncologist, DOCTOR, he seems to think I have a good prospect. I didn't undergo chemo. I didn't want to do that, even though they recommended it, but when I was told it would only give me an 8% benefit or 6%, I think they said benefit. I thought well, I'm not going to undergo that for 6% extra chance. A 6%, what is it? Less mortality or something, I can't remember. Anyway, I wasn't going to go through that, so I went along with the radio-- I didn't even want to have radiation because after what my mother had been through. I'd seen the burns and the pain. Then I didn't know a lot about her disease. I did see that when I was young, how much pain and

the torture she went through. Then I was convinced, they told me times have changed and things are a lot better and radiation is a lot better and more targeted and less painful, so I went ahead and had the radiation done. As I said, my radiation oncologist seems to think that I've got a good chance of having a good outcome. Participant 035_2021AUHRP

Yeah. So at the moment, they just tell you that they can only really tell you that the next five or 10 years, so it's all those percentages, which is really daunting, isn't it? So I've just finished chemo, probably not that long ago, so less probably about two months ago. And they've got another surgery to do, I just have another surgery just recently, like, probably three weeks, four weeks ago. And they've said that they've totally removed all the cancer now that they've accidentally but I didn't get clean margins to start off with after my double mastectomy. So they have to go back and do that. So now they're saying the, they're happy that they've got all the cancer that my chemo was sufficient. And that I think I've got a 94% survival rate for the next five years. And I think with hormone therapy and stuff, they're saying, you know, if I do that, too, obviously, it's an improve my longevity. Participant 048_2021AUHRP

Participant describes prognosis in relation to probable recurrence/cycle of recurrence

Favorable. I think when the oncologist explained it to me, he said that they are getting it down to probably in the realm of potential 15% chance of recurrence. Participant 050_2021AUHRP

Not not, in the words of saying, Oh, look, they shouldn't come back and you should be fine. with breast cancer, they tend to just do mammogram, and ultrasound, you don't have scans or anything. So it's just like, if you keep taking the letrozole, it'll add an increase chance they all talk about this five year survival. No one really talks about 10, 15, 20 years and every all the literature you read is all five years or 10 years, nothing goes beyond that. Okay. Participant 041_2021AUHRP

Okay, it's a bit wishy-washy. I've actually had a -- my other breast removed. I had a prophylactic mastectomy. with malignant phalloides tumours it has a very high reoccurrence rate. It's up around the

25-30% within two years. Distant and local mets are also a big issue. So, yeah, it was sort of the prognosis, unless you do something is quite poor. Participant 003_2021AUHRP

Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression

I'm scheduled for annual surveillance. I got told off for calling it screening, but it's surveillance now. No, actually there was nothing in the lymph nodes. They took a dye and a couple of lymph nodes out. They were clear. I did have to go back for a second surgery to make sure the margins were clear, but that was all good. The cancer itself was quite small, but there was quite a lot of calcium membrane situ around it more than I think anyone had anticipated. That was a bit freaky, but that's all gone.I had radiotherapy and I'm now on tamoxifen, but basically said it's a situation where the surgery is assumed to be pretty much curative, and the other things are relatively low-risk. Even though there's only a little bit of benefit on top of the surgery from doing them, it's worth doing. The additional benefits from chemotherapy would have been well outweighed by the side effects and therefore it wasn't recommended, which was quite a relief Participant 011_2021AUHRP

PARTICIPANT: I tell myself I'm all fine and I think it's so far so good. I had a raft of scans and tests and things towards the end of last year and I'm now only seeing a specialist once every six months.
INTERVIEWER: Okay.
PARTICIPANT: That's a good thing, I think. What else? Yes, I just hope I'm okay. I have regular tests and regular appointments and I don't think there's anything else I can do. Participant 039_2021AUHRP

Right now, I'm doing regular screening for, I should say, some cyst or lump that they found in my liver and my lungs and just a small area on my head which they believe that they're all benign but they are just watching what's happening with those. I've been told that the first three years I have a very high risk for the cancer coming back somewhere in my body, but that's also normal with a 50/50 chance of [unintelligible 00:09:54] survival. That's how it was described to me at the end of the treatment. Participant 049_2021AUHRP

Table 3.30: Understanding of prognosis

Understanding of prognosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	23	44.23	6	31.58	9	42.86	8	66.67	13	44.83	10	43.48	7	36.84	16	48.48
Participant describes prognosis in relation to it being positive: Manageable with treatment	22	42.31	9	47.37	9	42.86	6	50.00	9	31.03	14	60.87	10	52.63	13	39.39
Participant describes prognosis in relation to statistics such as five year survival rates	19	36.54	7	36.84	10	47.62	2	16.67	14	48.28	5	21.74	7	36.84	12	36.36
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	16	30.77	7	36.84	6	28.57	3	25.00	9	31.03	7	30.43	6	31.58	10	30.30
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	3	15.79	3	9.09

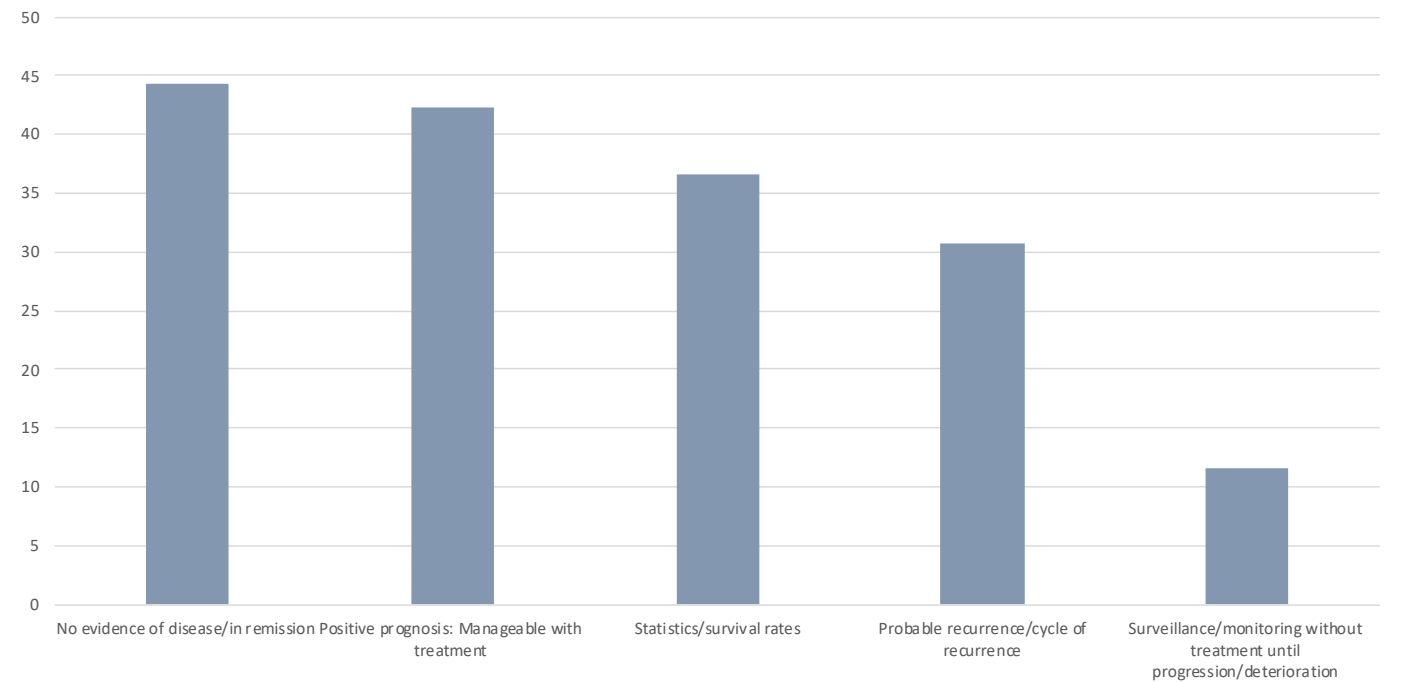| Understanding of prognosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	23	44.23	5	50.00	9	56.25	9	34.62	4	36.36	19	46.34	9	50.00	14	41.18
Participant describes prognosis in relation to it being positive: Manageable with treatment	22	42.31	4	40.00	8	50.00	12	46.15	5	45.45	18	43.90	8	44.44	15	44.12
Participant describes prognosis in relation to statistics such as five year survival rates	19	36.54	4	40.00	7	43.75	8	30.77	4	36.36	15	36.59	10	55.56	9	26.47
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	16	30.77	4	40.00	5	31.25	7	26.92	5	45.45	11	26.83	7	38.89	9	26.47
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	6	11.54	0	0.00	2	12.50	4	15.38	2	18.18	4	9.76	2	11.11	4	11.76

Figure 3.24: Understanding of prognosis (percent of all participants)

Table 3.31: Understanding of prognosis – subgroup variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to no evidence of disease or that they are in remission	Stage 0 and I	Stage III and IV Diagnosed in 2017 to 2019
Participant describes prognosis in relation to it being positive: Manageable with treatment	Aged 25 to 54	Aged 55 to 74 Trade or high school
Participant describes prognosis in relation to statistics such as five year survival rates	Stage III and IV Aged 55 to 74 Higher status	Stage II Aged 25 to 54 Mid to low status
Participant describes prognosis in relation to probable recurrence/cycle of recurrence		Regional or remote
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	Diagnosed in 2016 or before	