Section 3

Symptoms and diagnosis

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Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of triple negative breast cancer and the approximate date of diagnosis with triple negative breast cancer. Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

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=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with triple negative breast cancer. Participants reported between 1 and 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

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 general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness

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 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that 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 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that 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 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

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

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 = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them.

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%).

Current symptoms

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n=21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%).

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”. The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

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=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Participant describes finding a breast lump, which led to their diagnosis

Okay. Well, I first noticed a lump on my breast in the shower one day, and I felt like it was like the size of a marble. I hadn't noticed it before, so I wasn't overly concerned about it, but I thought it was worth getting it checked. Just to be on the safe side, I thought it was probably just [unintelligible 00:02:13] or something. I went to my doctor and from there, I went ahead and mammogram and then ultrasound. Participant_020

No. I don't really recall any signs or symptoms. I know one of my friends told me that it was getting harder to wake me up, so maybe I was a bit more tired than usual. Actually, I found the lump on my breast. I was in pain. My breast was sore, and I felt a lump there. Then when I looked at myself in the mirror, I don't know whether I was imagining or not, I swear I saw bruising, so I thought I'd injured myself at the time. That's pretty much what happened with me. Participant_028

Okay. It was actually on a Wednesday. I was getting ready for work. I noticed a large lump under my left arm, and I just thought that's a bit unusual. I went to work and mentioned it to a few people. What I actually did was I thought I'll ring up and make an appointment for the doctor on Friday. If the lump is still there on Friday, I'll go to the doctor. If it's not there, I'll cancel it. It was there on Friday, so I went to the doctor. Participant_046

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

PARTICIPANT: I didn't have any symptoms. I went for a regular mammogram and it was picked up in the mammogram.
INTERVIEWER: Okay, all right. Just a routine mammogram?
PARTICIPANT: Yes.
INTERVIEWER: From this, who then ordered the first tests, if you remember that, and what was the tests that were ordered? Yes, the initial tests that were ordered, and maybe you can remember who.
PARTICIPANT: Are we talking about just this particular mammogram or how far back do I go?
INTERVIEWER: After you had the mammogram.
PARTICIPANT: Oh, after I had the mammogram. I had that done in a BreastScreen LOCATION facility. It was then I got a phone call about two weeks later from BreastScreen LOCATION, I think, requesting that I go into the HOSPITAL, there's a Family History Clinic on the ground floor of the HOSPITAL. They requested that I go there for further investigations because they'd seen an anomaly come up on the mammogram. I did that towards the end of February. Then I had a barrage of tests done there. I had an ultrasound. Is it breast examination? Participant_014

I have a history of breast cysts, so I used to be monitored yearly for any changes in my breast. That got changed to two-yearly, literally two years prior to my diagnosis. I was diagnosed from mammograms. I'm a country patient. I live in LOCATION. I was sent to LOCATION to have a mammogram. Prior to the mammogram, on the day, I was given an ultrasound, and I knew myself from the ultrasound what we were looking at, even though no one said anything. By the time I got home, I was already in panic mode without having a diagnosis from anyone. I just knew myself what was going on. I'd done my own research to find a surgeon who I wanted to see, which was NAME at HOSPITAL. When my doctor phoned me the following day after my mammogram and ultrasound, he said, "How you going?" I said, "I know." He goes, "Right. What do you want to do?" I said, "This is who I want to see. Send me to LOCATION." That's how it went. Participant_034

Table 3.1: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes finding a breast lump, which led to their diagnosis	39	78.00	21	91.30	18	66.67	14	73.68	21	84.00	19	73.08	20	83.33	17	70.83	22	84.62
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	10.00	1	4.35	4	14.81	2	10.53	2	8.00	3	11.54	2	8.33	3	12.50	2	7.69
Other	6	12.00	1	4.35	5	18.52	3	15.79	2	8.00	2	7.69	4	16.67	4	16.67	2	7.69

Symptoms leading to diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes finding a breast lump, which led to their diagnosis	39	78.00	15	93.75	24	70.59	16	80.00	23	76.67	13	68.42	20	90.91	6	66.67
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Other	6	12.00	0	0.00	6	17.65	2	10.00	4	13.33	4	21.05	0	0.00	2	22.22

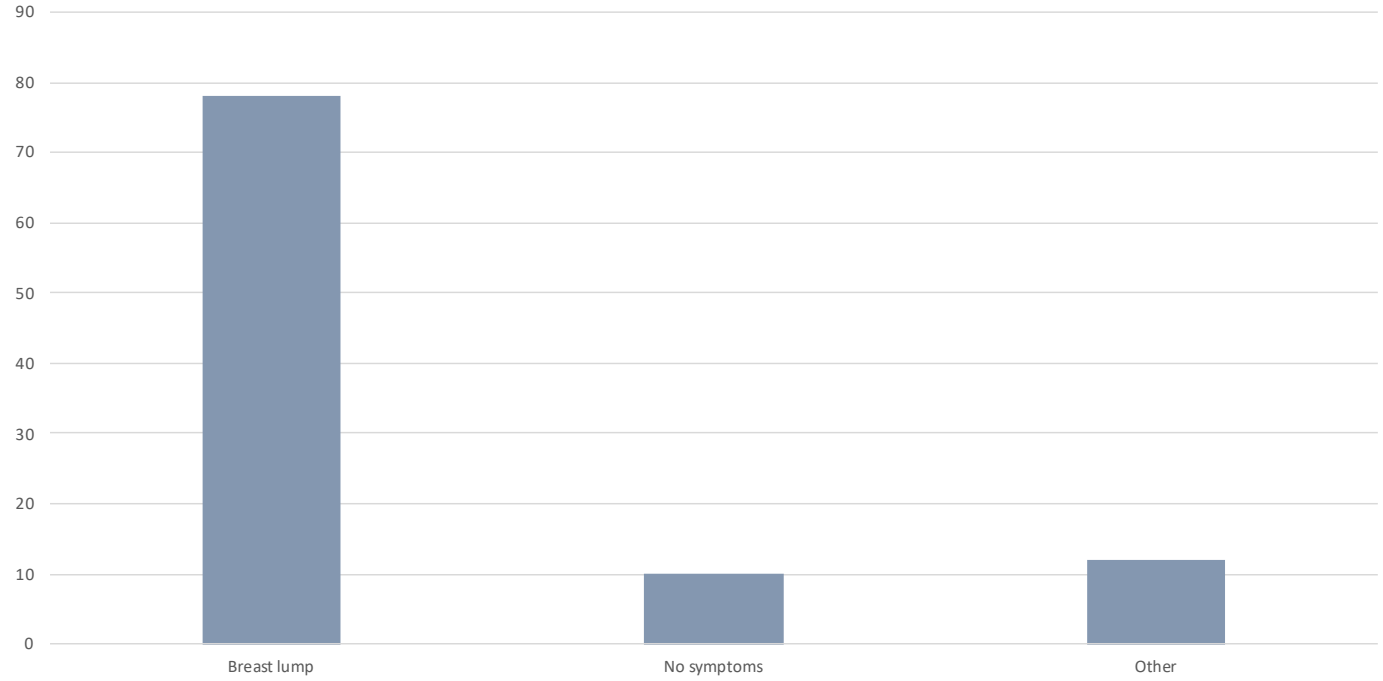

Figure 3.1: Symptoms leading to diagnosis

Table 3.2: Symptoms leading to diagnosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes finding a breast lump, which led to their diagnosis	Advanced breast cancer Aged 55 to 74	Early breast cancer Regional or remote Aged 45 to 54

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Participant describes having symptoms and seeking medical attention relatively soon

Okay, well, I wasn't under any surveillance because there's no history of cancer in my family. When I went to the doctor when I first noticed the lump, she sent me off to get a mammogram and an ultrasound done. Based on the ultrasound images, she then sent me to get a fine needle biopsy done. That was what showed us that it was a cancerous mass. Participant_027

Okay. Well, I first noticed a lump on my breast in the shower one day, and I felt like it was like the size of a marble. I hadn't noticed it before, so I wasn't overly concerned about it, but I thought it was worth getting it checked. Just to be on the safe side, I thought it was probably just [unintelligible] or something. I went to my doctor and from there, I went ahead and mammogram and then ultrasound. Participant_020

I had nothing before diagnosis. There was nothing worse than seeing a doctor regularly or anything like that. So I found the lump riding to see my GP. And because it was hurting, because I did it so not my doctor was you know, she's I remember him saying, you don't usually hit me. And she said it's probably just hit with it so much. But yes, she booked me in for an ultrasound. Outstanding mammogram or I think no, I think to start with, it was just an ultrasound. And I went to the radiology place and I had the ultrasound. And before I left, that had to mean that deadpan, I don't tell you anything, but before I left the like, OK, we need you to come back for biopsy. So I had set up to that, to that to wait and the biopsy and then I had the biopsy. And then this is the part that 12 or nine years later do shits me the most. I went to I think the doctor said call-back will come back in X amount and I days, something like that. So I went back and my doctor, she wasn't even like my regular doctor, but the doctor that had the biopsy, you know, all of that stuff was she was away. And I said, that's fine. I'll just say whoever so went in to see my doctor or the doctor of the day, how can I help you? And I said, oh, I'm here for some test results, you know? So she looked up and she was a young doctor and she could just see her face just basically in the head. I could see what she had to tell me, that the test results were positive, that, yes, I had cancer. And she was like, I'm so sorry. This should have been red flagged. We should have called you in. She had me walking into her office to tell me I had cancer, yet she had no idea what she was about to tell me. So I was quite floored myself because I went to the appointment by myself and my husband was on nightshift. He was asleep and I just found out I had cancer and I didn't know. Participant_003

Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the center there and told me the results of the biopsy and the further ultrasound. Participant_029

Participant describes having symptoms and not seeking medical attention initially

PARTICIPANT: Yes, so I was pregnant. It was in about May last year, 2020. I noticed a lump that had started, but I put that down to hormonal prepping for birth and breastfeeding and all that stuff, I didn't really think much of it. Then, it gradually grew bigger and bigger. Once I birthed my baby and when she was about four months old, I actually went and got it checked out.
INTERVIEWER: PARTICIPANT, can you describe how you came to be diagnosed? Now, for this, you can talk about any tests that were ordered and who ordered them for you if you can remember that. This might also include any ongoing management or surveillance that you might have been under before you were diagnosed.
PARTICIPANT: I went to my GP and had a referral for an ultrasound. Then, from that ultrasound, my GP referred me to a specialist, which was of my choosing because background-wise, I've got family history. I'd already been linked in with HOSPITAL previously and all the family history. My mother and my grandmother all went through HOSPITAL, so I requested for the referral to go to HOSPITAL. Then I had a sited biopsy and from that is when they did the diagnosis. Participant_030

PARTICIPANT: The first time I noticed was a lump, which I get lots of lipomas anyway so at first I thought, "I wonder if that's just the lipoma." It was right at the late February, early March last year and everybody was starting to get nervous and worried about COVID. I thought, "I'll just let that flow over and then I'll go to the doctor," [chuckles] thinking it's going to be a short-term thing.
INTERVIEWER: Yes. [chuckles] Unfortunately, not.
PARTICIPANT: Yes. When it got May and looked like things were not going to settle down and the lump was getting bigger, I thought, "I've got to do something." I had a telehealth appointment with my doctor and she said, "Get a check straightaway." Then I got scans and things.
INTERVIEWER: That leads me into my next question about how you came to be diagnosed. What tests did you have, PARTICIPANT? Who ordered those for you?
PARTICIPANT: It was my GP who ordered them. I had a mammogram and ultrasound. They called the doctor when I did the ultrasound and the doctor said they wanted a biopsy. My GP doesn't work every day. They ended up getting a referral from another GP for surgery because I wanted the biopsy the next day and I didn't want to wait. I knew already at that point that things weren't looking good. Then the biopsy confirmed it Participant_011

Thinking now before I was diagnosed, I was getting pins and needles down my arm and in my hand, on my right which is the same breast. I don't know whether it's linked or not, but I do remember that now. I do remember up in my lymph nodes, I do also remember feeling that they were enlarged and I did see my GP about it but she just said-- I think she did feel my breasts at that stage and she said, "Oh no, that's just whatever." She didn't even think about the cancer sort of thing. I also do think before I was diagnosed, probably a couple of months beforehand, I did have a tender breast but I didn't really think too much of it. I thought one of my kids had knocked me in my breasts and I didn't think too much of it. Participant_017

Table 3.3: Seeking medical attention

Seeking medical attention	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes having symptoms and seeking medical attention relatively soon	31	62.00	11	47.83	20	74.07	13	68.42	15	60.00	16	61.54	15	62.50	14	58.33	17	65.38
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	6	12.00	4	17.39	2	7.41	2	10.53	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes having symptoms and not seeking medical attention initially	6	12.00	4	17.39	2	7.41	2	10.53	4	16.00	2	7.69	4	16.67	2	8.33	4	15.38
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	8.00	3	13.04	1	3.70	1	5.26	1	4.00	2	7.69	2	8.33	3	12.50	1	3.85
Other	3	6.00	1	4.35	2	7.41	1	5.26	2	8.00	1	3.85	2	8.33	2	8.33	1	3.85

Seeking medical attention	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes having symptoms and seeking medical attention relatively soon	31	62.00	10	62.50	21	61.76	11	55.00	20	66.67	0	0.00	13	59.09	4	44.44
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	6	12.00	2	12.50	4	11.76	5	25.00	1	3.33	14	73.68	3	13.64	3	33.33
Participant describes having symptoms and not seeking medical attention initially	6	12.00	3	18.75	3	8.82	1	5.00	5	16.67	2	10.53	4	18.18	0	0.00
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	8.00	1	6.25	3	8.82	1	5.00	3	10.00	1	5.26	1	4.55	2	22.22
Other	3	6.00	0	0.00	3	8.82	2	10.00	1	3.33	2	10.53	1	4.55	0	0.00

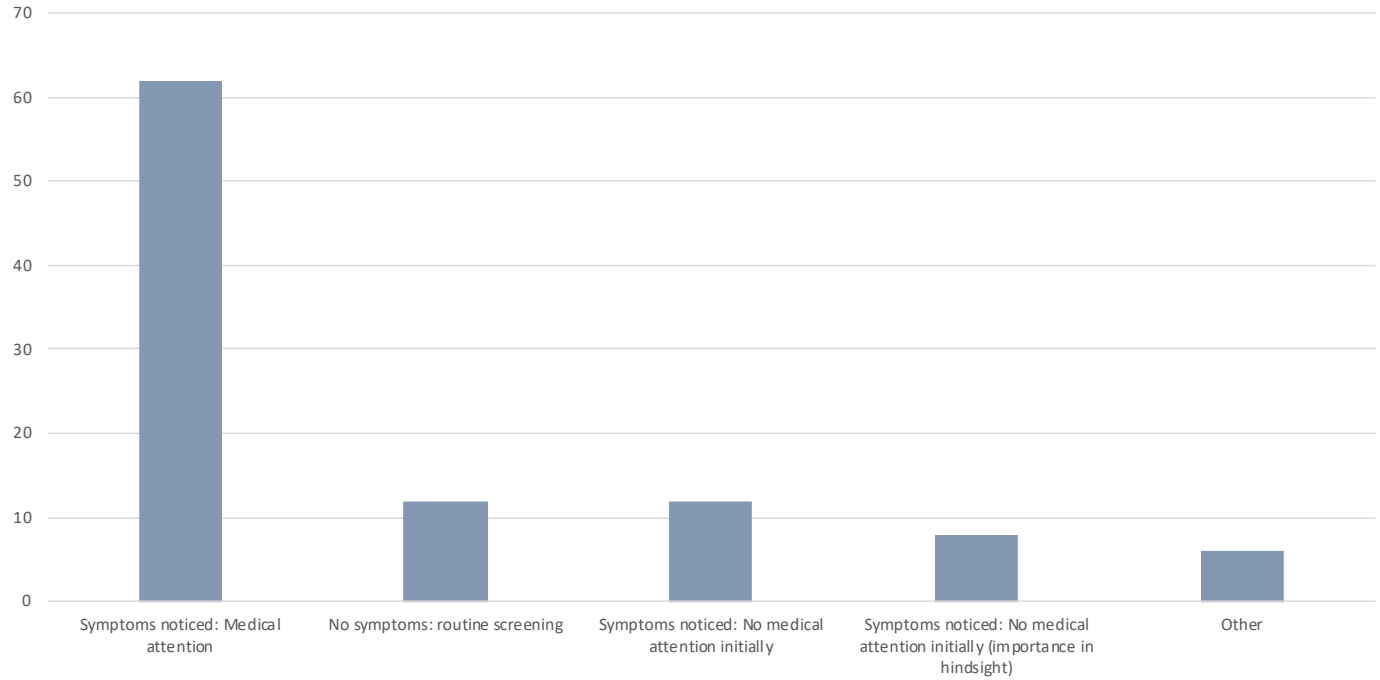

Figure 3.2: Seeking medical attention

Table 3.4: Seeking medical attention – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Early breast cancer Aged 25 to 44 Aged 55 to 74	Advanced breast cancer
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	-	Mid to low status Aged 25 to 44 Aged 55 to 74
Participant describes having symptoms and not seeking medical attention initially	Aged 55 to 74	-

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

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

OK, so I had no family history, no symptoms, so I wasn't any kind of surveillance. I went to the doctor and he ordered mammograms and said, look, I had already anticipated was going to be needed. So I actually ran up and made an appointment with a local clinic thinking, I'll be on my way to find out and have a look inside. So he ordered that and an ultrasound and I think he ordered to do a core biopsy to activate that. And so that was all through the GP. And then I went back to the GP diagnosis. Participant_002

When I went to the doctor, he felt the lump. He was concerned. He sent me off for a mammogram and then ultrasound on my breast, and also sent me to get blood tests. I had the mammogram and the ultrasound that afternoon. When I was having that done, I was very lucky I had the head of the place there doing my ultrasound. I said to him, "It's cancer that's gone to my lymph nodes, hasn't it?" Because my dad had cancer before, and I knew about the lymph nodes side of things. He said, "Yes, it has." He said, "You're going to have to have a biopsy. The doctor will order that for you," but he said, "If you want me to, I can do that now for you." I said, "Yes, go ahead. Do it now," so I had the biopsy done then and there. I had the blood tests done the next day. Then I had an appointment with the doctor on the Wednesday to get all the results. That's when he informed me that I had breast cancer. It was all very quick. Participant_046

OK, now I just after feeling the lump, I got up the courage three days later to go see my GP and he had a feel for it and they said, Oh, I'm going to send you for an ultrasound and biopsy for biopsy. I think it was. And I like, oh, OK. So what are you thinking? And he said, well, I need to check that it's not breast cancer. But he said that I had a feeling I knew it was. I remember feeling, you know, that he knows something here. And so a few days later, I got into the whole biopsy and the ultrasound and I knew from then I had trouble doing the biopsy, very painful. And then when I went back to the GP, he said to me, I just have to confirm you've got cancer in your breast. And I'm very sorry if you are, but I have breast cancer. And he said, yes, you have. And oh. Oh, hang on. I was expecting him to say that. And then he just basically said, well, now, but I refer you to a surgeon to have a lumpectomy and to see how we go from there. And then it all started. Participant_049

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

I was very, very healthy at the time, hardly went to the doctor. I found the lump. I made an appointment within a day or two to see-- I knew that it was not supposed to be there, so I went and saw my GP. He straight away felt it and was quite concerned. Sent me straight away for a mammogram, got in the next day for a mammogram and an ultrasound. The results came back, I think, the next day. I had to go there. There is definitely something there. They made me an appointment with a surgeon and I saw the surgeon within two days, basically. From that point on the surgeon sort of looked at it, felt it, realized that he thought it would be something. Sent me for a biopsy, I think. Some sort of scan, I can't exactly remember what it was but I do know I went for a biopsy. While having the biopsy, they basically told me that it was cancer. They didn't come out and say, "You have cancer" but they spoke about, "It looks like cancer" so you know, I've got five sisters, so I went back to the surgeon, he confirmed that, yes, it was. Put me in touch with an oncologist. Because of the triple-negative, they decided that I would do chemo first. Participant_035

I had my first mammogram in 2014, I think, because a friend of mine had breast cancer. I was only 46 at the time, I guess. A friend of mine had had breast cancer, so she said, "Oh, we should all--" The rest of us all went and had mammograms, and then I didn't have another one until 2019, I guess it was. Then, I found the lump myself just a few days before Christmas, and I went to see my GP. I called and got in to see her immediately that afternoon. She did a manual examination and sent me straight to CLINIC in LOCATION for a scan. Then the scan came back and she let me know that there was something that she felt needed some attention, so she organized a meeting to DOCTOR. Participant_041

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the center there and told me the results of the biopsy and the further ultrasound. Participant_029

Participant describes being diagnosed through a population screening program

I have a history of breast cysts, so I used to be monitored yearly for any changes in my breast. That got changed to two-yearly, literally two years prior to my diagnosis. I was diagnosed from mammograms. I'm a country patient. I live in LOCATION. I was sent to LOCATION to have a mammogram. Prior to the mammogram, on the day, I was given an ultrasound, and I knew myself from the ultrasound what we were looking at, even though no one said anything. By the time I got home, I was already in panic mode without having a diagnosis from anyone. I just knew myself what was going on. I'd done my own research to find a surgeon who I wanted to see, which was DOCTOR at HOSPITAL. When my doctor phoned me the following day after my mammogram and ultrasound, he said, "How you going?" I said, "I know." He goes, "Right. What do you want to do?" I said, "This is who I want to see. Send me to LOCATION." That's how it went. Participant_034

Table 3.5: Diagnostic pathway

Diagnostic pathway	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	29	58.00	14	60.87	15	55.56	11	57.89	15	60.00	16	61.54	13	54.17	13	54.17	16	61.54
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	11	22.00	2	8.70	9	33.33	4	21.05	6	24.00	4	15.38	7	29.17	7	29.17	4	15.38
Participant describes being diagnosed through a population screening program	5	10.00	4	17.39	1	3.70	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54
Other	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	1	3.85	4	16.67	2	8.33	3	11.54

Diagnostic pathway	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	29	58.00	11	68.75	18	52.94	8	40.00	21	70.00	11	57.89	14	63.64	4	44.44
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	11	22.00	3	18.75	8	23.53	5	25.00	6	20.00	5	26.32	3	13.64	3	33.33
Participant describes being diagnosed through a population screening program	5	10.00	2	12.50	3	8.82	5	25.00	0	0.00	0	0.00	3	13.64	2	22.22
Other	5	10.00	0	0.00	5	14.71	2	10.00	3	10.00	3	15.79	2	9.09	0	0.00

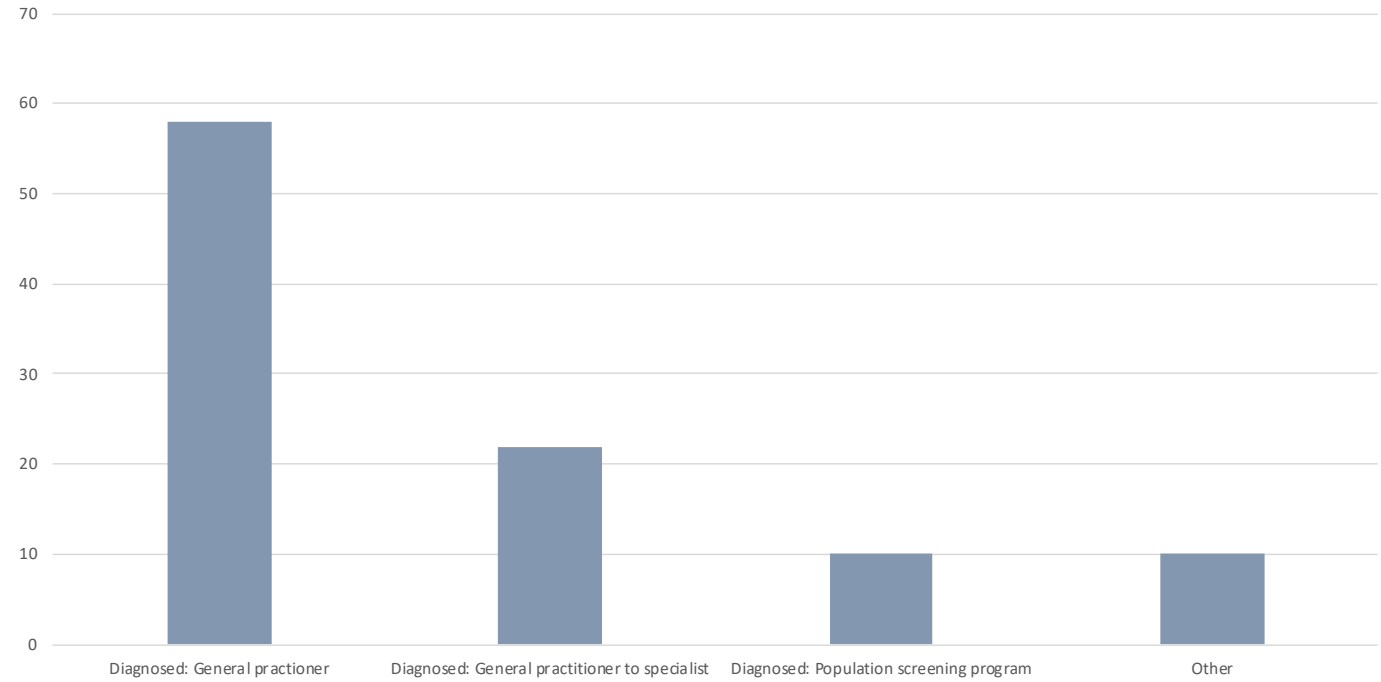

Figure 3.3: Diagnostic pathway

Table 3.6: Diagnostic pathway – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	Mid to low status Aged 55 to 74	Regional or remote Higher status
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Early breast cancer	Advanced breast cancer Aged 55 to 74
Participant describes being diagnosed through a population screening program	-	Mid to low status Aged 55 to 74

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

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=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Table 3.7: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=41)	Percent
Less than a month	6	14.63
Between 3 and 10 months	4	9.76
More than 12 months	8	19.51
No symptoms	23	56.10
Incomplete data	6	14.63

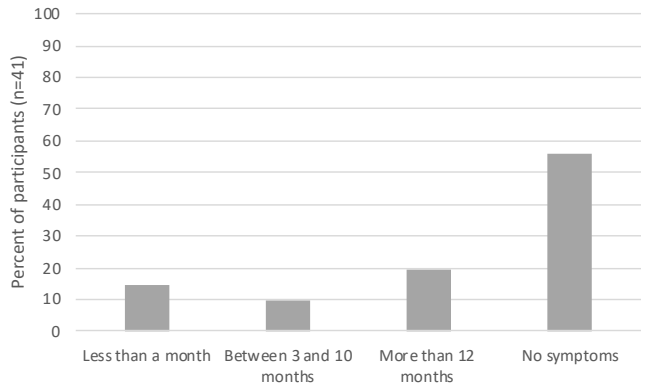

Figure 3.4: Time from symptoms to diagnosis

Table 3.8: Time from diagnostic test to diagnosis

Time from diagnostic tests to diagnosis	Number (n=47)	Percent
Less than 1 week	27	57.45
Between 3 and 4 weeks	2	4.26
Between 1 and 2 weeks	12	25.53
Between 2 and 3 weeks	3	6.38
4 weeks or more	1	2.13
Not specified	2	4.26

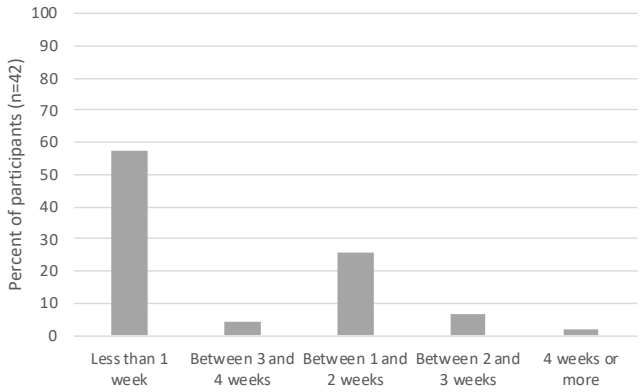

Figure 3.5: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with triple negative breast cancer. 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 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

Table 3.9: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=50)	Percent
1 to 2	11	22.00
3 to 4	38	76.00
5 to 6	1	2.00

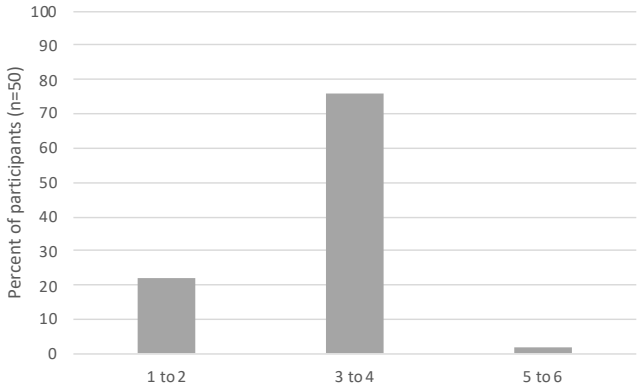

Figure 3.6: Number of diagnostic tests

Table 3.10: Diagnostic tests

Diagnostic tests	Number (n=50)	Percent
Breast ultrasound	42	84.00
Core biopsy (A wider needle is used to remove a piece of tissue)	41	82.00
Mammogram	39	78.00
Fine needle aspiration (A thin needle is used to take tissue from the breast lump)	17	34.00
Surgical biopsy	2	4.00
Vacuum assisted biopsy	2	4.00
Other	6	12.00

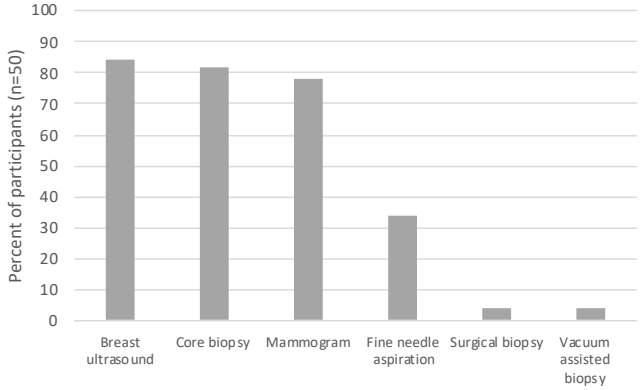

Figure 3.7: Diagnostic tests

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 general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon, and two participants (4.26%) were diagnosed by a general surgeon (Table 3.11, Figure 3.8).

Participants were most commonly given their diagnosis in the general practice (n = 24, 51.06%), this was followed by the Specialist clinic (n = 14, 29.79%), and by phone or telehealth appointment (n = 7, 14.90%) (Table 3.10, Figure 3.9).

Table 3.11: Diagnosis provider

Health professional gave diagnosis	Number (n=47)	Percent
General practitioner (GP)	28	59.57
Breast surgeon	13	27.66
General Surgeon	2	4.26
Specialist - other or not speciified	5	10.64

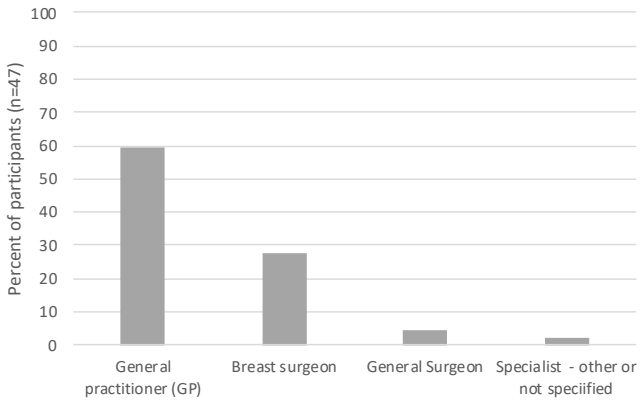

Figure 3.8: Diagnosis provider

Table 3.12: Diagnosis location

Location of diagnosis	Number (n=50)	Percent
General practice (GP)	24	51.06
Specialist clinic	14	29.79
Phone/telehealth	7	14.89
Other	2	4.26

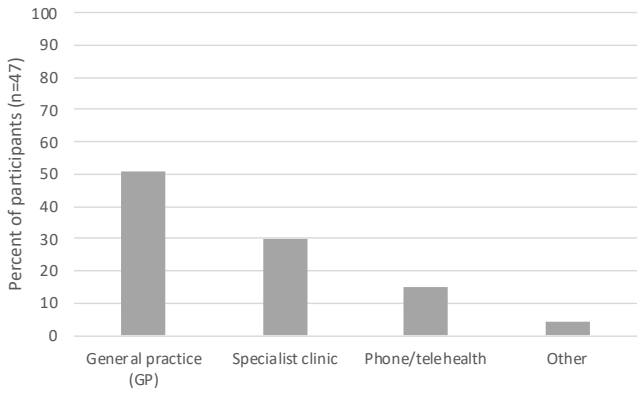

Figure 3.9: Diagnosis location

Breast cancer spread

Participants were asked in the online questionnaire if their breast cancer had spread. There were 24 participants (51.06%) with breast cancer that had not spread. The most common site of spread was to lymph nodes under arms (n=18, 38.30%) (Table 3.13, Figure 3.10).

Table 3.13: Breast cancer spread

Cancer spread	Number (n=47)	Percent
Lymph nodes under your arm	18	38.30
Lymph nodes lymph nodes inside your breast	4	8.51
Other lymph nodes	2	4.26
Distant sites	5	10.64
Cancer has not spread	24	51.06

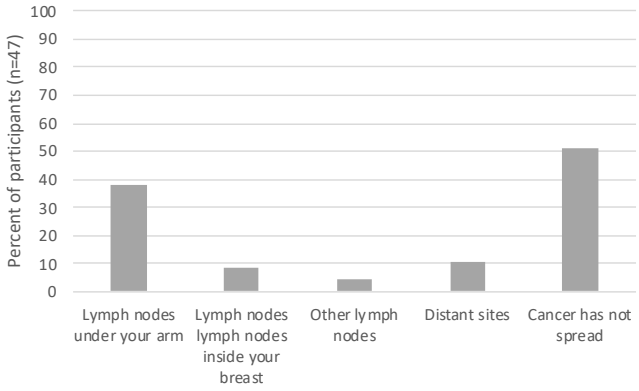

Figure 3.10: Breast cancer spread

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.14, Figure 3.11.

Participants were diagnosed between 2004 to 2021. There were 26 participants (53.06%) that were diagnosed in the last two years.

Table 3.14: Year of diagnosis

Year of diagnosis	Number (n=50)	Percent
Before 2015	5	10.64
2015 to 2019	19	38.78
2020 to 2021	26	53.06

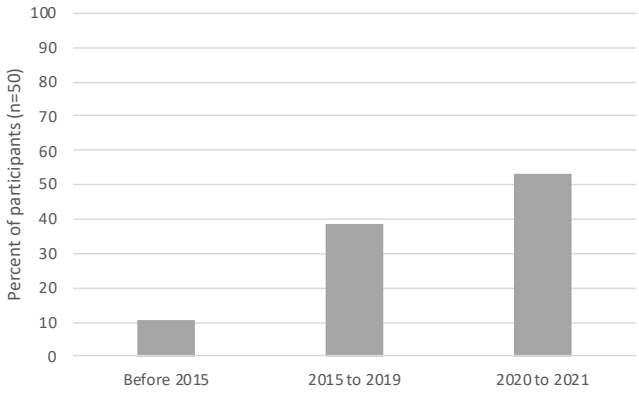

Figure 3.11: Year of diagnosis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness.

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

A lot. Due to our family history, I knew a lot. Obviously, there's all sorts of different types of breast cancer. Not everybody is the same and of course, mine was not hormone-based but I've had two sisters hormone- based, one sister who was triple-negative and my mum was triple-negative. Yes. Participant_022

I knew enough about the fact that it was a very aggressive cancer. I had just lost a friend 18 months earlier to the same cancer. She had orphaned three kids. We had been quite involved in-- I didn't know a lot about the treatment side of things, apart from she's had chemo. Then we all thought she was fine. Within a few weeks or months, she was told that-- she had a pain basically, which was in her shoulder. Then she thought it was just from the chemotherapy. Then going to the doctor afterwards said it had gone to her liver and it was a referred pain. She was given three months and died two and a half weeks later. I knew that being triple-negative was-- In my head, I sort of felt it was a death sentence. I knew that it was one of the worst cancers to get. Participant_036

I knew a bit, but I guess I knew a bit because I'm in nursing. [chuckles] Also, my nan also had breast cancer. I was quite young at the time, so I don't know. I guess it's through studying nursing that I knew a little bit to be able to arm myself to research for myself to try and get best care, I guess. Participant_034

Participant describes knowing very little about the condition at diagnosis

Not a huge amount, although I had a friend go through it four years before. I hadn't been closely involved with her through her treatment. She moved in with her mom during that time so I didn't see her quite as much. I went with her to chemo once so I'd seen what chemo involved. I didn't really know anywhere near as much as I do now. [chuckles] Participant_011

PARTICIPANT: I wasn't diagnosed until after surgery, when they found out it was triple-negative.
INTERVIEWER: When they told you what your diagnosis was and that it was triple-negative, did you know much about breast cancer, in general, at that time?
PARTICIPANT: I only knew about hormone breast cancer. I just knew that ladies would be on Tamoxifen. I'd had a few friends over the years that had been on Tamoxifen, but I had no idea that there was all the different subgroups and subtypes. Participant_040

Nothing. I thought breast cancer- I didn't know that there were different types of breast cancer. That was the first thing that I, had no idea. I thought breast cancer was breast cancer. I thought breast cancer, everybody lives, and it's really easy to cure. Because it's so common. I didn't know that obviously, there's Triple-negative, but it's high rate of people that don't survive., I learned so much, I knew nothing. Participant_019

Participant describes knowing nothing about the condition at diagnosis

I didn't know a lot because I haven't had anyone close to me have breast cancer before, so I really didn't know much at all. I knew the basic things of cancer equals possible operation, chemo, radiotherapy. I knew that sort of thing, but just what everyone assumes about cancer really. The fact that it was triple-negative breast cancer, I'd never heard of that before. When I looked into that, it completely freaked me out because everything you read about triple-negative is negative. Very negative indeed. [laughs] Participant_004

Not a lot and I guess the best example of how little I knew about it was, I went to see the surgeon. She said okay, well NAME do surgery, first of all, just to remove it. I said, that's fine not a problem. I have a trip overseas booked in three weeks, will I be better by then? She was like, no. Yes, it really was something that didn't sink in for quite some time, but it was a long hard process to go through. Participant_020

Nothing, zero. Absolutely zero. We were in the middle of COVID here in LOCATION. There were no resources. There was no emotional health. I felt very isolated, really lonely. Someone who has no family history, I wasn't offered a help from a nurse or anyone who's been through it, you know any volunteers. What to expect from the chemo. What other questions that I needed to ask? In fact, I had to fight to get my- Participant_042

Table 3.15: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	15	30.00	7	30.43	8	29.63	4	21.05	9	36.00	9	34.62	6	25.00	5	20.83	10	38.46
Participant describes knowing about the condition as they were given information by a healthcare professional during the diagnostic process	4	8.00	1	4.35	3	11.11	2	10.53	2	8.00	1	3.85	3	12.50	1	4.17	3	11.54
Participant describes knowing about the condition as they have a medical, research or relevant professional background	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	3	11.54	1	4.17	0	0.00	4	15.38
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	3	11.54	1	4.17	2	8.33	2	7.69
Participant describes knowing very little about the condition at diagnosis	10	20.00	7	30.43	3	11.11	4	21.05	4	16.00	6	23.08	4	16.67	5	20.83	5	19.23
Participant describes knowing very little about the condition at diagnosis through general public awareness	7	14.00	5	21.74	2	7.41	3	15.79	3	12.00	4	15.38	3	12.50	3	12.50	4	15.38
Participant describes knowing nothing about the condition at diagnosis	22	44.00	8	34.78	14	51.85	10	52.63	10	40.00	8	30.77	14	58.33	12	50.00	10	38.46

Understanding of disease at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	15	30.00	7	43.75	8	23.53	8	40.00	7	23.33	3	15.79	9	40.91	3	33.33
Participant describes knowing about the condition as they were given information by a healthcare professional during the diagnostic process	4	8.00	1	6.25	3	8.82	2	10.00	2	6.67	1	5.26	3	13.64	0	0.00
Participant describes knowing about the condition as they have a medical, research or relevant professional background	4	8.00	3	18.75	1	2.94	3	15.00	1	3.33	1	5.26	1	4.55	2	22.22
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	8.00	2	12.50	2	5.88	2	10.00	2	6.67	1	5.26	1	4.55	2	22.22
Participant describes knowing very little about the condition at diagnosis	10	20.00	2	12.50	8	23.53	2	10.00	8	26.67	5	26.32	2	9.09	3	33.33
Participant describes knowing very little about the condition at diagnosis through general public awareness	7	14.00	1	6.25	6	17.65	1	5.00	6	20.00	4	21.05	0	0.00	3	33.33
Participant describes knowing nothing about the condition at diagnosis	22	44.00	7	43.75	15	44.12	8	40.00	14	46.67	9	47.37	10	45.45	3	33.33

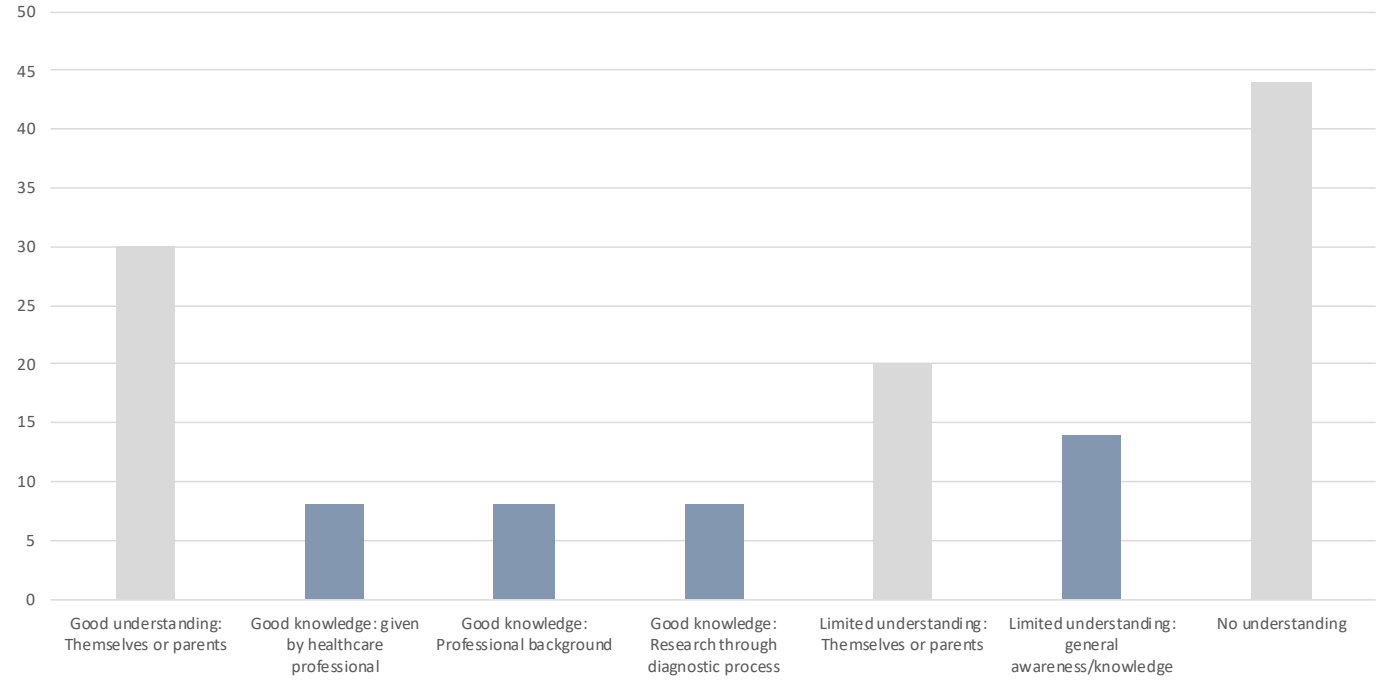

Figure 3.12: Understanding of disease at diagnosis

Table 3.16: Understanding of disease at diagnosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	Aged 25 to 44	Regional or remote Aged 45 to 54
Participant describes knowing very little about the condition at diagnosis	Aged 45 to 54	Early breast cancer Aged 55 to 74
Participant describes knowing nothing about the condition at diagnosis	Diagnosed before 2020 Aged 55 to 74	Diagnosed in 2020 or 2021

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 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that had no support (Table 3.78, Figure 3.13).

Subgroup variations of more than 10% are listed in Table 3.16

Table 3.17: Emotional support at diagnosis

Emotional support at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Enough support	11	25.00	8	40.00	3	12.50	5	26.32	6	24.00	6	27.27	5	22.73	3	14.29	8	34.78
Some support but it wasn't enough	9	20.45	1	5.00	8	33.33	3	15.79	3	12.00	5	22.73	4	18.18	6	28.57	3	13.04
No support	27	61.36	12	60.00	15	62.50	11	57.89	16	64.00	13	59.09	14	63.64	14	66.67	13	56.52

Emotional support at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Enough support	11	25.00	5	35.71	6	20.00	4	23.53	7	25.93	6	37.50	4	21.05	1	11.11
Some support but it wasn't enough	9	20.45	4	28.57	5	16.67	4	23.53	5	18.52	3	18.75	5	26.32	1	11.11
No support	27	61.36	7	50.00	20	66.67	11	64.71	16	59.26	7	43.75	13	68.42	7	77.78

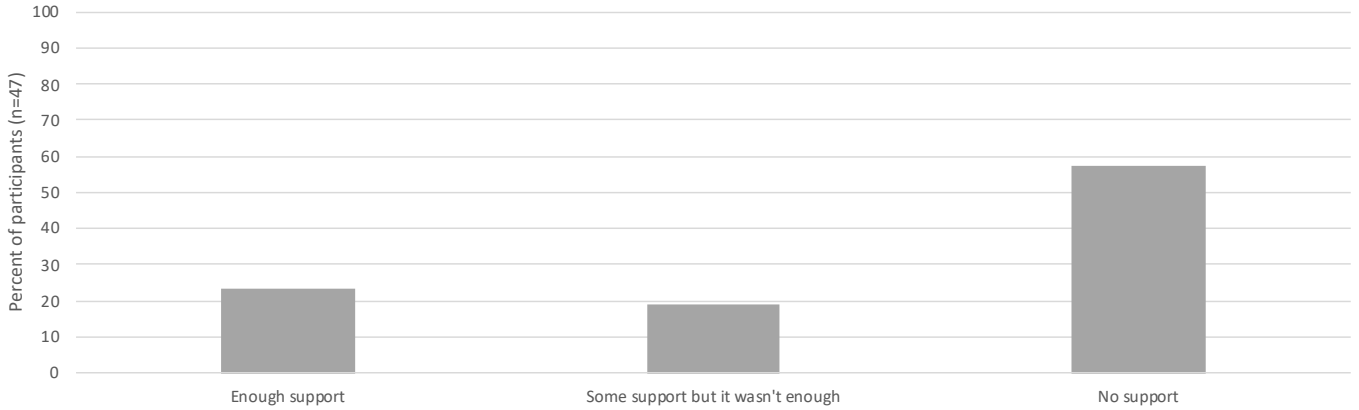

Figure 3.13: Emotional support at diagnosis

Table 3.18: Emotional support at diagnosis – subgroup variations

Emotional support at diagnosis	Less Frequently	More frequently
Enough support	Advanced breast cancer Trade or high school Aged 55 to 74	Early breast cancer Regional or remote Aged 25 to 44
Some support but it wasn't enough	Early breast cancer	Advanced breast cancer
No support	Regional or remote Aged 25 to 44	Aged 55 to 74

Information at diagnosis

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

There were 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that had no information (Table 3.19, Figure 3.14).

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

Table 3.19: Information at diagnosis

Information at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Enough information	21	47.73	11	55.00	10	41.67	7	36.84	13	52.00	11	50.00	10	45.45	8	38.10	13	56.52
Some information but it wasn't enough	20	45.45	7	35.00	13	54.17	9	47.37	9	36.00	10	45.45	10	45.45	12	57.14	8	34.78
No information	6	13.64	3	15.00	3	12.50	3	15.79	3	12.00	3	13.64	3	13.64	3	14.29	3	13.04

Information at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Enough information	21	47.73	6	42.86	15	50.00	8	47.06	13	48.15	8	50.00	9	47.37	4	44.44
Some information but it wasn't enough	20	45.45	8	57.14	12	40.00	10	58.82	10	37.04	7	43.75	10	52.63	3	33.33
No information	6	13.64	2	14.29	4	13.33	1	5.88	5	18.52	1	6.25	3	15.79	2	22.22

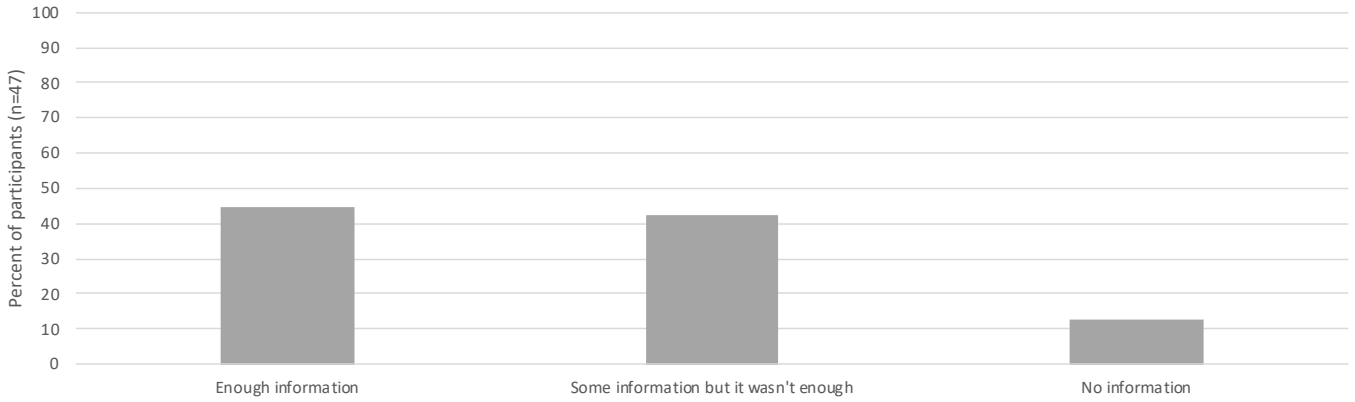

Figure 3.14: Information at diagnosis

Table 3.20: Information at diagnosis – subgroup variations

Information at diagnosis	Less Frequently	More frequently
Enough information	Poor physical function	-
Some information but it wasn't enough	Early breast cancer University Aged 55 to 74	Trade or high school Regional or remote Mid to low status

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 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

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 20 participants (58.82%) the cost was slightly or not at all significant. For seven participants (20.59%) the out-of-pocket expenses were somewhat significant, and for seven participants (20.59%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.22, Figure 3.16).

Table 3.21: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=47)	Percent
$0	13	27.66
Less than $500	10	21.28
$500 to $1000	11	23.40
More than $1000	4	8.51
Not sure	9	19.15

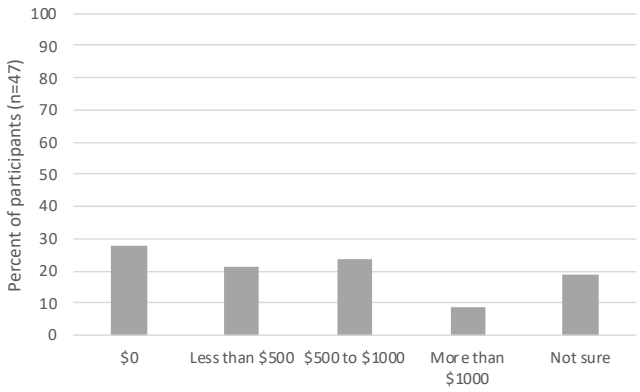

Figure 3.15: Out of pocket expenses at diagnosis

Table 3.22: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=34)	Percent
Not at all significant	8	23.53
Slightly significant	12	35.29
Somewhat significant	7	20.59
Moderately significant	5	14.71
Extremely significant	2	5.88

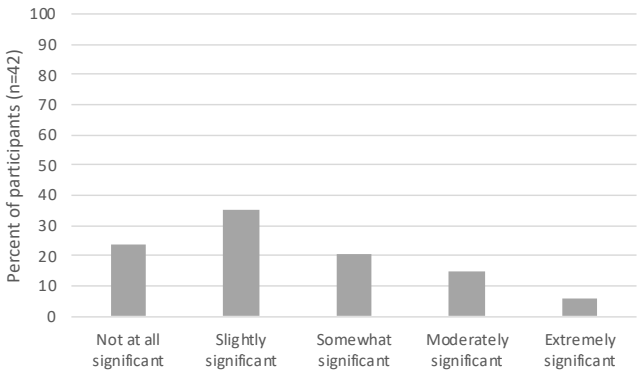

Figure 3.16: Burden of diagnostic costs

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 = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them (Table 3.23, Figure 3.17).

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.

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

Table 3.23: Discussions about biomarkers

Discussions about biomarkers	Number (n=47)	Percent
Participant brought up the topic with doctor for discussion	7	14.89
Doctor brought up the topic with participant for discussion	27	57.45
Participant had no discussion about this type of test	13	27.66

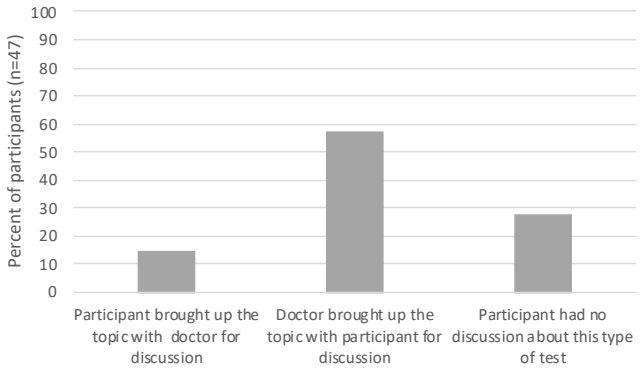

Figure 3.17: Discussions about biomarkers

Table 3.24: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=47)	Percent
Participant had this test and did not have to pay out of pocket for it	28	59.57
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	4	8.51
Participant did not have this test and is not interested in it	1	2.13
Participant did not have this test but would like to	14	29.79

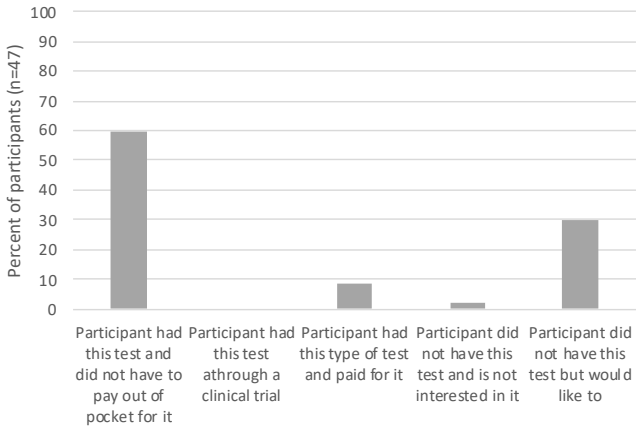

Figure 3.18: Experience of genetic tests and biomarkers

Biomarker status

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%) (Table 3.25, Figure 3.19).

While all participants knew that they had triple negative breast cancer, this question addresses their know

Table 3.25: Biomarker status

Biomarkers	Number (n=50)	Percent
TNBC	35	70.00
BRCA	19	38.00
ER	2	4.00
HER2	2	4.00
PR	2	4.00
Other	3	6.00
Not sure/Not tested	8	16.00

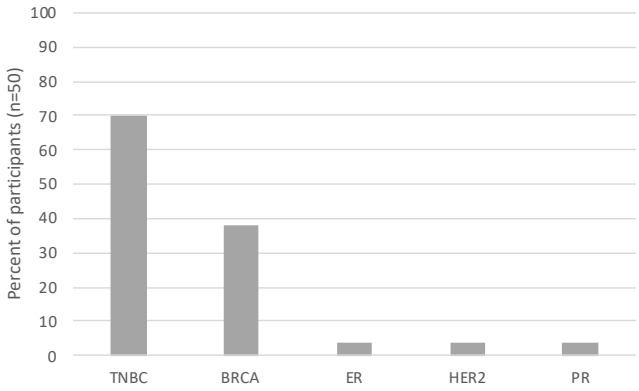

Figure 3.19: Biomarker status

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.

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

Type of current symptoms

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n = 21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%) (Table 3.27, 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” (Table 3.27, Figure 3.22).

The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

Table 3.26: Number of current symptoms

Number of symptoms per participant	Number (n=47)	Percent
0	26	55.32
5 to 6	3	6.38
7 to 8	8	17.02
9 to 10	6	12.77
11 to 12	4	8.51

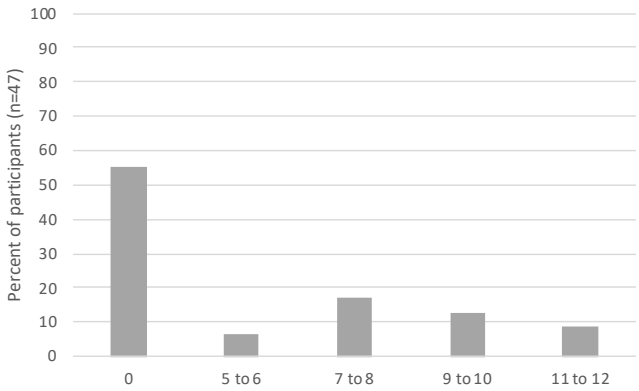

Figure 3.20: Number of current symptoms

Table 3.27: Type of current symptoms

Symptom	Number (n=50)	Percent	Quality of life	
			Mean	SD
No symptoms	26	52.00	NA	NA
Anxiety/anxious mood	21	44.68	3	3
Fatigue	21	44.68	3	2
Thinking and memory problems	20	42.55	3	2.25
Depression/depressed mood	19	40.43	4	2
Weight and muscle changes	18	38.30	3	1
Pain	18	38.30	3	2.5
Sleep problems	17	36.17	3	2
Sexual function/ability to have inimate relationships	14	29.79	2.5	2
Bone problems	14	29.79	4.5	2
Bladder problems	6	12.77	4.5	1.75
Other	13	27.66	-	-

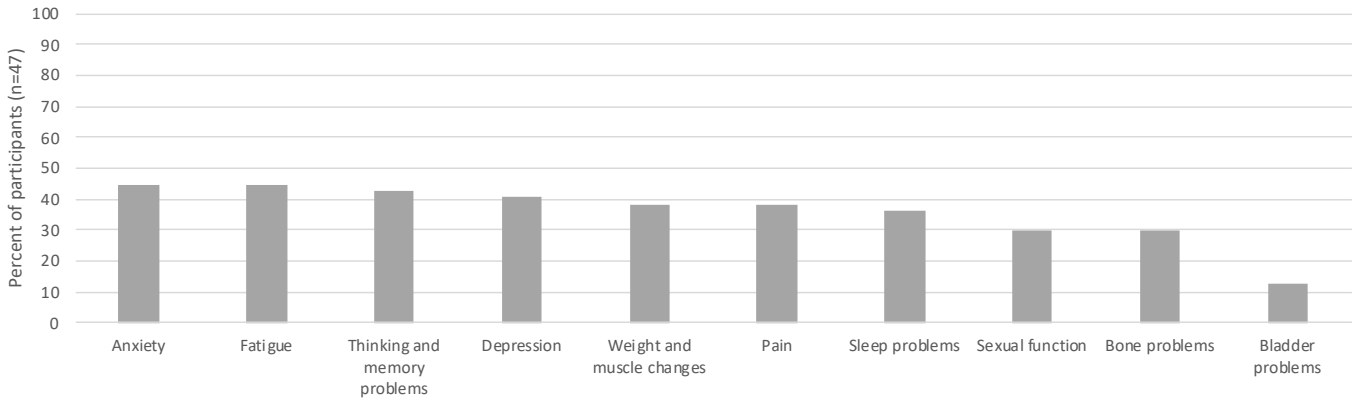

Figure 3.21: Type of current symptoms

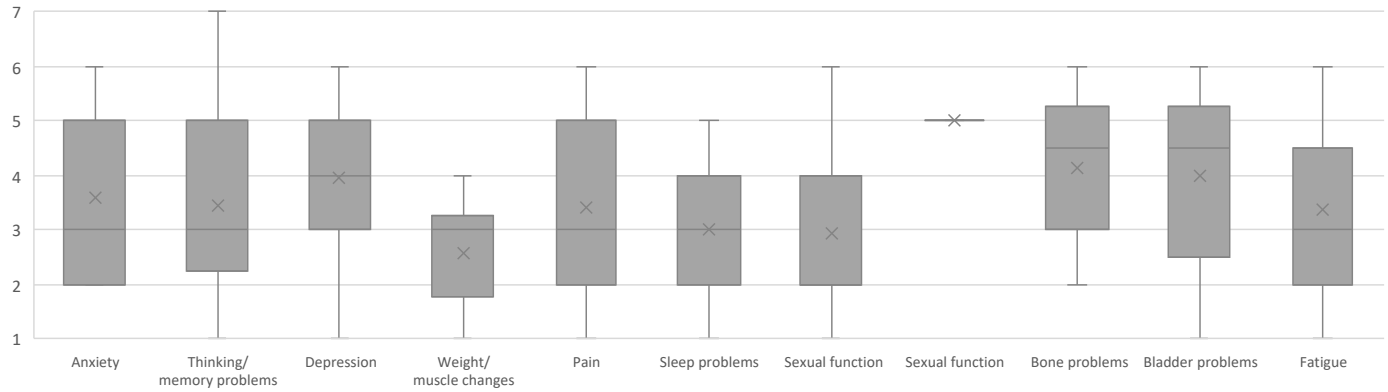

Figure 3.22: Quality of life from current symptoms

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=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

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

I'm NED at the moment and we're just doing the chemotherapy and the radiation to mop up, is my understanding, and make sure there's no very small particles in there that could be growing to reoccur. Participant_007

I finished radiation on Friday. I had a complete response, so I did chemo then surgery, then radiation. I had a complete response to chemo. Both of my tumors- I've had three tumors were all dead. My prognosis is good, but they don't give statistics. Participant_019

I hate the word remission. Apparently, they don't use it anymore. But to me, I don't have cancer. In my eyes, I was told because I had triple negative breast cancer. You know, I said I remember them saying if if it's going to come back, it'll come back in the first five years after that. If I get breast cancer again, it'll be a completely it's not like my breast cancer would have metastasised or come back to haunt me. Said if I get it again, it's literally bad luck to have nothing to do with my first case that. Yeah. So in terms of my career, I think I'm in the clear and if I get it again, it's like lightning. Participant_003

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

Yes. I've got no evidence of the disease, and they're not expecting that it's to return, because next year, I think I'm at five years, and I had a very good response to everything. My lump was also quite small and caught very early. Participant_005

Well, when you look at statistics, mine's triple-negative, obviously that's the worst-case breast cancer you can get. My outlook was technically, if I can get beyond the 5 years, I've got a good chance of surviving 10 and then further if I had have had all my treatment, that's the big if. I did not have all my treatment because I reacted to the chemo. Because of that, they stopped the chemo. Obviously, I know my outlook is a lot less. I have seen my oncologist, my last oncology appointment, my oncologist did say "Oh, you know, you're coming up to three years, that's really awesome." I said, "I didn't think I'd make it to three years." He said, "I didn't think you would either." I've made it past 3 years and I'm happy with that and I'm hoping to last another 10, 15 years but obviously, I know the risks and I know the chances of it becoming metastatic is a lot higher than normal. Participant_022

Well, since then I have been diagnosed with the PALB2 gene, once, I got that diagnosis, the specialist told me that it was more likely that the cancer would return because I had the gene. I had a double mastectomy and reconstruction. Later on, the risk for the PALB2 gene of ovarian cancer increased. Last year I had a hysterectomy and my ovaries removed. Now I've got less risk than the general population of getting breast cancer again because of both procedures. Participant_037

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

Well, currently, I've been told I have a good prognosis. My cancer is really aggressive, so there's still a high chance that it can come back in the next three years. I'm being closely monitored but other than that, I've been told it's still on the positive side because I got a good response to chemo. Participant_016

Because I've had chemotherapy already and that reduced my tumor but it didn't get rid of it, so I had a double mastectomy and there's still tumor tissue, cancer in my lymph nodes and and in my breast but they've obviously removed it all so I've got clear margins. I'm now doing 5 weeks of radiotherapy and 6 months of oral chemo. I don't know what my chances are. It can still come back. Participant_017

Yes. At the moment, I've had really good reactions to all of my treatments. I have apparently, like a 15% chance of it coming back. I'm now officially two years since my diagnosis. I've got another three years to go before I'm technically, go back to the same percentage of getting cancer, go back to the same percentage as someone else in the general population of having cancer. Participant_025

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

I'm still waiting for the buy the clearance, but it can come back any time. So, OK, so I still have to keep doing so. I have to do yearly surveillance and then after five years I'll drop to still daily surveillance that I might be a breath team. I'll be your normal surveillance. Participant_006

Yes, well I finished all treatment. I've had my six-month checkup and everything was all clear. Now I'm at the stage where I'm getting checked every six months to make sure it continues to be all clear. Participant_020

Yes. I've had pathological complete results, so no evidence of disease anymore. All being clear. I've had a double mastectomy and do a reconstruction at the same time. At the moment, it's just three monthly checkups with oncologists and my breast surgeon. I have had lots of nerve issues from having that done. I've got an ongoing treatment for that. Participant_036

Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment

Yep. So in four years into my five year survival period, I'm triple negative. So once I've had my treatment, 15 percent chance of recurrence in the initial phase, three years. So my prognosis now is yes. Participant_002

As far as I'm aware, good. The tumor was tiny. I had a lumpectomy and a sentinel node biopsy. They got all of the tumor, and they only needed to take out three lymph nodes, and it hadn't gone anywhere which is good. As far as I'm aware, my outlook is good apart from all of the surgeries I'm going to have to go moving forward. [laughs] Participant_014

Yes. I'm currently undergoing an oral chemo now just to clean up if there's any residual. I will undergo monitoring for the next few years really and because of the type that I have, which is triple-negative, the chances of reoccurrence is extremely high, so I need to have that monitoring. Then, as the years go on, the chances decrease of it recurring. Participant_030

Table 3.28: Understanding of prognosis

Understanding of prognosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	26	52.00	15	65.22	11	40.74	10	52.63	12	48.00	13	50.00	13	54.17	13	54.17	13	50.00
Participant describes prognosis in relation to statistics such as five year survival rates	18	36.00	9	39.13	9	33.33	3	15.79	12	48.00	13	50.00	5	20.83	11	45.83	7	26.92
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	14	28.00	6	26.09	8	29.63	3	15.79	8	32.00	7	26.92	7	29.17	9	37.50	5	19.23
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	11	22.00	4	17.39	7	25.93	2	10.53	7	28.00	6	23.08	5	20.83	6	25.00	5	19.23
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	7	14.00	4	17.39	3	11.11	4	21.05	3	12.00	1	3.85	6	25.00	2	8.33	5	19.23

Understanding of prognosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	26	52.00	9	56.25	17	50.00	10	50.00	16	53.33	12	63.16	9	40.91	5	55.56
Participant describes prognosis in relation to statistics such as five year survival rates	18	36.00	8	50.00	10	29.41	9	45.00	9	30.00	6	31.58	10	45.45	2	22.22
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	14	28.00	6	37.50	8	23.53	7	35.00	7	23.33	8	42.11	5	22.73	1	11.11
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	4	21.05	5	22.73	2	22.22
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	3	15.79	4	18.18	0	0.00

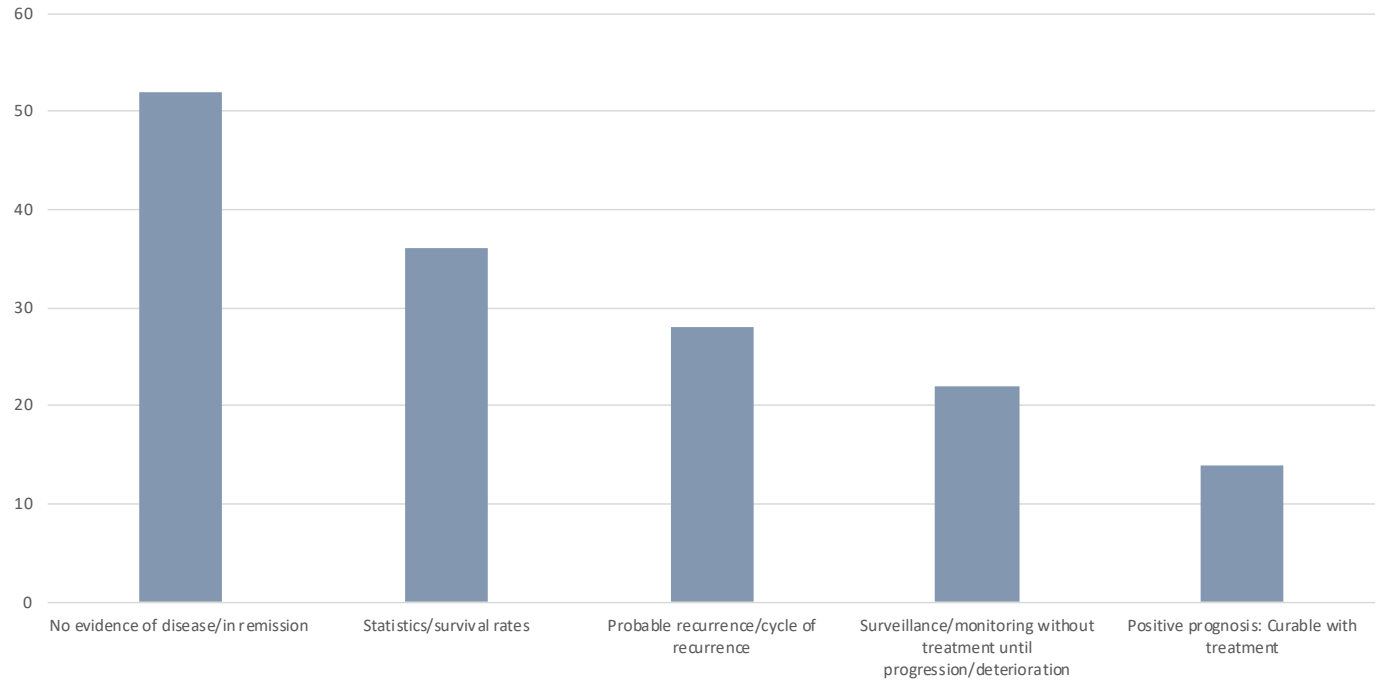

Figure 3.23: Understanding of prognosis

Table 3.29: Understanding of prognosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to no evidence of disease or that they are in remission	Advanced breast cancer Aged 45 to 54	Early breast cancer Aged 25 to 44
Participant describes prognosis in relation to statistics such as five year survival rates	Poor physical function Diagnosed in 2020 or 2021 Aged 55 to 74	Good physical function Diagnosed before 2020 Regional or remote
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	Poor physical function Aged 55 to 74	Aged 25 to 44
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	Poor physical function	-
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	Diagnosed before 2020 Aged 55 to 74	Diagnosed in 2020 or 2021