

Section 6

Information and communication

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Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 28 participants (56.00%) was the internet (including health charities). There were 18 participants (36.00%) that described Facebook and/or social media and 17 participants (34.00%) that described their treating clinician. Other types of information accessed included other patient's experience (n=16, 32.00%), books, pamphlets and newsletters (n=11, 22.00%), and nursing staff (n=10, 20.00%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 19 participants (38.00%) was other information from people's experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment), and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning when diagnosed (n=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Health professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participants that had positive communication, described the reason for this was because communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%). The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Ability to take medicines as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n = 23, 52.27%), and 18 participants (40.91%) responded that they took medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines as prescribed.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about Treatment options (n=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were Clinical trials (n = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Information accessed

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not. Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good.

Access to information

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Where participants described a specific health charity, they most commonly referred to the Breast Cancer Network Australia (n = 20, 40.00%), followed by the Cancer Council (n = 9, 18.00%). There were 7 participants (14.00%) that described the National Breast Cancer Foundation, 2 participants (4.00%) that described the Pink Hope Organisation, and 2 participants (4.00%) that described Mummy's Wish.

Participant describes accessing information through the internet in general

The breast cancer network. I think it's the breast cancer network. I listened to quite as much as their podcasts and looked at their website and found that really good and informative. I also mentioned that I joined a couple of Facebook groups. I learned things through the Facebook groups as well. Just by the by things really. Those were probably my main two sources of information. Participant_004

I'm been really looking online. I've got a Facebook group for my cancer type, triple-negative Australia and New Zealand. They are really, really good. They say, "Everyone says don't Google or whatever, but their information is always accurate." Some of the groups can be wild accusations, but this is pretty normal. I've read a fair few books. I look at functional and integrated medicine doctors, especially in America, who are treating cancer, and listen to a lot of doctors, breast care oncologists' podcasts, and integrated medicine doctors podcast. That's probably the main ones. Participant_008

Most of it is on the internet, and I've learnt to be very wary of what I read about on the internet to make sure that it's coming from a reliable source, like the Cancer Council will tell you, or the National Breast Cancer Foundation. Something that's valid, and also if I'm looking on the internet, looking at the date

because if you read something that's a research paper from 2012, that's probably completely irrelevant to now. Participant_020

Mainly off the internet, like going on to the Cancer Australia. Is that what it's called? Cancer Australia website, National Breast Cancer Foundation website. On Facebook, I found that a group of women in Australia and New Zealand who have the same type of cancer that I had. A triple-negative and that was actually quite a good source of support. If you had questions like, "Oh, this happened to me, or this happened to anyone else. Should I go and see my doctor?" That was more moral support, but mostly on the internet from reliable sources. Participant_027

Participant describes accessing information primarily through Facebook and/or social media

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Oh, sorry, I forgot to mention, I did get information from Facebook as well. I know this is not ideal but there was a triple-negative-- there's a breast cancer book specific to my cancer. I know all the information on it isn't 100%, but sharing my experience, reading other people's experiences and having a little friendship group where people understand what we are going through, that was helpful. Participant_016

Participant describes primarily accessing information through treating clinician

Okay, I think the best resource for me was BCNA website. They were very clear in explaining the different types of breast cancers and understanding my report and everything else, so that was an excellent resource. Cancer Council was another good resource, and obviously, my oncologist and all the advice they had. Plus, being from a medical background, and my husband's from medical background too, we did know radiologists directly. One of my uncle's a radiologist, so he was quite good as well in guiding us through the process and pre-empting, telling me what to expect. The hospital I received radiotherapy, they had excellent nurses and support network. Participant_016

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043

Oh, tons of it. [scoffs] My oncologist gave me some really good information from, I think it was Queensland or New South Wales. Anyway, with just good information about the drugs. I've just done heaps and heaps of Googling through PubMed and other sorts of-- not doctor Googling. I'm looking at reputable journal articles. I'm a member of a number of forums through Breast Cancer Australia, and also a couple of closed Facebook groups for people on the particular drugs and with the same sort of diagnosis that I have. I read a lot. I'm on alert for drug trials, and I read details. I do quite a bit of reading and research all the time. Participant_050

Participant describes primarily accessing information through other patient's experience

I have [unintelligible 00:55:31] different forums, so internet, breast cancer Australia and so forth to just get information about my type of cancer. I've joined some different forums on Facebook, which have-- it's like different groups, so then there's a support network there. If any there's questions you have, you can ask, "Has anybody else experienced this?" That's how I've gained a lot of my questions and [inaudible] I've learnt a lot too because-- Participant_015

Okay, I just sought out everything. I think I've had access to My Journey through Breast Care-- what's it? National Association which had then information groups, little blogs, and webinars, and things that you could access. I found through Breast Cancer Care WA, they have had classes and courses like Look Good, Feel Good. Also, stress management, all sorts of, yes, lots. Lots on menopause. I've sought out a menopause specialist since finishing treatment. What else? Facebook triple-negative groups, go to my same cancer treatment and also, young peoples under-45's local support groups. They send the information. Yes, I probably surf the net and I try to find as much as I can that way talking to other people that have been through it. Participant_036

I've been on the Cancer Council Foundation website, the Breast Cancer WA website. They're probably the main two, and then obviously you've got your other things like Facebook. You've got your own little groups in there that you join with other people going through the same thing. Participant_017

Participant describes receiving information from books, pamphlets and newsletters

The booklets from the hospital, and the Breast Care Network or whatever that is, BCNA. The Breast Cancer Association whatever. I also joined some Facebook groups. Okay. Participant_007

I've relied heavily on the Breast Cancer Network Associations information pages. My specialist, my breast surgeon on the first day that I saw him, gave me a book, called, Getting To Know Early Breast Cancer or You've Been Diagnosed With Early Breast Cancer. I actually really heavily relied on that book as my Bible. It actually travelled with me for the first three weeks of my diagnosis and I read things on the train and I treated that as the encyclopaedia of things. I really avoided going on and googling stuff or finding people's opinions that have been through my type of cancer. I had two friends, two family members not biological family members, but external family members who had gone through cancer, who I actually had them as a great support to kind of talk to about things but I never got them to tell me all the bad stuff or the... They never gave me the bad stories and it was only as things happen that I would call them and be like, "Oh, I had this happen," and they're like, "Yes, we had that too, it's completely normal." I didn't use a lot of the forums and I didn't use a lot of the Facebook pages until I was quite well far into my journey. It was probably almost done through chemotherapy before I even kind of joined any

Facebook pages for support or any of the forums to support because I relied on making sure that I was getting the information from accurate breast cancer websites rather than some person who set up a breast cancer website. This book, which I think has now become My Journey tool with Breast Cancer Network Association, that really, for me was my-- if this is what it says in here, then this is what it says. Participant_025

You go to the hospital and you get a lot of pamphlets and they give you a lot of information from there. Of course, you tend to get on the internet, but sometimes I think that can be a little harmful to your psyche. I joined a couple of Facebook support groups, but I found, probably three months into it, I left because it can be very depressing. They were suggesting things that I think you have to find those things out for yourself anyway. The doctor would give you a whole heap of stuff and I found them probably the best rather than looking at the Internet. Participant_035

Participant describes receiving information through nursing staff

Probably the most information that I had thought out is just in relation to the types of breast cancer that I had, and outcomes, survival rates, and what the current therapies are for that type of cancer, where there's been any advancement in treatment. I tend to try and keep up to date with that. I either do that through BCNA, so the Breast Care Network Australia. Through our support group, we're all members of that network, so you do get regular updates on what's happening We can link into podcasts and virtual conferences. We also have access to our Breast Care Nurse, thermograph Breast Care Nurse. She does attend our support meetings, if she's available, and keeps us abreast of any updates in relation to breast cancer treatments. That's probably the main thing. Obviously, there's things that pop up on the internet as well, but I tend to go to recognized sites if I have any queries, so mostly the BCNA. Also the breast care trials website as well. Participant_013

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043

OK, so I've had a bit of good stuff. Everyone Googles. I've had a try after joining a support group with breast cancer care WA, I learnt a lot through that with through the counsellor giving us information and also a breast nurse who was constantly updating me with anything that was on. And then my oncologist, he would give me information Participant_049

Participant describes accessing information from a specific health charity: Breast Cancer Network Australia

I came to look at information through BCNA and I think it's hugely valuable and I've read a lot of research to what comes up through. Like, obviously Facebook knows I've had breast cancer research information about it so that I get it from there and, you know, through the media. And then I'll go and read this study through my oncologist. I do some volunteer stuff that integrated suddenly integrated cancer services and we felt we could treat those kind of body. Participant_002

The breast cancer network. I think it's the breast cancer network. I listened to quite as much as their podcasts and looked at their website and found that really good and informative. I also mentioned that I joined a couple of Facebook groups. I learned things through the Facebook groups as well. Just by the by things really. Those were probably my main two sources of information. Participant_004

Participant describes accessing information from a specific health charity: Cancer Council

Lots of stuff from the hospital. There was a whole pack that I brought home that had pretty much everything that I could wonder about. I also telephoned the Cancer Council website just with some questions before I started chemo to ask about how long the side effects take to occur and all that. The man at the Cancer Council was very informative about many different things. He also told me about a particular grant that they give you through the Cancer Council that you can apply for to have. It's just a one-off thing, of a bill paid. It's worth \$300 or \$350 or something like that, that you can apply for and then they give it to you, and that just helps out with the bill or it helps out with some legitimate cost. That I would never have known had he not just thrown it into the conversation. Where else have I sought? Definitely online. Not so much looking for, again, anything questionable, but on websites like the Cancer Council and other things that are specific to triple-negative breast cancer, because it seems to be a little bit more harder to come

by. The doctors, I just ask questions if I'm ever needing to know anything. They were full of information. Afterwards, I joined a triple-negative breast cancer Facebook page, but I was past everything by then. I wasn't really getting information from them, it was more of a support thing. It was more depressing, really than anything else so I don't look at it too often. Where else have I gotten information from? That would be about it. The breast care nurse, she was a very, very huge source of information, and the cancer nurses-- What are they called? Chemo nurses as well were a wealth of information. That's about it, I think. Just everyone. Everyone who I came into contact with. Participant_005

The very first thing I did was looked up what all the pathology meant. [chuckling]. The pathology report had all these words I'd never heard before. Just to understand exactly what the diagnosis meant. On my first day into the chemo, they gave me the Cancer Council pack with all the relevant booklets in it for me.

That was also quite useful. Then I did a lot of reading up about the different surgeries and different options in terms of reconstruction. I also did look up the different chemo drugs that I was being given. What else? That's probably the main things, I guess. Participant_011

Okay, I think the best resource for me was BCNA website. They were very clear in explaining the different types of breast cancers and understanding my report and everything else, so that was an excellent resource. Cancer Council was another good resource, and obviously, my oncologist and all the advice they had. Plus, being from a medical background, and my husband's from medical background too, we did know radiologists directly. One of my uncle's a radiologist, so he was quite good as well in guiding us through the process and pre-empting, telling me what to expect. The hospital I received radiotherapy, they had excellent nurses and support network. Participant_016

Table 6.1: Access to information.

Access to information	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 accessing information through the internet in general	28	56.00	16	69.57	12	44.44	11	57.89	12	48.00	14	53.85	14	58.33	13	54.17	15	57.69
Participant describes accessing information primarily through Facebook and/or social media	18	36.00	8	34.78	10	37.04	8	42.11	8	32.00	7	26.92	11	45.83	6	25.00	12	46.15
Participant describes primarily accessing information through treating clinician	17	34.00	6	26.09	11	40.74	3	15.79	11	44.00	10	38.46	7	29.17	9	37.50	8	30.77
Participant describes primarily accessing information through other patient's experience	16	32.00	6	26.09	10	37.04	8	42.11	5	20.00	8	30.77	8	33.33	8	33.33	8	30.77
Participant describes receiving information from books, pamphlets and newsletters	11	22.00	5	21.74	6	22.22	3	15.79	7	28.00	6	23.08	5	20.83	6	25.00	5	19.23
Participant describes receiving information through nursing staff	10	20.00	5	21.74	5	18.52	5	26.32	3	12.00	7	26.92	3	12.50	3	12.50	7	26.92

Access to information	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 accessing information through the internet in general	28	56.00	9	56.25	19	55.88	11	55.00	17	56.67	12	63.16	10	45.45	6	66.67
Participant describes accessing information primarily through Facebook and/or social media	18	36.00	5	31.25	13	38.24	3	15.00	15	50.00	12	63.16	3	13.64	3	33.33
Participant describes primarily accessing information through treating clinician	17	34.00	7	43.75	10	29.41	8	40.00	9	30.00	6	31.58	8	36.36	3	33.33
Participant describes primarily accessing information through other patient's experience	16	32.00	6	37.50	10	29.41	8	40.00	8	26.67	8	42.11	6	27.27	2	22.22
Participant describes receiving information from books, pamphlets and newsletters	11	22.00	2	12.50	9	26.47	3	15.00	8	26.67	3	15.79	5	22.73	3	33.33
Participant describes receiving information through nursing staff	10	20.00	5	31.25	5	14.71	6	30.00	4	13.33	5	26.32	3	13.64	2	22.22

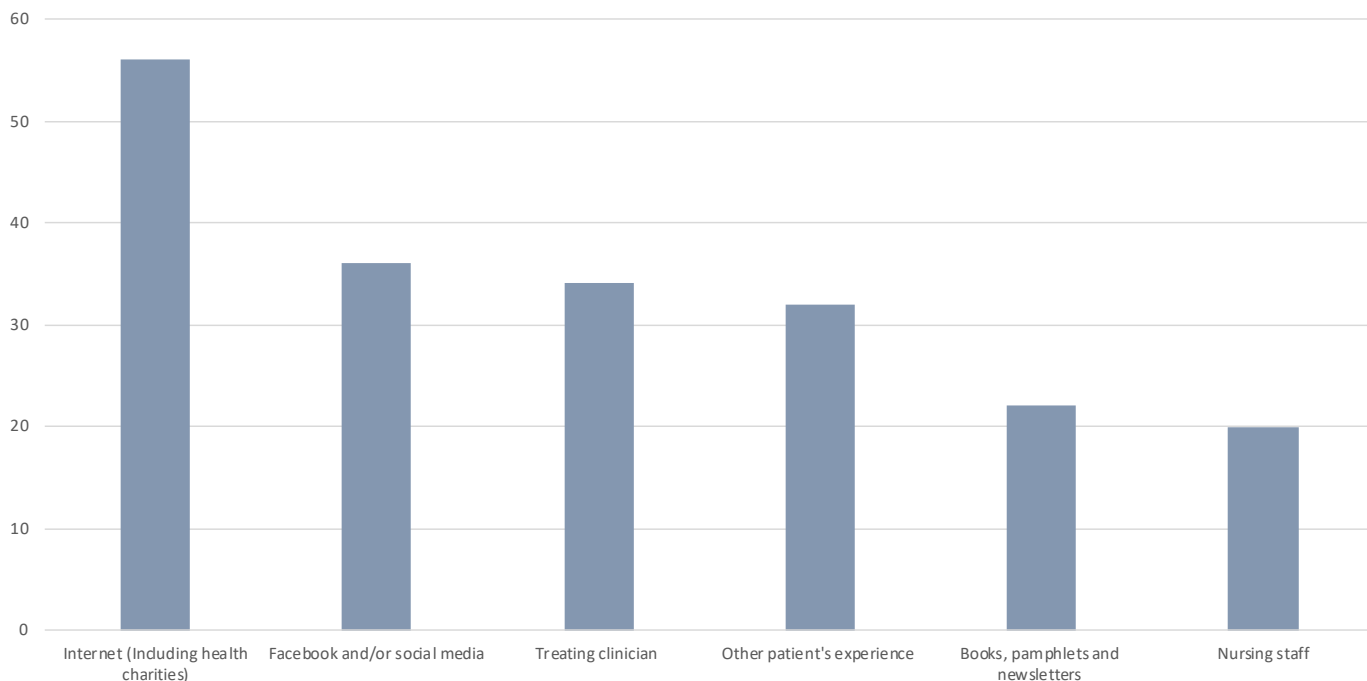


Figure 6.1: Access to information

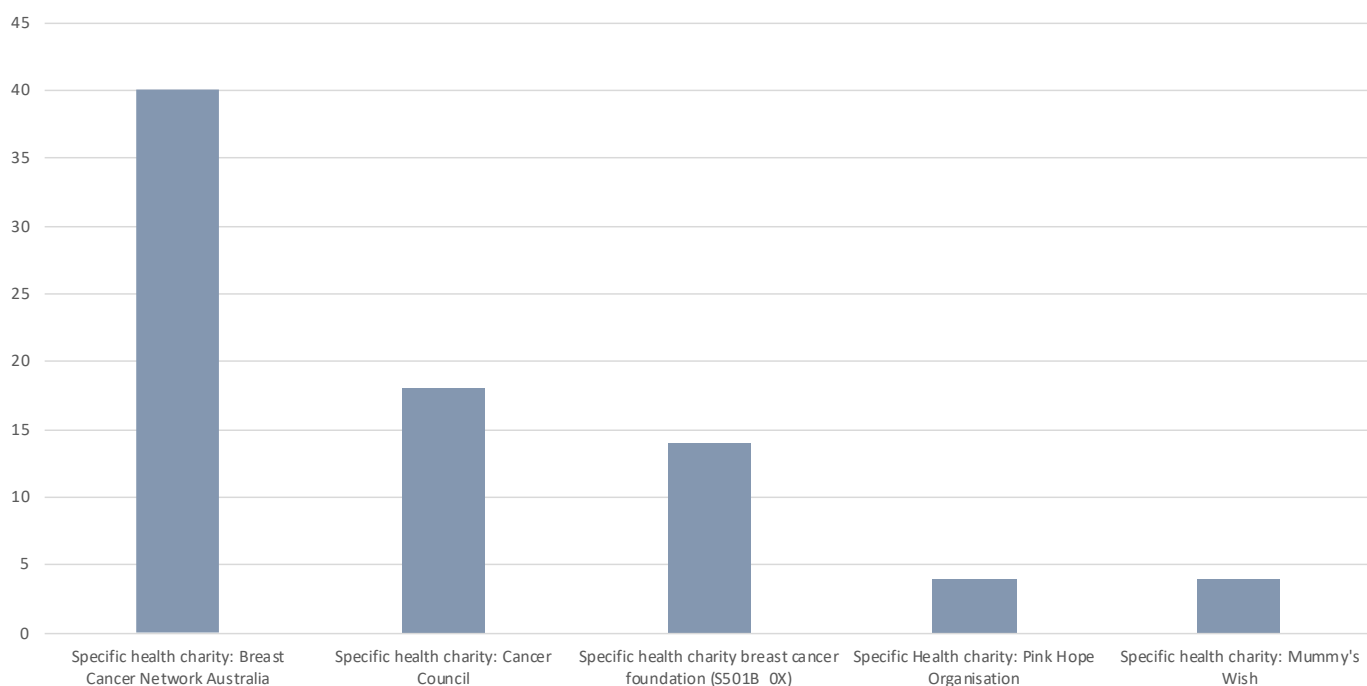


Table 6.2: Access to information – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Advanced breast cancer Aged 45 to 54	Early breast cancer Aged 55 to 74
Participant describes accessing information primarily through Facebook and/or social media	Trade or high school Mid to low status Aged 45 to 54	University Higher status Aged 25 to 44
Participant describes primarily accessing information through treating clinician	Poor physical function	-
Participant describes primarily accessing information through other patient's experience	Good physical function	Poor physical function Aged 25 to 44
Participant describes receiving information from books, pamphlets and newsletters	-	Aged 55 to 74
Participant describes receiving information through nursing staff	-	Regional or remote

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 19 participants (38.00%) was other information from people's experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment), and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

Participant describes other people's experiences as helpful (Peer-to-peer)

The most helpful was the sort of direct support from women who are also going through it. So the connexions I made with other women who were able to say, this is how I coped with this, this is what I find. This is this is what it looks like to have a mastectomy. And even that was one lovely woman who said, do you want to feel like you should see and feel the reconstruction was like. So that was the most useful was real people sharing their experiences. That was the information I needed. The actual reality, rather than just a paragraph on, you know, triple negative means this and that. Whatever it was, the real experiences themselves. Participant_001

Actually, the most helpful information that I've had is from previous cancer patients. Participant_009

I think it's the experience of all the other women, what they've been through at the time of that particular [UNINTELLIGABLE], having a chemotherapy without going through radiation. It's hearing true stories of what other women have have gone through. And for you to know what to expect or not expect to understand that not everyone has the same side effects over time, even if so, knowing in advance information. Participant_049

Participant describes information about what to expect as helpful (Disease progression)

I think probably listening to the Breast Cancer Network podcast was really helpful because they addressed all sorts of different aspects of having breast cancer in those podcasts. I found those really useful. Participant_004

The most helpful, I would say, would have been at the start when I've got all the information of what type of cancer it was and what happens and stages and so forth and what to expect. Apart from that the other most helpful information I've been given is from the chemo nurses, and obviously of side effects and what to expect, and their help was just tremendous. Participant_018

I guess the most helpful has been finding out about the outcomes and the recurrence rate versus the survival rate. I guess that kind of thing about what the future potentially had in front of me. Participant_027

Participant describes information specific to their condition (and sub-types) as helpful

I guess all of it has been helpful, depending on where I was in the particular journey. Yes, I would have to say, if I think, definitely that phone call with the Cancer Council. That was infinitely incredible. The discussions that I would have with the breast care nurse, definitely. My lymphatic massage therapist was a huge source because she's an oncology massage therapist, and she just was delving right into it. She was huge in my learning curve, and the chemo nurses, I would say, as Participant_005

I think the most helpful is knowing that it's okay and it's really normal and that the type of cancer I had is treatable. At the beginning, as I said, realistically, none of my specialists told me too much about triple-negative and the really negative connotations it has, but the really scary side effects or the scary prognosis that you can find on a lot of pages now when you start to do your research. It was nice to get information that was really necessarily necessary but wasn't too much information. For example, everyone talks about the stage of breast cancer they have. I remember asking my surgeon two appointments in what stage mine was. We knew it was grade three, which was really aggressive, but he said to me the stages-- He implied that the staging is really old school terminology, and they talk either early breast cancer or metastatic

breast cancer. I've never done the, "Oh, I'm a stage 2B grade 4, whatever type of breast cancer." I just have always been early breast cancer. Having done my own research, I'm fortunate to know I was stage 1. I was pretty early stage. I think for me the benefit of getting information that was absolutely necessary, but not too much and not too scary, I suppose, the really positive information. Participant_025

Probably the pamphlets and the sheets that they printed off from your chemo place, from your oncologist, from your breast cancer. Anything like that is the best thing. They give you a book, which I probably didn't read until two or three weeks, four weeks into my treatment because I just couldn't process what was going on. Going back, I found a lot of that was helpful as well. The information that they give you when at the time of your diagnosis mightn't help you right at the start because you're still trying to understand what's going on. Being able to go back and look at it, I think, is a good thing as well. Participant_035

Being specific to my type of cancer because a lot of the time it's to do with hormonal cancer. Most people just presume that if you've got breast cancer, it's a hormonal type, having people understand there's different types of finding specific information for me has been helpful. Participant_036

Participant describes talking to healthcare staff as helpful

I guess all of it has been helpful, depending on where I was in the particular journey. Yes, I would have to say, if I think, definitely that phone call with the Cancer Council. That was infinitely incredible. The discussions that I would have with the breast care nurse, definitely. My lymphatic massage therapist was a huge source because she's an oncology massage therapist, and she just was delving right into it. She was huge in my learning curve, and the chemo nurses, I would say, as Participant_005

Probably from my breast care nurse. If she doesn't know it, she'll find it. The BCNA is sort of helpful. There's been a couple of times where I've looked in there and I'm like, "Hmm, can't find anything," but not to do with what I wanted to find out about. My breast care nurse and also the support group. There's a brave young women's breast cancer, they've got a support group on Facebook, which is full of other breast cancer ladies. If you pose a question on there, sometimes you get some information place to go and find it anyway. Participant_012

The most helpful? I can't think of any one thing. Most helpful? Just being about to talk to somebody, as I said just to confirm if...because with the triple-negative, you have this underlying fear of it returning, so any little ache and pain, is, "Is that cancer coming back?" Which I did ask the doctor yesterday. I said, "Is there anything I should really look out for, or worry about?" He said, "Well, the first thing you don't do, is you don't worry." [chuckles] Which is really nice and positive. Participant_029

Participant describes information about treatment options as helpful

When I went and saw the oncologist the first time, they gave me wads of paper with the different types of chemo that I'm going to be having. I had an education session in the chemo- What do you call it?-chemo ward? I don't know, with a nurse and she gave me so many brochures and it was good but it was really information overload. Whilst it's all good, I found my most effective method of research has been on that website. Participant_014

I guess at the outset, the research showing the effectiveness of the treatments that I'm on was encouraging, and more recently, I probably find some of the forums where people discuss side effects and things that occur when they're on the [unintelligible] treatments to me and also the same psychological issues that we deal with. I find that helpful, seeing that other people go through the same sorts of things and looking at how other people have dealt with some side effects. It's given me some ideas to pursue and follow and often reject, but [laughs] sometimes you could go on with [unintelligible] Participant_050

I got provided a booklet at very beginning on breast cancer. I can't remember what it's called, but it basically walks you through each step-by-step, which is offered from [unintelligible] from the National Breast Cancer Council. That was my best resource. Participant_024

Participant describes health charities information as helpful

I think probably listening to the Breast Cancer Network podcast was really helpful because they addressed all sorts of different aspects of having breast cancer in those podcasts. I found those really useful. Participant_004

Probably the most helpful would be the BCNA virtual conferences. There was a recent one on Living Your Best Life After Breast Cancer, and I found that quite useful. It supported what I'm currently doing. Also our breast support group, as well. We all keep trying to keep ourselves pretty well up to date with what's actually happening in the breast cancer treatment world, and keeping one another informed as well. Trying to stay away from myths, and rumors, and gossip in relation to breast cancer. Participant_013

Good question, trying to think. I think when I was first diagnosed, before I started any of my treatments, I went in for an appointment at the cancer care center I went to. They gave me a whole lot of literature brochures from the Cancer Council about some of the side effects, and how I would feel, and then how people around me could help. I think it was beneficial that you could read about it and go, "Oh okay, this may happen." Then, [unintelligible] be like "Oh gosh, that doesn't feel right,". Participant_020

Table 6.3: Information that was helpful

Information that was helpful	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 other people's experiences as helpful (Peer-to-peer)	19	38.00	9	39.13	10	37.04	11	57.89	5	20.00	9	34.62	10	41.67	8	33.33	11	42.31
Participant describes information about what to expect as helpful (Disease progression)	14	28.00	7	30.43	7	25.93	5	26.32	9	36.00	8	30.77	6	25.00	7	29.17	7	26.92
Participant describes information specific to their condition (and sub-types) as helpful	13	26.00	5	21.74	8	29.63	4	21.05	7	28.00	7	26.92	6	25.00	5	20.83	8	30.77
Participant describes talking to healthcare staff as helpful	9	18.00	6	26.09	3	11.11	4	21.05	4	16.00	2	7.69	7	29.17	5	20.83	4	15.38
Participant describes information about treatment options as helpful	9	18.00	5	21.74	4	14.81	4	21.05	4	16.00	5	19.23	4	16.67	3	12.50	6	23.08
Participant describes health charities information as helpful	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	3	11.54	2	8.33	4	16.67	1	3.85

Information that was helpful	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 other people's experiences as helpful (Peer-to-peer)	19	38.00	9	56.25	10	29.41	7	35.00	12	40.00	9	47.37	7	31.82	3	33.33
Participant describes information about what to expect as helpful (Disease progression)	14	28.00	4	25.00	10	29.41	3	15.00	11	36.67	5	26.32	6	27.27	3	33.33
Participant describes information specific to their condition (and sub-types) as helpful	13	26.00	7	43.75	6	17.65	3	15.00	10	33.33	7	36.84	4	18.18	2	22.22
Participant describes talking to healthcare staff as helpful	9	18.00	3	18.75	6	17.65	3	15.00	6	20.00	3	15.79	4	18.18	2	22.22
Participant describes information about treatment options as helpful	9	18.00	3	18.75	6	17.65	3	15.00	6	20.00	2	10.53	5	22.73	2	22.22
Participant describes health charities information as helpful	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	0	0.00	2	9.09	3	33.33

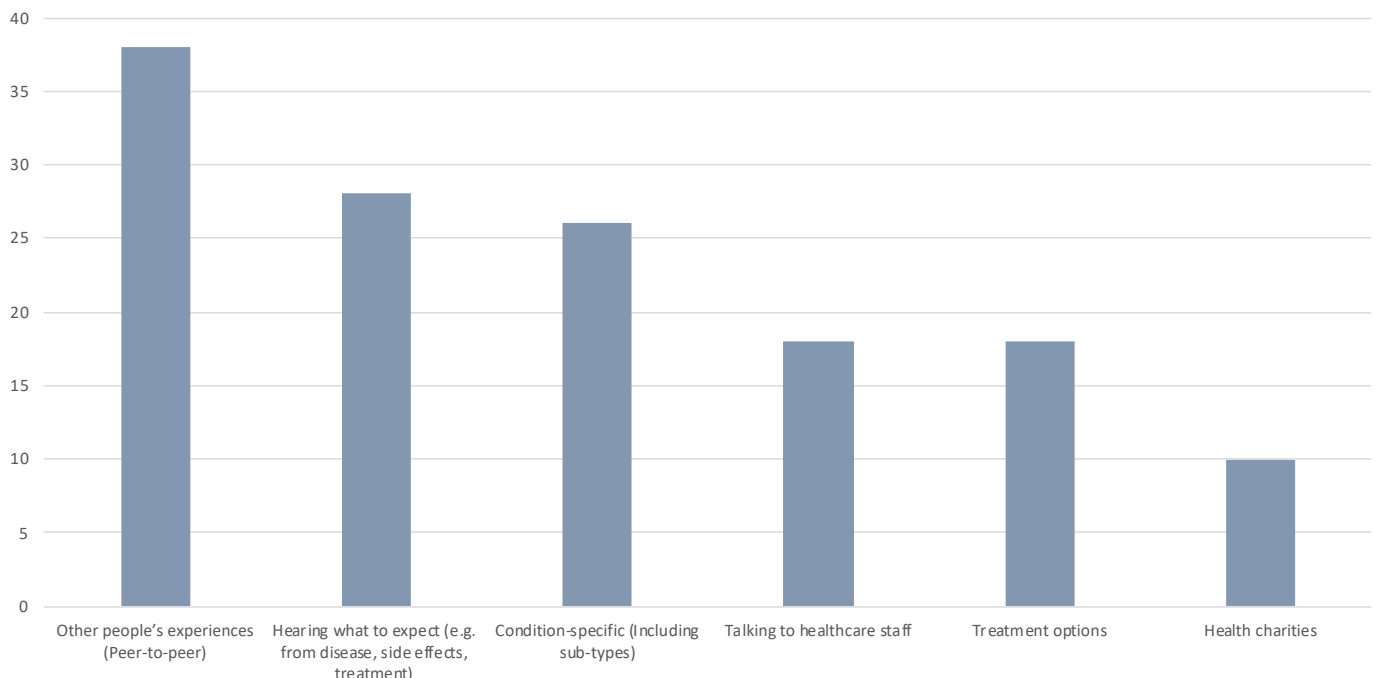


Figure 6.3: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes other people's experiences as helpful (Peer-to-peer)	Good physical function	Poor physical function Regional or remote
Participant describes information about what to expect as helpful (Disease progression)	Mid to low status	
Participant describes information specific to their condition (and sub-types) as helpful	Mid to low status	Regional or remote Aged 25 to 44
Participant describes talking to healthcare staff as helpful	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes health charities information as helpful	-	Aged 55 to 74

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

In general. I think googling is not helpful. Using Google to look up breast cancer and generally in triple-negative breast cancer, that was very unhelpful. Participant_004

No, I think the only things that were upsetting or unhelpful were non cancer patients just giving stupid advice or other cancer patients giving you advice when they've got different cancers or different types of breast cancer and their mentality around that type of cancer compared to mine, I guess. Participant_010

Well, once again, just probably gossip that's either come third hand through different conversations that you've had or also it might be social media things like Facebook. Often, things will pop up on there that are not very helpful, I tend to stay clear of stuff like that. Probably, having that medical background or health background that does help avoid a lot of that because you're aware of whether things are actual information or whether it's just garbage Participant_013

Only the things that I found by myself on Google, they weren't helpful. I joined a Facebook group and left within 10 minutes, that wasn't helpful at all. Those sorts of blogs and stories, they haven't been helpful at all for me. Maybe they are for other people, but for me, that wasn't helpful at all. Just typing in triple-

negative breast cancer into Google is probably the most unhelpful thing that you can do. I found that out the hard way. Participant_033

Participant describes no information being not helpful

I wouldn't say nothing, it's not helpful for me, it's more that it's unnecessary, more than unhelpful. Participant_003

Like my oncologist? Oh, I didn't say that, sorry. No, not really. I found that 95% of the people I've dealt with have been great, and were definitely there to listen, and to help. Participant_020

No, I don't think there's anything. I think the more information you have, the better you are Participant_049

Participant describes the healthcare staff/hospital as being not helpful

I think yes, one thing that wasn't helpful. I was seeing the breast surgeon, and she was basically about to hand me over to an oncologist. She said, "You can see this doctor, and you'll see him pretty soon, but if you see him through the hospital, then you'll be waiting forever." I diligently went and made an appointment with him privately, to then find out that what she told me wasn't the case. That I could have just gone and seen him through the public hospital, and I wouldn't be waiting because I do have private health, but my private health doesn't cover cancer. I thought, "Well, that's what the government's for," but because of her saying that, I was like, "Oh my God, I can't be waiting for weeks. I need to get onto this quickly, quickly, quickly." I was getting ready to spend hundreds and hundreds and hundreds of dollars to go privately because I really wanted to get started on it when that wasn't the case. That was probably the biggest stress and unhelpful thing that could have happened. It all got sorted out, and I think I didn't mean for her to get in trouble, but ultimately that did, I'm pretty sure, get back to the people that need to address that sort of

stuff. I think her understanding was corrected, and maybe she was working off old information where there was a massive wait at the hospital or something, but yes, that was pretty diabolical at the time. Participant_005

The public hospital system. It's not been all that, I don't want to seem like I'm not thankful because I really am, but it's not been all bad. It's the really the actual people that, the doctors and the nurses and the my breast care nurse and everybody. They're great, I just think it's the system thing. If there were different processes is in play, that yes, it probably would give the patient a bit more of a-- To me, it's about me being aware of what's happening, and I feel like I just was not kept in the loop. It was not patients focused. It was just very medically driven. You have for each section, surgeon, and then the medical oncologist, they come together, and then pathology. They all come together and have those discussions about me, but what about me? I'm not a part of that journey at all, I'm just pretty much told, "Well, this is what you need to do." Why do I need to do that? I don't feel like some of the responses I got from the oncologists, either, were informed responses. I think they were just, "This is just how we do it." It's almost like they just follow a specific protocol, process, that they don't look outside. It's kind of black and white and they don't look at the gray, and look at what other options could be available. Whether, again, that that's just a public system of, "This is what we do," or whether it's just how it works in that hospital I was in, I don't. It really was not a great experience in that sense. Participant_015

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think

that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the-- In hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst. Participant_029

Participant describes a lack of new information as not helpful

I guess looking back, that that pink book, because it was I don't know, I guess maybe things are different now, but because it was posted out and it took a few weeks or whatever for me to be on the mailing list and for it to be shipped out by the time it arrived, I'd already gone through. I guess maybe I was into my treatment and I just looked to even want to look at it. And so that was such a waste that I think I'd donate to someone else. So that was to like so that was particularly useful. What other information was useful? I don't know, because I didn't actually get a lot of information and the lack of information wasn't useful. So when I first went to my GP and he gave me that initial diagnosis, the lack of information was really not useful, not being told about this parallel private health system that was really not useful because that could have set me back weeks and not knowing that it was triple negative and so fast growing, that could have made a difference if I had sought out the information and had a friend to do that for me. Participant_001

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical

oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the—in hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty

unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst... With breast cancer, nobody will tell you, "Have a lumpectomy," or, "Have a mastectomy," and then you have an oncologist tell me, "Oh, why wouldn't you just have a mastectomy?" Then you have somebody having a lumpectomy. Everybody just has an opinion one way or the other, really, you're torn about what you want to do about that. There's no clear guideline about which way to go. I found that the most distressing time for me. It wasn't until I went and saw DOCTOR the second time and he said, "I don't think you need put yourself through that unless you have an underlying condition." It just seemed to be the right thing. He said the right thing at the right time, to me, anyway. Participant_029

Table 6.5: Information that was not helpful

Information that was not helpful	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 information from sources that are not credible as not helpful (Not evidence-based)	17	34.00	9	39.13	8	29.63	4	21.05	10	40.00	8	30.77	9	37.50	7	29.17	10	38.46
Participant describes no information being not helpful	13	26.00	5	21.74	8	29.63	5	26.32	5	20.00	6	23.08	7	29.17	9	37.50	4	15.38
Participant describes the healthcare staff/hospital as being not helpful	11	22.00	5	21.74	6	22.22	5	26.32	6	24.00	6	23.08	5	20.83	3	12.50	8	30.77
Participant describes a lack of new information as not helpful	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	4	15.38	2	8.33	2	8.33	4	15.38

Information that was not helpful	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 information from sources that are not credible as not helpful (Not evidence-based)	17	34.00	7	43.75	10	29.41	7	35.00	10	33.33	6	31.58	7	31.82	4	44.44
Participant describes no information being not helpful	13	26.00	5	31.25	8	23.53	6	30.00	7	23.33	3	15.79	7	31.82	3	33.33
Participant describes the healthcare staff/hospital as being not helpful	11	22.00	1	6.25	10	29.41	2	10.00	9	30.00	6	31.58	4	18.18	1	11.11
Participant describes a lack of new information as not helpful	6	12.00	2	12.50	4	11.76	3	15.00	3	10.00	3	15.79	2	9.09	1	11.11

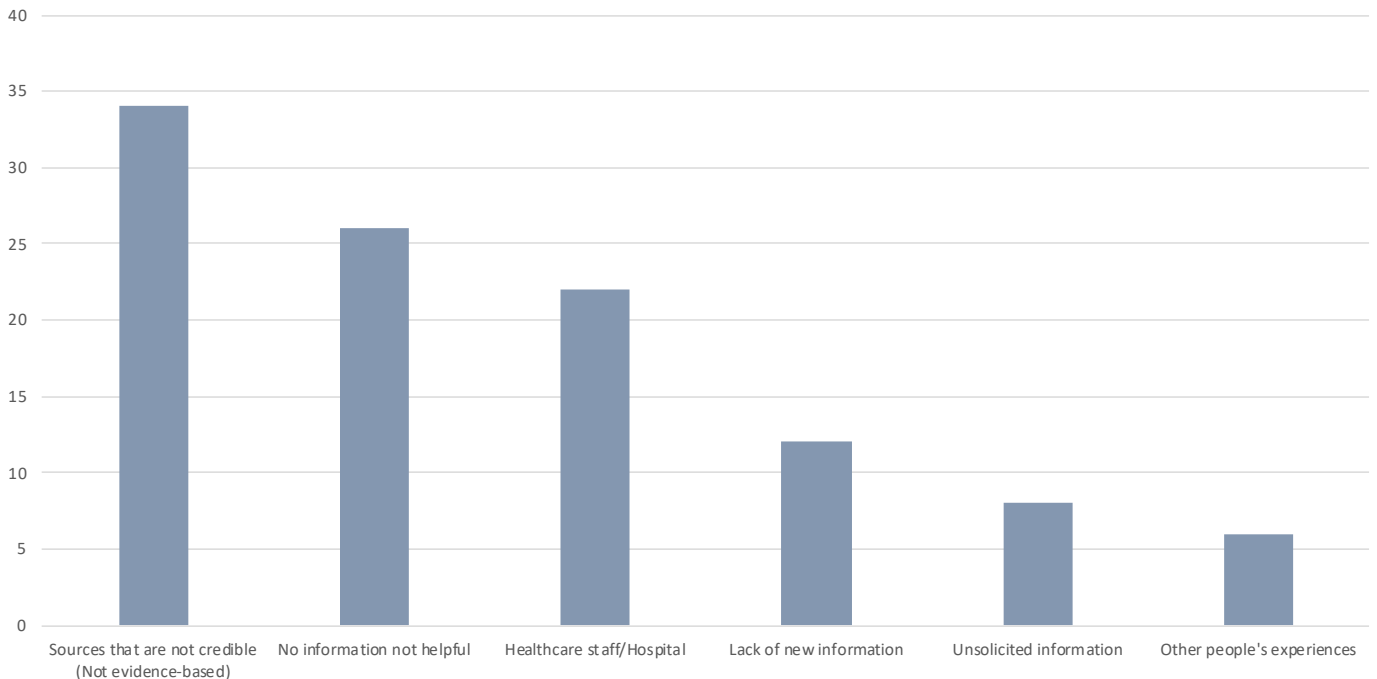


Figure 6.4: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Poor physical function	Aged 55 to 74
Participant describes no information being not helpful	University Aged 25 to 44	Trade or high school
Participant describes the healthcare staff/hospital as being not helpful	Regional or remote Mid to low status Aged 55 to 74	

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

Participant describes online information as main preference

Generally, online, because I'm a researcher. I like to get on and have a look and read and find information myself. Participant_018

Probably online because you can access it any time and you're not filling a bookshelf full of books and pamphlets that you will probably never look at again, and definitely you've got an in-person thing too. Participant_030

Online information probably, because I can read it and then reread it and I can print it out. I can give it to my partner to read and then we can discuss things and I can bounce ideas with him. Phone conversations, I think you don't retain all the detail from a phone conversation. I know you I don't. Participant_050

Participant describes talking to someone as main preference

I'd prefer talking to someone, a professional, because then all the information they have is accurate. The next preference is online because, again, I know where to look, I know which journals to look at and things like that, so I believe I do have a good process of filtering this information myself, for myself. Participant_016

I would prefer to talk face-to-face, if I can. Otherwise, booklets when you've got time to actually comprehend things. I also do like the resources of emails, works I contact or somebody that you can contact.

INTERVIEWER: *What's your reason for preferring a face-to-face conversations?*

PARTICIPANT: *I think that face-to-face is easier to talk about it, instead of like with an email. You can certainly talk about it as well, but face-to-face, you have got that personal contact, so you feel like there's somebody on the other end that's listening. Participant_024*

PARTICIPANT: *Probably talking to someone. One-on-one seems to be a lot easier these days.*

INTERVIEWER: *Are there other reasons why you prefer one-on-one?*

PARTICIPANT: *Not really, no. I think when you're actually sitting with somebody that you absorb more probably. Participant_032*

I think talking to someone is the best because you've got the interaction, that personal side of things, you can ask questions then and there, that sort of thing, yes. Participant_046

Participant describes talking to someone plus online information as main preference

Probably I would probably start with a reliable online source with it. You know, my dad said he had jumped onto this website. This is what I recommend. Have a rate of that. I would do that and then either speak to a GP or briskness. If I'd been had questions that online, didn't you know that I didn't comprehend the information, not then speak to someone so it could be explained one on one. Participant_003

I like to do my research online. I don't tend to use apps very often unless I have to. I kind of forget about them. Then I like to go and talk to someone about it or talk on the phone, whatever it is. Participant_008

I'm probably online because it's small world wide, and you can get a wide range of outcomes, a wide range of knowledge. And I do like to talk to people as well just because, you know, you can get some really interesting information from different people. So it's open to communication and knowledge. So if anybody has any information that they know that I can learn from that out and Participant_044

Participant describes written information as main preference

I think booklets because sometimes when you get overwhelmed, you forget things and you could always like booklets and pamphlets. You can go back to and go, oh, okay, that's what it said. Whereas if you told something, you forget about it and you want to clarify something, you can go back to the booklet. Participant_006

I like written or online information. Talking to people is lovely, but I don't always-- I think when you're in a new diagnosis state, I know that I don't always remember what they've said or I remember incorrectly. I've found written information the most useful for me that I can go back to and look again, whether that be printed and handed out in booklet form, I don't mind, but online is great too. It's just knowing where to go and what to read, and not going rogue. Participant_033

I think the booklet. Online is easy, but I think you can get a lot of misinformation online. You've got to be very careful where you look in. I think there's a couple of good places that we were encouraged to join from the hospitals that have been quite good. I think a book that you can, every now and again, go back and have a look is also something that is quite good. Probably, I find book-type stuff rather than online because, like I said, online, you're just not too sure where it's coming from. Participant_035

Table 6.7: Information preferences

Information preferences	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 online information as main preference	15	30.00	6	26.09	9	33.33	6	31.58	7	28.00	6	23.08	9	37.50	9	37.50	6	23.08
Participant describes talking to someone as main preference	12	24.00	3	13.04	9	33.33	4	21.05	6	24.00	6	23.08	6	25.00	4	16.67	8	30.77
Participant describes talking to someone plus online information as main preference	11	22.00	7	30.43	4	14.81	6	31.58	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes written information as main preference	11	22.00	5	21.74	6	22.22	3	15.79	8	32.00	6	23.08	5	20.83	4	16.67	7	26.92

Information preferences	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 online information as main preference	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	4	21.05	10	45.45	1	11.11
Participant describes talking to someone as main preference	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	6	31.58	4	18.18	2	22.22
Participant describes talking to someone plus online information as main preference	11	22.00	4	25.00	7	20.59	3	15.00	8	26.67	3	15.79	4	18.18	4	44.44
Participant describes written information as main preference	11	22.00	4	25.00	7	20.59	6	30.00	5	16.67	3	15.79	5	22.73	3	33.33

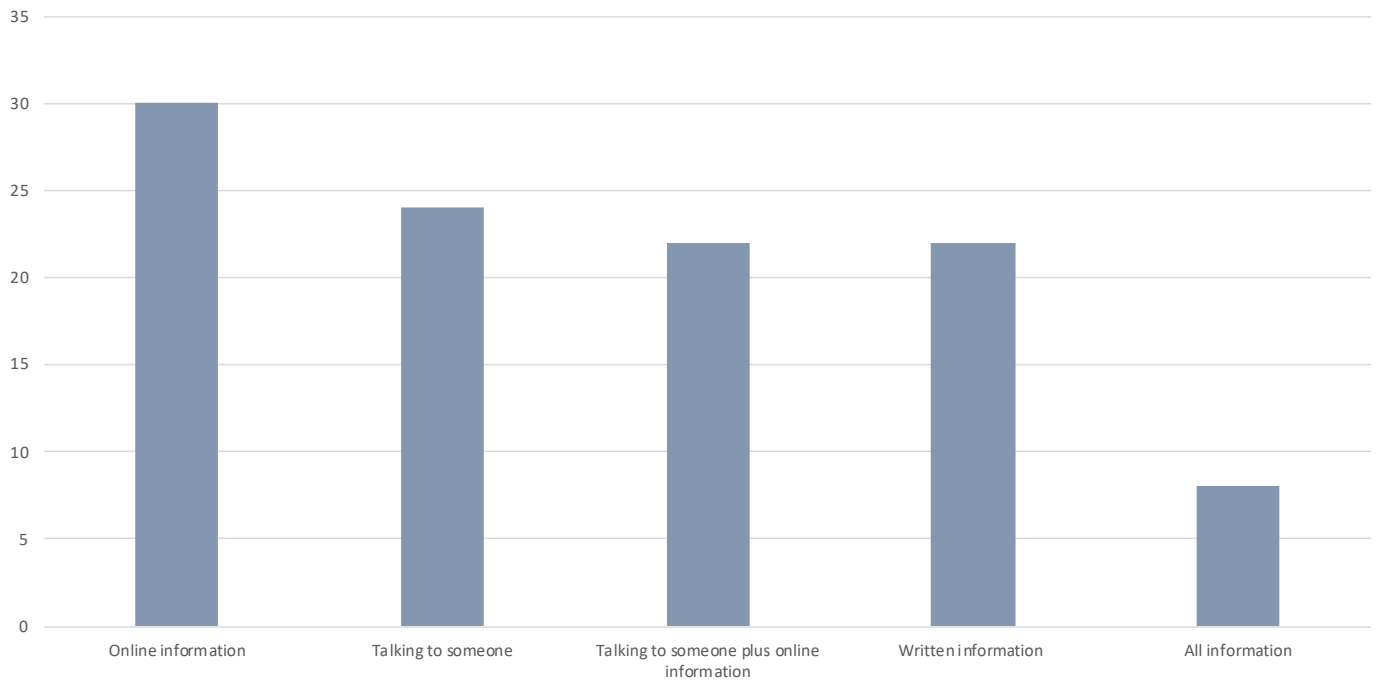


Figure 6.5: Information preferences

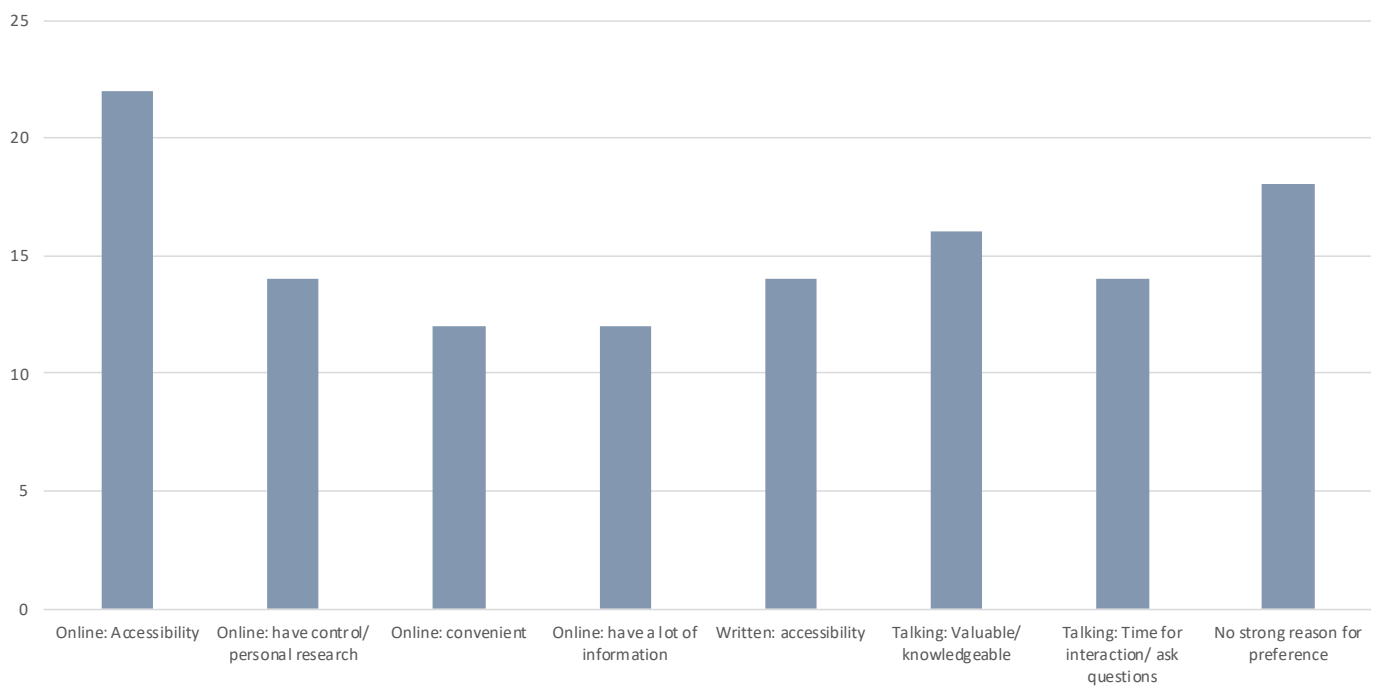


Figure 6.6: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes online information as main preference	Aged 55 to 74	Aged 45 to 54
Participant describes talking to someone as main preference	Early breast cancer	-
Participant describes talking to someone plus online information as main preference	-	Aged 55 to 74
Participant describes written information as main preference	-	Aged 55 to 74

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning when diagnosed (n=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Participant describes being receptive from the beginning (diagnosis)

Well, I wanted every scrap of information from that. Right now I'm different to average, but I know it something that point of diagnosis is it's too much to take all the data within clinicians, which, like I said, I want to know what is available right to someone in my situation. So I was asking for more detail and being provided. It helps. I say that point of diagnosis being absolutely overloaded could be. Participant_002

I was very hungry for information straightaway. It was probably a little bit overwhelming because it was so much to learn at that stage. Everything was new. Even the friend of mine who had had cancer had a totally different type of breast cancer to me. The treatments that they used for her were different to mine and all that sort of thing. Really everything was new even though I had some idea of some of what she'd been through. It was a little bit overwhelming, but it was necessary for me. I really needed to find that info at the beginning. It was probably easier to absorb info a little bit further into the process when I was familiar with what was happening and how chemo worked and all that kind of thing because it wasn't so much to take in all at once. Participant_011

This is a good question. I think at the very beginning, all this is quite good up to a point, and then you freak out [chuckles] and stop taking it in. During treatment was really hard because concentration was not my friend. I was ill anyway, probably about a year to two years down them check post-diagnosis and at the very beginning. That was probably two key moments that I went research-mad about and I wanted to find out stuff. That's when I got the information that I wanted. During treatment, it's hard because your

concentration span and your ability to retain information is quite difficult because you're struggling with other things and dealing with other things. Participant_012

Participant describes being receptive to information during treatment

Definitely not at the start, definitely not probably even partway through treatment. Probably not until I was in the latter part of my treatment, because up until then you're so busy surviving each day that any information you get doesn't really necessarily sink in. I used to take a notepad and pen with me to any of my appointments. If I had questions I thought of, I'd write them down, because I knew I wouldn't remember them. I'd write down any important things that they'd say, the doctor or the specialist would say. Participant_020

Probably after my surgery, once that sort of complete whirlwind in the first two weeks of testing, diagnosis, and surgery. Then I was at home and I had a month off work, so I had time in my own time to process and to ask or to find the information I was looking for. When I was asking it, it was a breather in-between everything else. Participant_021

Probably I didn't start fully taking the information until after I started chemo. I think, right up to the moment that the surgeon was drawing on for surgery, I was in that, "This isn't really happening mindset. Maybe at the point of surgery, and then again at the point of where chemo started because I guess until then, I didn't really know what was going to happen. They can tell you, "Okay, you you're going to get an IVA." Until you're actually in there and having the nurse explain, "This is what we're going to do. This is how long it's going to take. This is why we're doing it." That's where it all becomes real. Participant_027

Participant describes being receptive to information after the shock of diagnosis

Definitely. I mean, maybe I should have been given something printed. I had that very. Diagnosis at the GP that then once I got home and sort of recovered from the shock of it, then I could have read that then because that kind of wasn't as scary as when I had the results of after the lumpectomy, when I was told what kind of cancer it was. And then I was going to have to have the mastectomy and the chemo because that was really shocking that at that point. I was I would not have been receptive, because I know when the surgeon said mastectomies, I remember hearing it, but it sounded sort of all echoey and weird, so I was not receptive. Then at that, that's when I was told the type of cancer. But probably shortly after that, I was really wanting to get into the research and find out all about the chemo. Participant_001

Funnily enough, I think probably when I was most receptive probably would have been when I was almost finished treatment. I think that initial diagnosis, you're very shell shocked. I think probably the initial reaction is to go and search for all of the information you possibly can. I do remember my Breast Care Nurse saying to me, "Please do not go online and Google, triple-negative breast cancer because you won't like what you see. It's made to sound a lot worse than it actually is." Of course, the first thing I did was Google it, and as soon as I started reading, I just shut it down. I closed the article and didn't go back again. What I found most useful was my journey kit that I was given. I know that are all online now, but when I was diagnosed, it was in hard form copy. I tended to use that, and the diaries that was given just to map my treatment, but also just to refer back to if I needed to. I was also given some information by the oncology nurses at the HOSPITAL. That probably answered some of my questions as well, or if it didn't, it gave me the resources of where I could access that information. Initially, I was just too consumed with my actual treatment that was happening at the time. I think going through chemotherapy every week, all I was concentrating on was getting through the chemotherapy, dealing with the side effects, making sure that I was keeping myself in the best health that I could. For example, trying to keep my diet up and my energy levels, and just really concentrating on being well, more than anything. Asking the questions that I needed to at the time. I think I was just trading water through that first six months. Really, it was until I was probably through the worst of that chemotherapy that I started looking more at what was actually happening to me? What

my diagnosis was? What the implications of that were? What were the survival rates? What was the best treatment? Both questions came later Participant_013

I think, to begin with, you've got no ability to take information in, there's so many-- You're scared shitless and you don't know what to do. As soon as you have a plan, I think you can start to take information in. Once I went and got a plan from the medical oncologist. I knew what NAME had said, "Get the surgery, but there's going to be chemotherapy and radiation." I needed a plan. Until I had that plan, I just couldn't-- there's no point reading anything, you don't know what you're going to get. It's just too confusing. Once I got Gavin's plan and then I understood a little bit more about it-- everyone else was reading pathology results and I'm like, "I don't know what all that means. I don't know how to deal with that." For me, sometimes it was too much and so I just, I don't know, I just stepped away from it. When it was, I have to say halfway through, so when I talked to the genetic specialist, she was great. She gave me more-- when we were talking to her, I could prep up questions. That was really good because it made me think you had to focus on certain elements. Then when I came away from that, I did more research. That was halfway through the chemotherapy. I was in a better position to listen and not be so scared. Participant_047

Participant describes being receptive to information before starting treatment

Definitely not at the start. Probably once I had my first visit with the oncologist, I think I was okay with all the information that I'd been given once I'd gotten the okay from the surgeon and he jumped up and down for joy to tell me that he got it all and that he was very, very happy. Then because I saw the surgeon and the oncologist on the same day, I guess once I'd gotten that information then I was able to go, "Okay, I can now move forward. It hasn't gone anywhere. It's all okay, so now we can start this fire and get this bugger." Participant_014

Before I started treatment. Participant_028

Probably before the operation. Yes, before she operated, I saw her a few times and she explained things quite well and my new oncologist is very good. Participant_032

Participant describes being receptive to information with a week after diagnosis

I think probably a week or two after the initial shock of being diagnosed would have been the best time to receive good information. Helpful information. I think that would have helped me in my decision-making. All through, honestly, all through the whole thing at different points in time, it would have been. It's useful to have information all through. Participant_004

Probably a wait after diagnosis because you sort of had to come to terms with it and then, yes, maybe a week after. Participant_006

Probably a week after my diagnosis. Participant_016

Participant describes being receptive to information two to three weeks after diagnosis

Three weeks after my diagnosis. For the first three weeks, I was going along and doing everything, but I literally was still reeling from the shock. Participant_045

Probably, early on. A couple of weeks into my diagnosis because I did a lot of research in how to manage the side effects and what have you? I proactively did that because my mom had had lung cancer, so I'd seen her side effects. I was trying to work out how to trick them all and not get them. I think probably, just before each stage because then I was dealing with the information about chemo. Then once

that was finished or coming to a close, then I'd start to look at the information about surgery. Once that was finished, I start to look at that healing. [laughter]. I think it's most relevant when it's coming up next. Participant_008

I think in a couple of weeks after the diagnosis, when I'd accepted it and understood a little bit more, that was a good time to give information, but right at the beginning, I feel like there probably wasn't enough information given at the diagnosis time. Hence, why I Googled on my own because I had a lot of questions and they weren't necessarily answered and I didn't understand anything. I think at that point, more targeted information would have been really good, whether I'd read it there and then I don't know, but to have been given it and had it at hand so that when I was ready, I had something that was useful and helpful to look at. Rather than when I was ready, taking to Google because I didn't know stuff and thought that's what I needed to find out. The diagnosis day, I don't think enough information was given at all. It was really a case of, "This is what we're going to do. We're going to get you into surgery. You're booked in two weeks' time da da and this is what's happening." I hadn't even understood the different grades of cancer or stages or what triple-negative cancer was. I didn't know anything. It was really a lack of information at diagnosis I found. That would have been helpful. Whether I'd read it or not, I don't know, but it would have been good to have. Participant_033

Table 6.9: Timing of information

Timing of information	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 receptive from the beginning (diagnosis)	12	24.00	7	30.43	5	18.52	3	15.79	8	32.00	6	23.08	6	25.00	6	25.00	6	23.08
Participant describes being receptive to information during treatment	11	22.00	5	21.74	6	22.22	4	21.05	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes being receptive to information after the shock of diagnosis	8	16.00	5	21.74	3	11.11	3	15.79	5	20.00	5	19.23	3	12.50	2	8.33	6	23.08
Participant describes being receptive to information before starting treatment	8	16.00	1	4.35	7	25.93	3	15.79	5	20.00	5	19.23	3	12.50	4	16.67	4	15.38
Participant describes being receptive to information with a week after diagnosis	5	10.00	5	21.74	0	0.00	1	5.26	3	12.00	2	7.69	3	12.50	2	8.33	3	11.54
Participant describes being receptive to information three weeks after diagnosis	5	10.00	1	4.35	4	14.81	5	26.32	0	0.00	2	7.69	3	12.50	1	4.17	4	15.38

Timing of information	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 receptive from the beginning (diagnosis)	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	2	10.53	8	36.36	2	22.22
Participant describes being receptive to information during treatment	11	22.00	3	18.75	8	23.53	5	25.00	6	20.00	9	47.37	2	9.09	0	0.00
Participant describes being receptive to information after the shock of diagnosis	8	16.00	1	6.25	7	20.59	3	15.00	5	16.67	1	5.26	4	18.18	3	33.33
Participant describes being receptive to information before starting treatment	8	16.00	2	12.50	6	17.65	2	10.00	6	20.00	1	5.26	4	18.18	3	33.33
Participant describes being receptive to information with a week after diagnosis	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	2	10.53	1	4.55	2	22.22
Participant describes being receptive to information three weeks after diagnosis	5	10.00	2	12.50	3	8.82	3	15.00	2	6.67	3	15.79	2	9.09	0	0.00

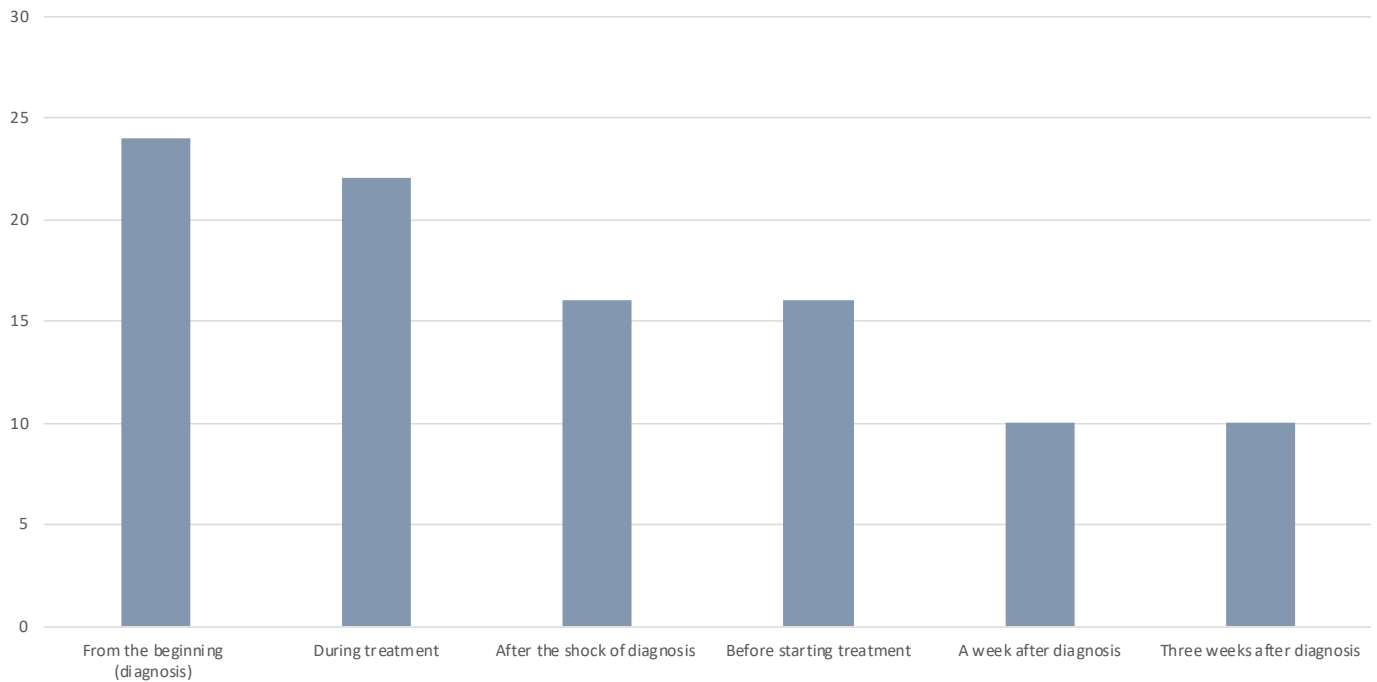


Figure 6.7: Timing of information

Table 6.10: Timing of information – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Aged 25 to 44	Aged 45 to 54
Participant describes being receptive to information during treatment	Aged 45 to 54 Aged 55 to 74	Aged 25 to 44
Participant describes being receptive to information after the shock of diagnosis	Aged 25 to 44	Aged 55 to 74
Participant describes being receptive to information before starting treatment	Early breast cancer Aged 25 to 44	Aged 55 to 74
Participant describes being receptive to information with a week after diagnosis	-	Early breast cancer Aged 55 to 74
Participant describes being receptive to information three weeks after diagnosis	-	Poor physical function

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participant describes health professional communication as overall positive

Outstanding. My surgeon says he looks after me and if I have any overall questions, I'm to contact him in terms of overall care. He's been very clear that he'll be seeing me after all the treatment's over to make sure we're keeping a good eye on it

not coming back. When I was all stressed about diagnosis, I didn't ever have to pick up the phone to make an appointment or anything. All the scans everything, the oncology, everything was booked for me by [unintelligible]. Participant_007

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025

It's been good. Regular check-ups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046

I think it's been good. I've got a very open doctor who's happy to work with me and not just tell me what he thinks should happen and respect that I'm going to be talking to other people and is happy to sit and talk to me about any questions I have or we negotiate when I'll have restaging scans and how I'll manage appointment times around going on holidays and he's great from that point of view. Participant_050

Participant describes health professional communication as overall positive, with the exception of one or two occasions

Overall, they've been fine and nice and everything and pretty helpful, but very much looking at everything just from their medical point of view. It didn't ever feel very holistic. It was fine. They were good, they explained things well, but it was all very medical. Participant_004

I would say pretty good. I know, I'm probably sounding like I haven't had an amazing, but I would say that on a whole-- If I looked at all of my healthcare professionals, there'd be a couple where I'd go, "Uh, that needed to be different." As a whole, I just feel like if the system could be more patient-focused, then it would be 100% better. Overall, I still think that individually, it was okay. Participant_015

Look, every time I've seen a doctor or a nurse they've been fabulous. I could not complain about any of the health professionals that I saw apart from the plastic surgeon. I thought his bedside manner could have done with some improvement. They're all fabulous, but there was this underlying thing of that they're just so overworked that you feel for them. Participant_029

I would class it as good. Because I'm obviously going to a big hospital, sometimes you're not getting back the information that you need in a timely manner I guess, or what I consider a timely manner. I did butt heads with my surgeon. Don't get me wrong, she's a brilliant surgeon, but we did butt heads on a few occasions in regards to my treatment because I felt like I was being forced

down a path without being given options. Participant_034

Participant describes health professional communication as a mix of positive and negative

Not bad, not great kind of average, you know, like even now, like I'm going to see my doctor next week and I'm still like I still every year have to go. OK, so are you sending me a referral or do I wait for a phone call from the hospital to make an appointment like I never know from year to year exactly what's going to happen. Like even last year's mammogram, for example, was light because my doctor didn't get off to the hospital and I'm ringing the hospital saying I'm due for one and a lot, but we don't have the referral. So little bit lacking that sense. And, you know, my initial actual diagnosis appointment was the worst experience I've ever had in my life. But between then, you know, between you know, I have like a year like when I used to see my oncologist, I'd go see I went in October 2015, he would give me the piece of paper to go to the hospital 12 months later, and I would just pin it on my pin up at home. And it would be so some aspects of it were really reliable then, because you using different care providers that don't all have the same level of service. Participant_003

It's been good and bad. I honestly expected a bit more care and personal-- a little bit more care factor. I have switched oncologists. I would have preferred a little bit more empathy and care overall, but then my radiation oncologist and my surgeon were fantastic, so I did appreciate their care. I think it just depends on who your treating doctor is. Participant_016

It's hard to differentiate because it's been a year, a year-long journey. I would say I had two different practices that I was part of. The first one, it was really false hope, not giving me enough information. It was only telling me, "You're fine. Keep going. You're fine." Brushing it off, like not making appointments in person or through certain phone calls. Just really, really poor. Second time, unfortunately, I'm in a situation where I have to be taken quite seriously. My doctors have been very thorough and my oncologist saved my life because pretty much, I had days to live before they were going to affect my brain. Participant_042

Participant describes health professional communication as overall negative

The communication has been I might get a recall for an appointment or I have a question. I have to try and chase up and find someone to answer it. But really, there's been it's definitely not been holistic at all or anything about emotional wellbeing at all. It's been very functional. Participant_001

PARTICIPANT: Pretty poor.

INTERVIEWER: Do you have any examples that come to mind that you would like to share?

PARTICIPANT: My main problem with my oncologist who [chuckles] she made assumptions about my treatment rather than checking my file before she put me on different medications. She doesn't return phone calls, she doesn't return emails. Her lack of follow-up is very frustrating. The turning point for me was when she put me on medication and when I did my annual research and contacted her and said, "Should I really be on this?" She was like, "Well, this is why I put you on it." I'm like, "That's not why I was taking that." She said,

"Oh, yes. I forgot." It was like I lost all confidence at that time. Participant_027

The thing is no one, actually, has come back to me and said, "All the guidelines have changed, maybe you should go and get genetically tested." None of my breast care providers did that. It was only that I had a, what do you call them, my gastroenterologist. I have ulcerative colitis and it's in remission, so every three years, I have a colonoscopy. Then one of my colonoscopies he found these flat hollowed. He said that I should look into getting genetically tested for breast cancer because there can be a link between bile cancer and breast cancer. He told me to go and get genetically tested. Then, when I got my results, I happened to see him again and I'd been to the breast clinic and explained to them and I'd say, "We'll just monitor the condition." My gastroenterologist said, "No, no, no, you need to go and get a different opinion and see this breast specialist because she specializes in genetic conditions as well." I went and saw her. Whenever the guidelines changed for being able to be genetically tested, I think I should have been notified back then. Participant_037

Table 6.11: Healthcare professional communication.

Healthcare professional communication	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 health professional communication as overall positive	26	52.00	11	47.83	15	55.56	11	57.89	15	60.00	14	53.85	12	50.00	9	37.50	17	65.38
Participant describes health professional communication as overall positive, with the exception of one or two occasions	10	20.00	6	26.09	4	14.81	4	21.05	5	20.00	3	11.54	7	29.17	7	29.17	3	11.54
Participant describes health professional communication as a mix of positive and negative	8	16.00	4	17.39	4	14.81	3	15.79	2	8.00	4	15.38	4	16.67	4	16.67	4	15.38
Participant describes health professional communication as overall negative	4	8.00	2	8.70	2	7.41	0	0.00	2	8.00	3	11.54	1	4.17	2	8.33	2	7.69

Healthcare professional communication	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 health professional communication as overall positive	26	52.00	8	50.00	18	52.94	9	45.00	17	56.67	8	42.11	14	63.64	4	44.44
Participant describes health professional communication as overall positive, with the exception of one or two occasions	10	20.00	5	31.25	5	14.71	4	20.00	6	20.00	2	10.53	3	13.64	5	55.56
Participant describes health professional communication as a mix of positive and negative	8	16.00	3	18.75	5	14.71	4	20.00	4	13.33	5	26.32	3	13.64	0	0.00
Participant describes health professional communication as overall negative	4	8.00	0	0.00	4	11.76	1	5.00	3	10.00	2	10.53	2	9.09	0	0.00

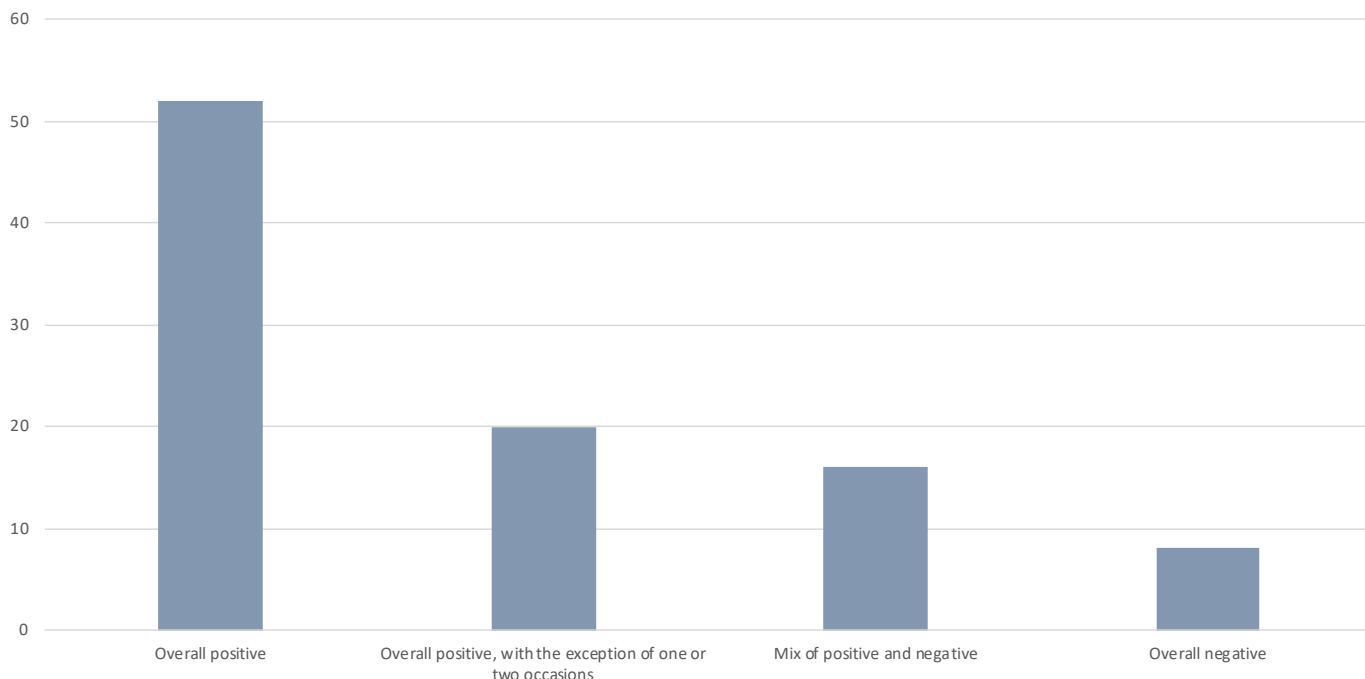


Figure 6.8: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes health professional communication as overall positive	Trade or high school	University Aged 45 to 54
Participant describes health professional communication as overall positive, with the exception of one or two occasions	-	Regional or remote Aged 55 to 74
Participant describes health professional communication as a mix of positive and negative	Aged 55 to 74	Aged 25 to 44

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%).

The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Excellent, excellent. Everyone's on the same page. No one's contradicting each other and all that sort

of stuff. Everyone's clear, optimistic, and good. Participant_005

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025

It's been good. Regular checkups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046

Participant describes health professional communication as helpful

I think I can't fault them. They have been very attentive, and they got me in very, very quickly. Within a week, I was basically about to receive chemo and all that kind of stuff. I've never found any of my doctors-- There were a couple that are a little bit abrupt. That's just doctors. If you ask the right questions, they've always been very helpful. I think the oncologist was probably the most helpful out of all of them. I've not really had a problem. The health care nurse was good when I saw her, but I just didn't see her enough. There has been time after it where I wouldn't have minded talking to someone, but I just didn't really know we could go to get that. Participant_035

I've been very lucky that I have a beautiful oncologist and he answers all my questions and to my parents questions, takes my concerns into consideration and will do follow up scans of anything. But we're unsure of my surgeon is the same, although she doesn't do sarcasm as much as I do and so much more serious conversation with her. But once again, she answers all my questions, gives me all the information, and I guess both of them have learnt the way I think and that I, I personally feel more control and power having lots of information, especially being a nurse as well. Whereas I've got friends that ignorance is bliss and they don't want to know the statistics or the ins and outs. I feel more in control knowing that stuff. So they'll give me a lot more of that information than they might. Just a general cancer patient and my McGraw nurses and the twenty four hour line were always able to pick up my phone calls and answer any questions I had or come with me if I had any concerns. We also have a it's called the Kinkier Wellness Programme, and so it offered weekly torchy and weekly art classes. That was something that I accessed. And so I was able to meet other cancer patients. And I think even that level of communication is really important because no one in your life understands what you're going through. So it connects it with other people that you can vent to when they're not going to say stupid, positive hallmark saying back to try and make you feel better or they'll just understand what you're saying. And I think even that communication within the community was really helpful. Participant_010

Overall, they've been fine and nice and everything and pretty helpful, but very much looking at everything just from their medical point of view. It

didn't ever feel very holistic. It was fine. They were good, they explained things well, but it was all very medical. Participant_004

Participant describes healthcare communication as limited (not forthcoming/lacking)

Pretty okay. I think I've had one or two doctors where I thought, okay. For the next ones come on...I think it was because I was getting conflicting information. One person was telling me one thing, another person was telling me something else. I was like, "Well, Hmm. I don't know what's going on here. I'll just wait," and it was incorrect information in the end. Participant_012

Great. If I ask a question, they will answer. The nurses and breast care nurses have been great, but they're not forthcoming with bad news, so to speak. They will only be forthcoming with good news. They don't like to talk about what the bad things could happen. They rather just focus on the good, which has been great, which you need, but then sometimes you need to face reality as well. Participant_018

PARTICIPANT: Vague.

INTERVIEWER: Okay. [laughs] Not much information from your perspective.

PARTICIPANT: It almost feels like nobody knows anything, but I obviously know that they do. They just don't tell you anything. Participant_019

Participant describes health professional communication as being dismissive (One way conversation)

A bit mixed because sometimes they're a bit like-- Even my oncologist with the side effects sometimes she's like, "Well, maybe it's just menopause." I'm like, "No, I'm fairly sure that all of this isn't just menopause. It's early menopause." I found that her admitting that it's the drugs that she gave me that were causing these symptoms that sometimes wasn't always there. She sometimes was trying to say it was just normal women going through menopause, that kind of stuff. I actually got a strong personality obviously and so I said, "No, I know that this drug causes this, and this drug causes this." She goes, "Oh, yes. Okay. Yes." Getting believed about why and what sometimes is a bit difficult. No one told me about menopause and what happened. either because [chuckles] I was only 42, 43. I hadn't really worked out the

symptoms of menopause and what that can do to you as well. I was a bit surprised that I wasn't warned about that. Participant_008

It's hard to differentiate because it's been a year, a year-long journey. I would say I had two different practices that I was part of. The first one, it was really false hope, not giving me enough information. It was only telling me, "You're fine. Keep going. You're fine." Brushing it off, like not

making appointments in person or through certain phone calls. Just really, really poor. Second time, unfortunately, I'm in a situation where I have to be taken quite seriously. My doctors have been very thorough and my oncologist saved my life because pretty much, I had days to live before they were going to affect my brain. Participant_042

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	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 health professional communication as holistic (Two way, supportive and comprehensive conversations)	20	40.00	9	39.13	11	40.74	7	36.84	13	52.00	10	38.46	10	41.67	6	25.00	14	53.85
Participant describes health professional communication as helpful	5	10.00	3	13.04	2	7.41	1	5.26	4	16.00	3	11.54	2	8.33	3	12.50	2	7.69
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	22.00	5	21.74	6	22.22	2	10.53	4	16.00	5	19.23	6	25.00	7	29.17	4	15.38
Participant describes health professional communication as being dismissive (One way conversation)	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	3	11.54	2	8.33	1	4.17	4	15.38
Participant describes no specific reason for healthcare communication	13	26.00	6	26.09	7	25.93	8	42.11	5	20.00	6	23.08	7	29.17	7	29.17	6	23.08

Healthcare professional communication (Rationale for response)	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 health professional communication as holistic (Two way, supportive and comprehensive conversations)	20	40.00	7	43.75	13	38.24	7	35.00	13	43.33	7	36.84	9	40.91	4	44.44
Participant describes health professional communication as helpful	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	1	5.26	0	0.00	4	44.44
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	4	21.05	4	18.18	3	33.33
Participant describes health professional communication as being dismissive (One way conversation)	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	4	21.05	1	4.55	0	0.00
Participant describes no specific reason for healthcare communication	13	26.00	5	31.25	8	23.53	5	25.00	8	26.67	3	15.79	8	36.36	2	22.22

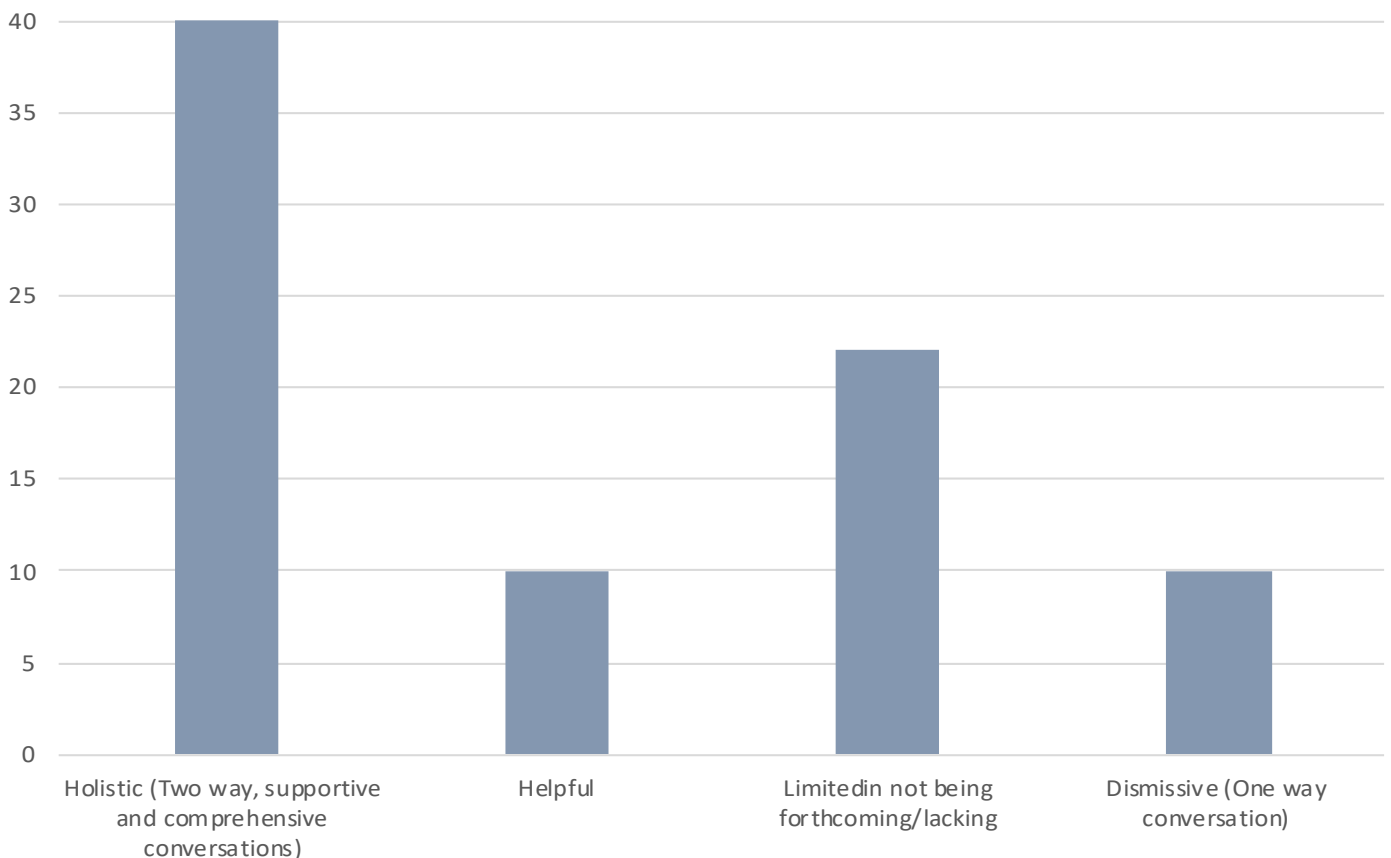


Figure 6.9: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Trade or high school	Good physical function University
Participant describes health professional communication as helpful	-	Aged 55 to 74
Participant describes healthcare communication as limited (not forthcoming/lacking)	Poor physical function	Aged 55 to 74
Participant describes health professional communication as being dismissive (One way conversation)	-	Aged 25 to 44
Participant describes no specific reason for healthcare communication	Aged 25 to 44	Poor physical function Aged 45 to 54

Partners in health

The Partners in Health questionnaire (PIH) measures an individual’s knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Comparisons of Partners in health have been made based on **breast cancer stage** (Tables 6.16 to 6.17, Figures 6.10 to 6.14), **physical function** (Tables 6.18 to 6.19, Figures 6.15 to 6.19), **year of diagnosis** (Tables 6.20 to 6.21, Figures 6.20 to 6.24), **education**, (Tables 6.22 to 6.23, Figures 6.25 to 6.29), **location** (Tables 6.24 to 6.25, Figures 6.30 to 6.34), **socioeconomic status** (Tables 6.26 to 6.27, Figures 6.35 to 6.39), and **age** (Tables 6.28 to 6.29, Figures 6.40 to 6.44).

The **Partners in Health questionnaire (PIH)** measures an individual’s knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge*	25.98	3.51	26.50	5.00	0 to 32	5
Coping*	16.18	4.26	16.00	8.00	0 to 24	4
Recognition and management of symptoms	19.61	2.66	20.00	2.50	0 to 24	5
Adherence to treatment	14.45	1.65	15.00	2.00	0 to 16	5
Total score*	76.23	8.93	76.00	12.50	0 to 96	4

*Normal distribution use mean and SD as measure of central tendency

Partners in health by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage III or Stage IV).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.16), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No significant differences were observed between participants by **breast cancer stage** for any of the Partners in health scales.

Table 6.16: Partners in health by breast cancer stage summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Early breast cancer	20	45.45	26.20	3.32	0.38	42	0.7059
	Advanced breast cancer	24	54.55	25.79	3.73			
Coping	Early breast cancer	20	45.45	15.20	4.67	-1.41	42	0.1655
	Advanced breast cancer	24	54.55	17.00	3.79			
Recognition and management of symptoms	Early breast cancer	20	45.45	19.15	2.92	-1.06	42	0.2968
	Advanced breast cancer	24	54.55	20.00	2.41			
Total score	Early breast cancer	20	45.45	75.05	9.23	-0.80	42	0.4309
	Advanced breast cancer	24	54.55	77.21	8.74			

Table 6.17: Partners in health by breast cancer stage summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Adherence to treatment	Early breast cancer	20	45.45	15.00	2.25	265.50	0.5419
	Advanced breast cancer	24	54.55	14.50	2.00		

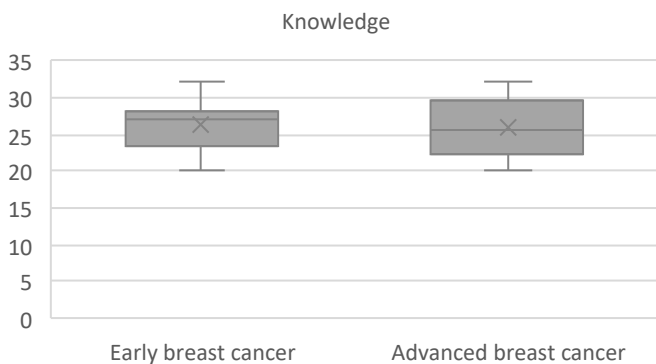


Figure 6.10: Boxplot of Partners in health: knowledge by breast cancer stage

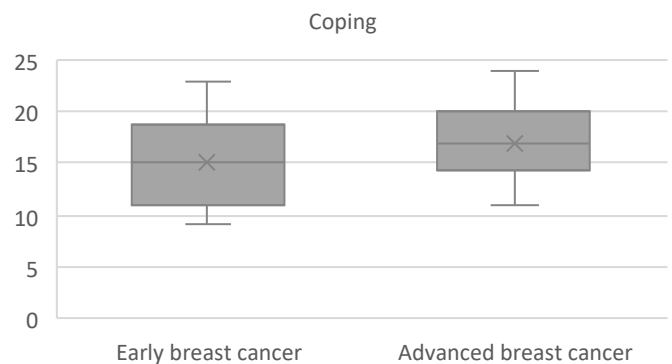


Figure 6.11: Boxplot of Partners in health: coping by breast cancer stage

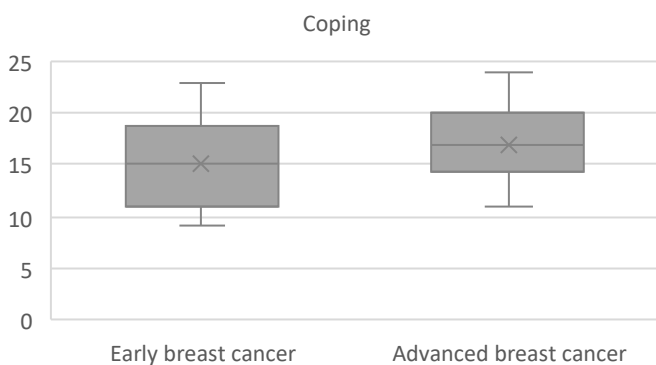


Figure 6.12: Boxplot of Partners in health: recognition and management of symptoms by breast cancer stage

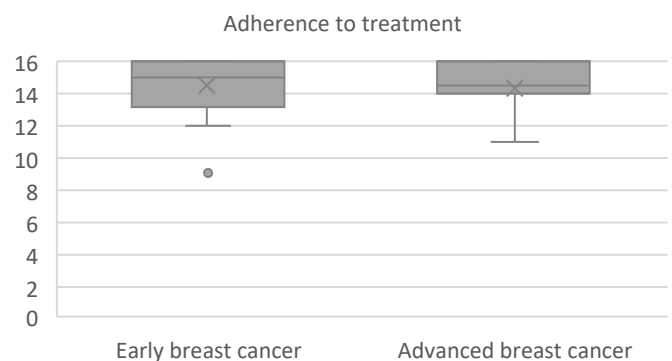


Figure 6.13: Boxplot of Partners in health: adherence to treatment by breast cancer stage

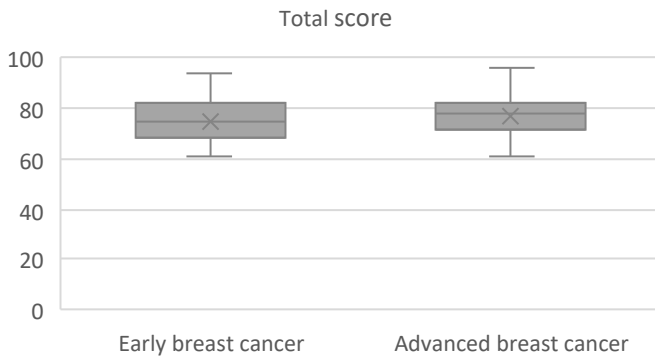


Figure 6.14: Boxplot of Partners in health Total score by breast cancer stage

Partners in health by Physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the *Good physical function* subgroup (n=25, 56.82%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

No significant differences were observed between participants by **physical function** for any of the Partners in health scales.

Table 6.18: Partners in health by physical function summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Poor physical function	19	43.18	26.26	3.51	0.47	42.00	0.6435
	Good physical function	25	56.82	25.76	3.57			
Coping	Poor physical function	19	43.18	15.21	4.64	-1.33	42.00	0.1907
	Good physical function	25	56.82	16.92	3.88			
Recognition and management of symptoms	Poor physical function	19	43.18	19.05	3.01	-1.23	42.00	0.2269
	Good physical function	25	56.82	20.04	2.34			
Total score	Poor physical function	19	43.18	75.21	9.54	-0.65	42.00	0.5165
	Good physical function	25	56.82	77.00	8.55			

Table 6.19: Partners in health by physical function summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Adherence to treatment	Poor physical function	19	43.18	15.00	2.00	270.00	0.4325
	Good physical function	25	56.82	14.00	2.00		

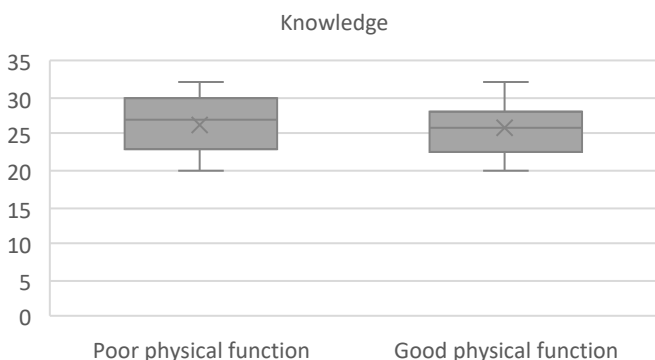


Figure 6.15: Boxplot of Partners in health: knowledge by Pphysical function

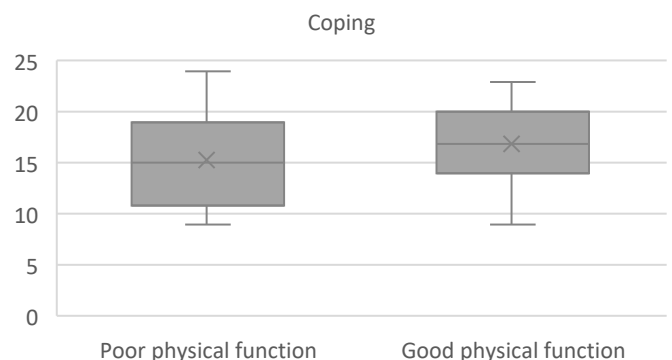


Figure 6.16: Boxplot of Partners in health: coping by physical function

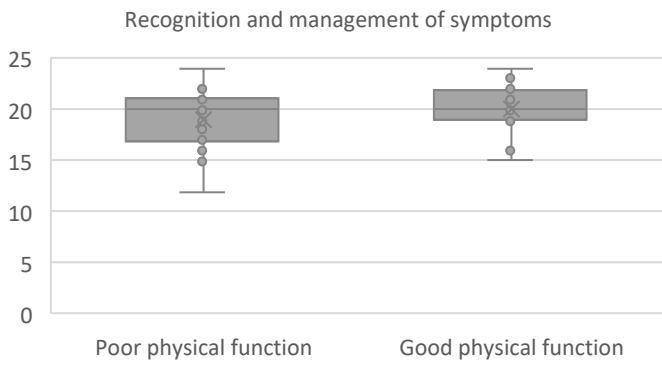


Figure 6.17: Boxplot of Partners in health: recognition and management of symptoms by physical function

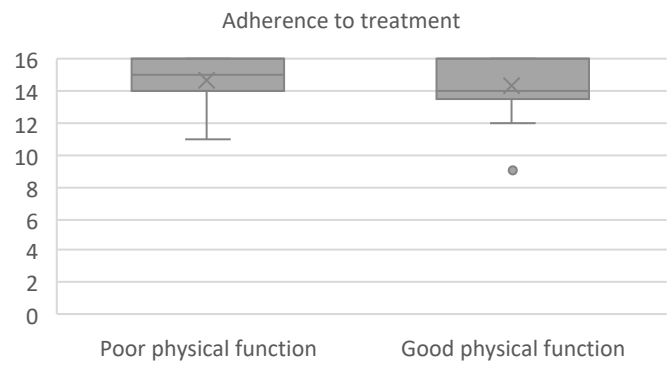


Figure 6.18: Boxplot of Partners in health: adherence to treatment by physical function

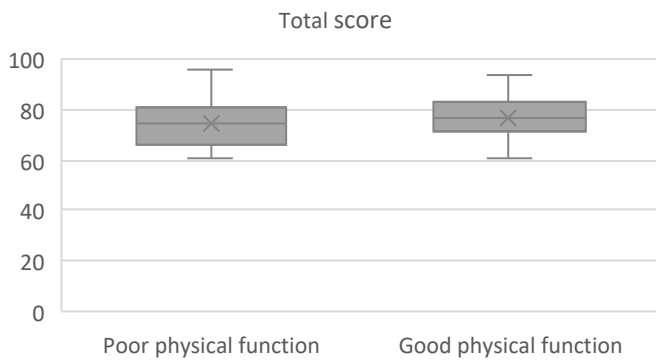


Figure 6.19: Boxplot of Partners in health Total score by physical function

Partners in health by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants by **year of diagnosis** for any of the Partners in health scales.

Table 6.20: Partners in health by year of diagnosis summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Coping	Diagnosed before 2020	22	50.00	16.64	3.71	0.70	42	0.4856
	Diagnosed in 2020 or 2021	22	50.00	15.73	4.79			
Recognition and management of symptoms	Diagnosed before 2020	22	50.00	19.86	2.25	0.62	42	0.5394
	Diagnosed in 2020 or 2021	22	50.00	19.36	3.05			
Total score	Diagnosed before 2020	22	50.00	77.09	8.56	0.64	42	0.5273
	Diagnosed in 2020 or 2021	22	50.00	75.36	9.40			

Table 6.21: Partners in health by year of diagnosis summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Knowledge	Diagnosed before 2020	22	50.00	27.50	6.50	276.50	0.4226
	Diagnosed in 2020 or 2021	22	50.00	25.50	4.50		
Adherence to treatment	Diagnosed before 2020	22	50.00	15.00	2.00	235.00	0.8745
	Diagnosed in 2020 or 2021	22	50.00	15.00	2.00		

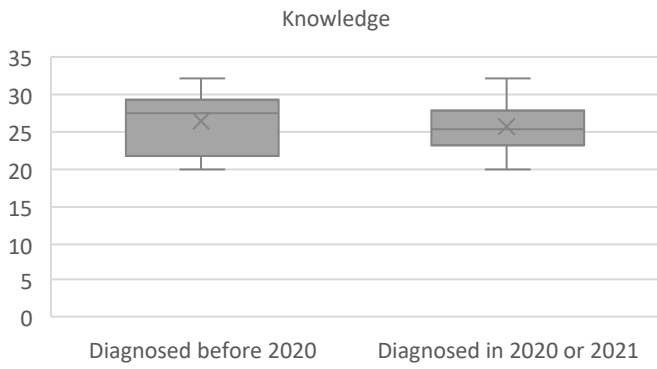


Figure 6.20: Boxplot of Partners in health: knowledge by year of diagnosis

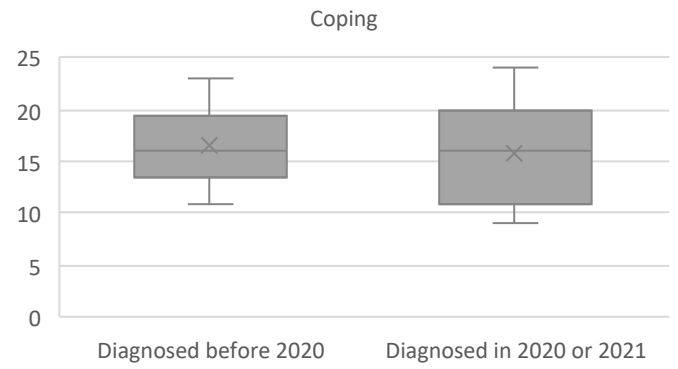


Figure 6.21: Boxplot of Partners in health: coping by year of diagnosis

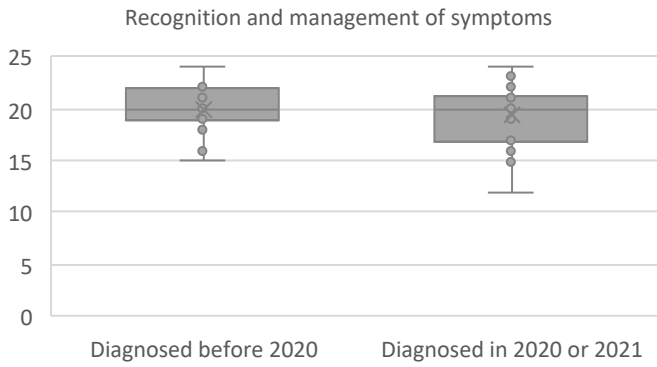


Figure 6.22: Boxplot of Partners in health: recognition and management of symptoms by year of diagnosis

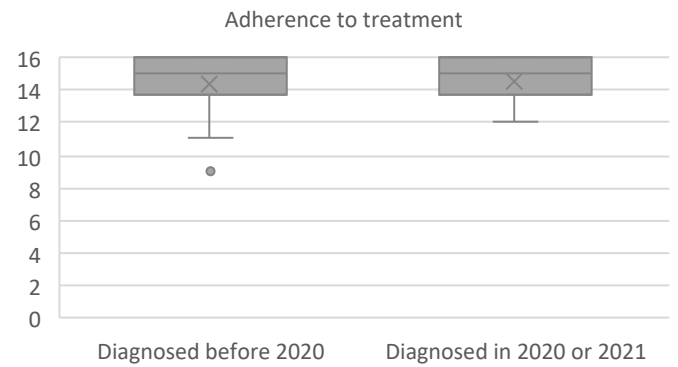


Figure 6.23: Boxplot of Partners in health: adherence to treatment by year of diagnosis

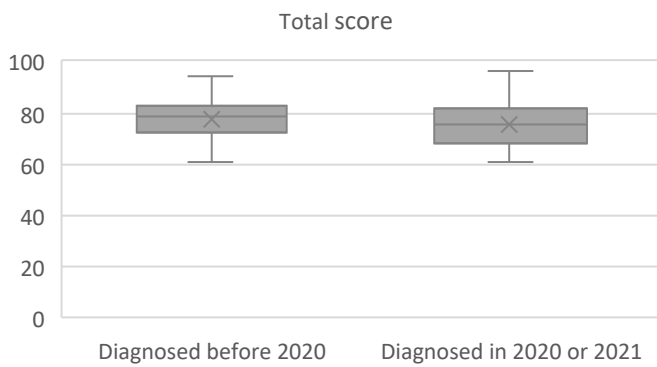


Figure 6.24: Boxplot of Partners in health Total score by year of diagnosis

Partners in health by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

No significant differences were observed between participants by **education** for any of the Partners in health scales.

Table 6.22: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Trade or high school	21	47.73	25.62	3.63	-0.64	42	0.5246
	University	23	52.27	26.30	3.46			
Coping	Trade or high school	21	47.73	16.05	4.08	-0.20	42	0.8445
	University	23	52.27	16.30	4.51			
Total score	Trade or high school	21	47.73	75.43	8.17	-0.56	42	0.5767
	University	23	52.27	76.96	9.69			

Table 6.23: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Trade or high school	21	47.73	20.00	2.00	220.00	0.6182
	University	23	52.27	21.00	5.00		
Adherence to treatment	Trade or high school	21	47.73	14.00	3.00	200.50	0.3246
	University	23	52.27	15.00	2.00		

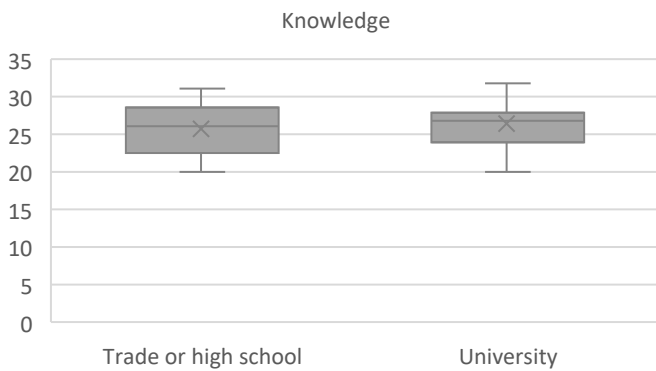


Figure 6.25: Boxplot of Partners in health: knowledge by education

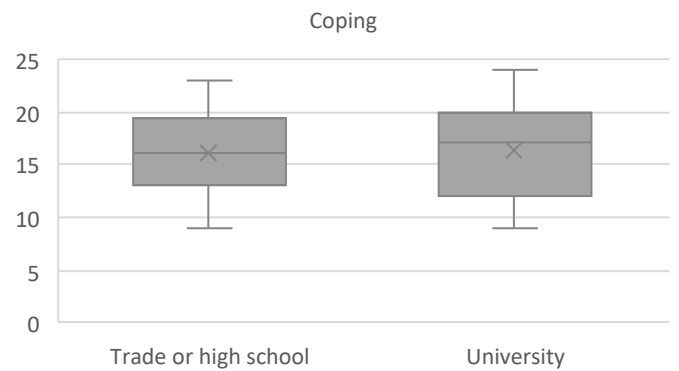


Figure 6.26: Boxplot of Partners in health: coping by education

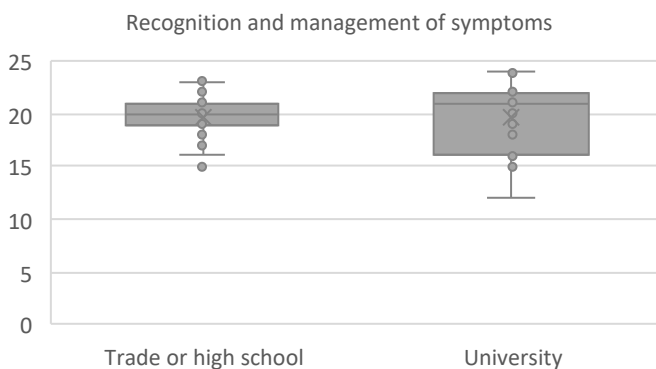


Figure 6.27: Boxplot of Partners in health: recognition and management of symptoms by education

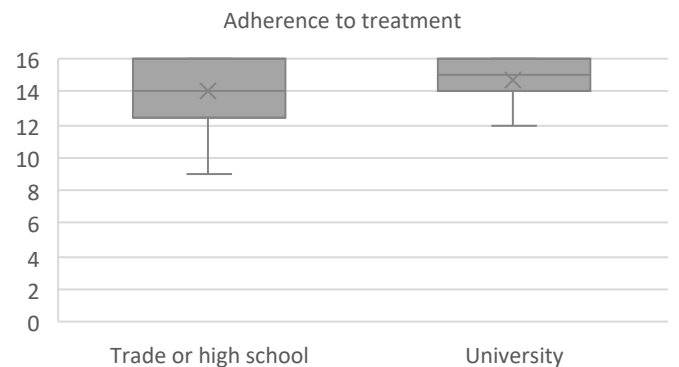


Figure 6.28: Boxplot of Partners in health: adherence to treatment by education

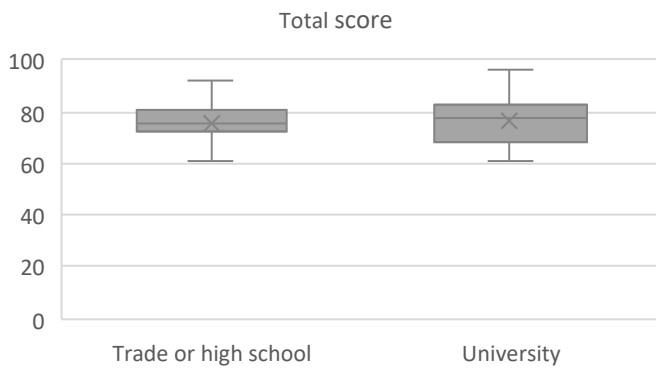


Figure 6.29: Boxplot of Partners in health Total score by education

Partners in health by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas, *Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

No significant differences were observed between participants by **location** for any of the Partners in health scales.

Table 6.24: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Regional or remote	14	31.82	27.14	3.44	1.53	42	0.1345
	Metropolitan	30	68.18	25.43	3.47			
Coping	Regional or remote	14	31.82	17.57	4.33	1.50	42	0.1413
	Metropolitan	30	68.18	15.53	4.14			

Table 6.25: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Regional or remote	14	31.82	20.00	1.75	259.00	0.2170
	Metropolitan	30	68.18	20.00	4.75		
Adherence to treatment	Regional or remote	14	31.82	15.00	2.00	233.00	0.5573
	Metropolitan	30	68.18	15.00	3.00		
Total score	Regional or remote	14	31.82	79.00	6.75	284.50	0.0619
	Metropolitan	30	68.18	73.00	15.25		

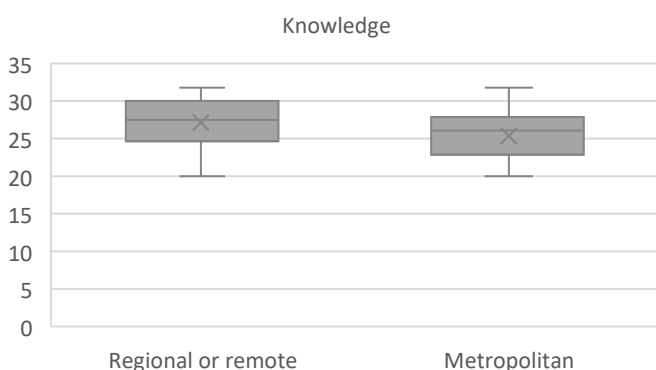


Figure 6.30: Boxplot of Partners in health: knowledge by location

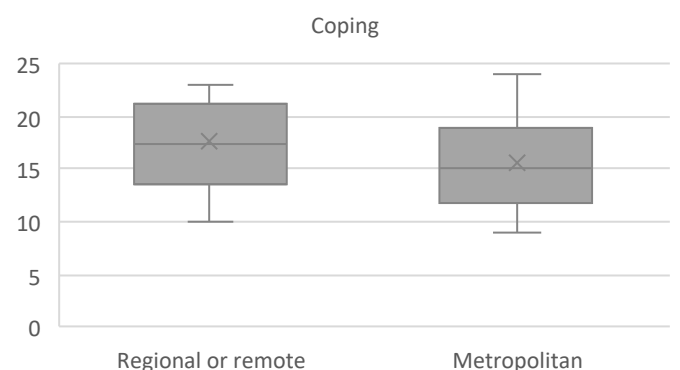


Figure 6.31: Boxplot of Partners in health: coping by location

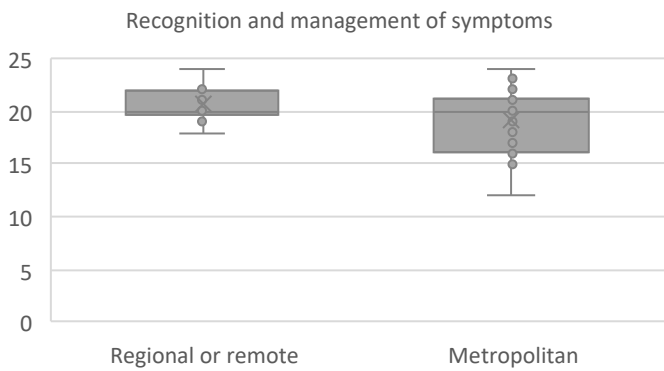


Figure 6.32: Boxplot of Partners in health: recognition and management of symptoms by location

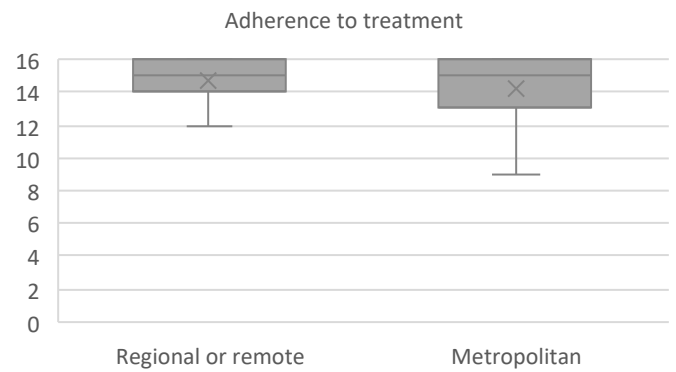


Figure 6.33: Boxplot of Partners in health: adherence to treatment by location

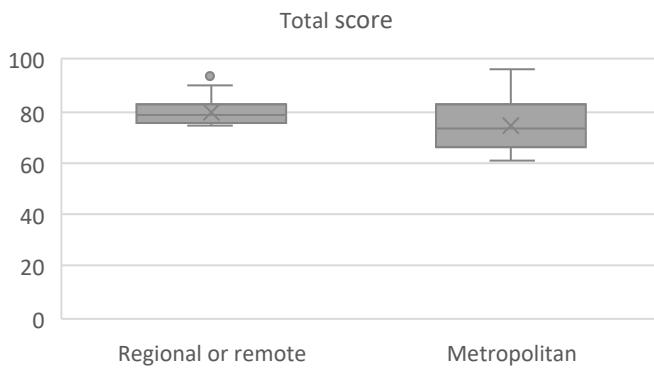


Figure 6.34: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n = 20, 40.00%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n = 30, 60.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.27).

No significant differences were observed between participants by **socioeconomic status** for any of the Partners in health scales.

Table 6.26: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Mid to low status	17	38.64	26.35	3.16	0.56	42	0.5797
	Higher status	27	61.36	25.74	3.76			
Coping	Mid to low status	17	38.64	16.71	4.63	0.64	42	0.5237
	Higher status	27	61.36	15.85	4.06			
Total score	Mid to low status	17	38.64	77.65	7.42	0.83	42	0.4088
	Higher status	27	61.36	75.33	9.79			

Table 6.27: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Mid to low status	17	38.64	21.00	1.00	268.50	0.3485
	Higher status	27	61.36	20.00	4.00		
Adherence to treatment	Mid to low status	17	38.64	15.00	2.00	257.00	0.5005
	Higher status	27	61.36	14.00	2.50		

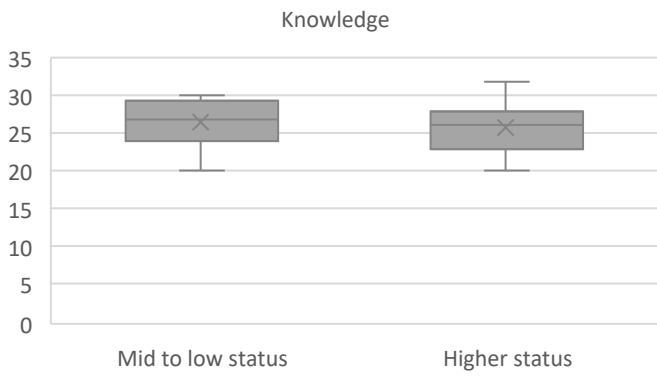


Figure 6.35: Boxplot of Partners in health: knowledge by socioeconomic status

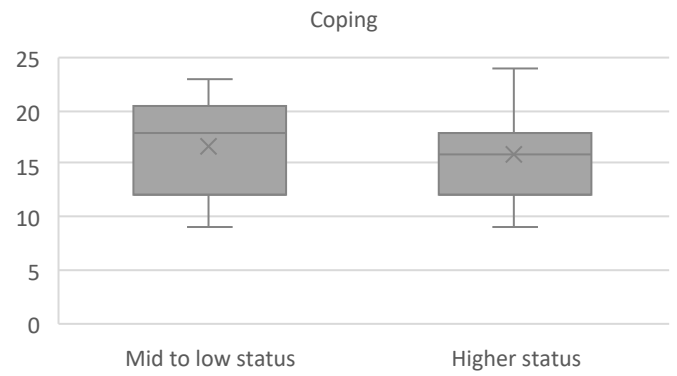


Figure 6.36: Boxplot of Partners in health: coping by socioeconomic status

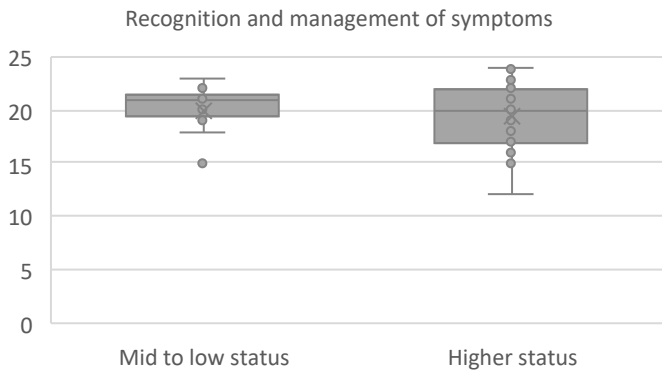


Figure 6.37: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

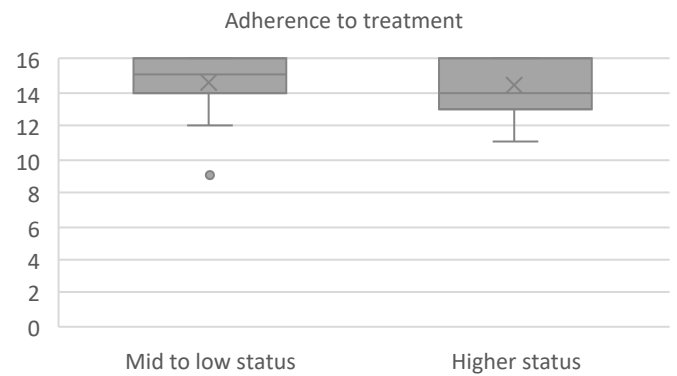


Figure 6.38: Boxplot of Partners in health: adherence to treatment by socioeconomic status

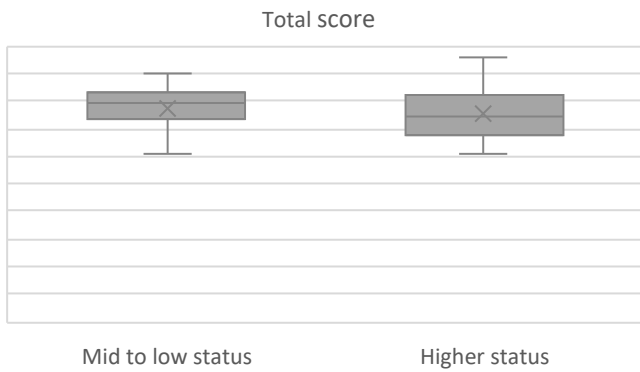


Figure 6.39: Boxplot of Partners in health Total score by socioeconomic status

Partners in health by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were

equal (Table 6.28). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.29).

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.28: Partners in health by age summary statistics and one-way ANOVA test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	Aged 25 to 44	16	36.36	15.81	3.62	Between groups	10.30	2	5.14	0.27	0.7620
	Aged 45 to 54	19	43.18	16.05	5.12	Within groups	770.30	41	18.79		
	Aged 55 to 74	9	20.45	17.11	3.59	Total	780.60	43			
Recognition and management of symptoms	Aged 25 to 44	16	36.36	19.88	2.19	Between groups	3.02	2	1.51	0.21	0.8150
	Aged 45 to 54	19	43.18	19.32	3.18	Within groups	301.41	41	7.35		
	Aged 55 to 74	9	20.45	19.78	2.44	Total	304.43	43			
Total score	Aged 25 to 44	16	36.36	76.31	7.10	Between groups	44.00	2	22.09	0.27	0.7660
	Aged 45 to 54	19	43.18	75.32	9.89	Within groups	3382.00	41	82.48		
	Aged 55 to 74	9	20.45	78.00	10.39	Total	3426.00	43			

Table 6.29: Partners in health by age summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	C ²	dF	p-value
Knowledge	Aged 25 to 44	16	36.36	26.50	4.25	0.94	2	0.6264
	Aged 45 to 54	19	43.18	26.00	5.50			
	Aged 55 to 74	9	20.45	28.00	7.00			
Adherence to treatment	Aged 25 to 44	16	36.36	15.00	2.00	0.97	2	0.6143
	Aged 45 to 54	19	43.18	15.00	2.00			
	Aged 55 to 74	9	20.45	14.00	3.00			

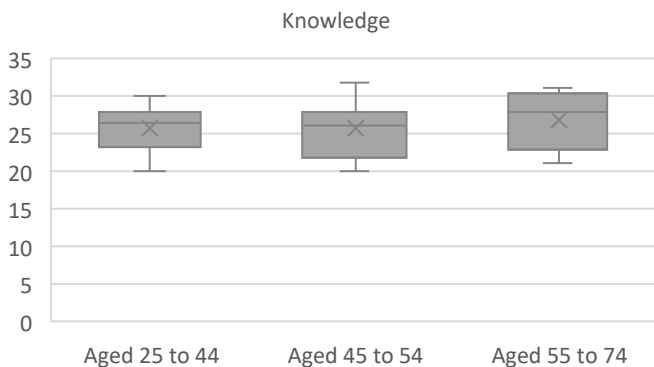


Figure 6.40: Boxplot of Partners in health: knowledge by age

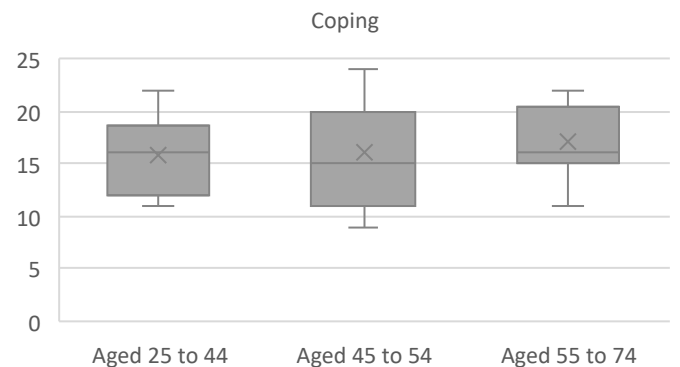


Figure 6.41: Boxplot of Partners in health: coping by age

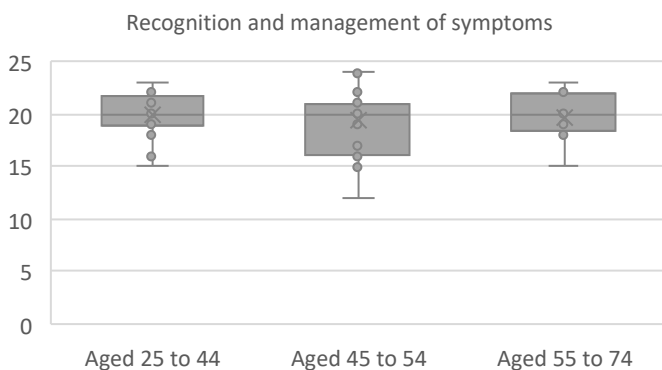


Figure 6.42: Boxplot of Partners in health: recognition and management of symptoms by age

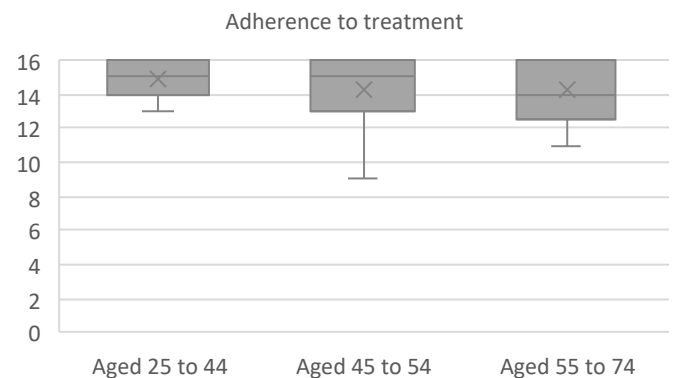


Figure 6.43: Boxplot of Partners in health: adherence to treatment by age

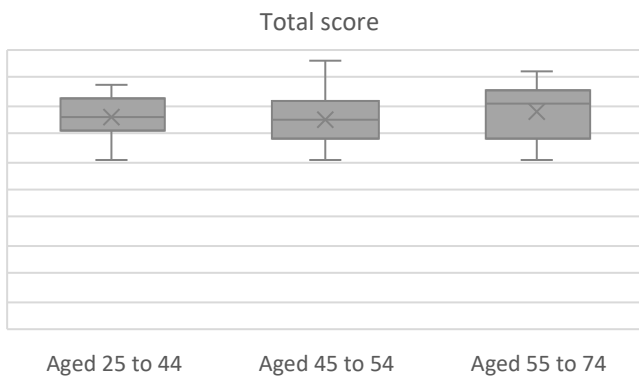


Figure 6.44: Boxplot of Partners in health Total score by age

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n = 23, 52.27%), and 18 participants (40.91%) responded that they took

medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines as prescribed (Table 6.30, Figure 6.45).

Table 6.30: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=44	Percent
All of the time	23	52.27
Most of the time	18	40.91
Sometimes	3	6.82
Rarely	0	0

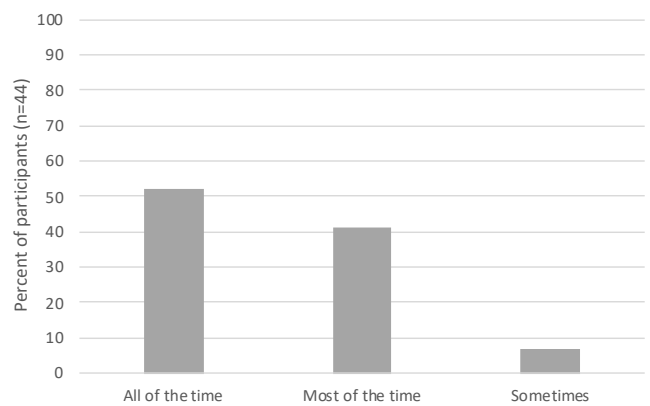


Figure 6.45: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about Treatment options (n=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about

Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) were given least often (Table 6.31, Figure 6.46).

Subgroup variations of more than 10% are listed in Table 6.32.

Table 6.31: Information given by health professionals

Information given by health professionals	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=44	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Disease Cause	11	25.00	6	30.00	5	20.83	4	21.05	7	28.00	7	31.82	4	18.18	7	33.33	4	17.39
Treatment options	41	93.18	18	90.00	23	95.83	17	89.47	24	96.00	21	95.45	20	90.91	19	90.48	22	95.65
Disease management	26	59.09	9	45.00	17	70.83	10	52.63	16	64.00	16	72.73	10	45.45	11	52.38	15	65.22
Complementary therapies	6	13.64	2	10.00	4	16.67	3	15.79	3	12.00	4	18.18	2	9.09	2	9.52	4	17.39
Interpret test results	6	13.64	3	15.00	3	12.50	4	21.05	2	8.00	4	18.18	2	9.09	1	4.76	5	21.74
Clinical trials	6	13.64	3	15.00	3	12.50	5	26.32	1	4.00	4	18.18	2	9.09	2	9.52	4	17.39
Dietary	11	25.00	3	15.00	8	33.33	6	31.58	5	20.00	6	27.27	5	22.73	5	23.81	6	26.09
Physical activity	20	45.45	6	30.00	14	58.33	10	52.63	10	40.00	10	45.45	10	45.45	10	47.62	10	43.48
Psychological/ social support	20	45.45	9	45.00	11	45.83	11	57.89	9	36.00	11	50.00	9	40.91	10	47.62	10	43.48
Hereditary considerations	30	68.18	14	70.00	16	66.67	12	63.16	18	72.00	15	68.18	15	68.18	16	76.19	14	60.87

Information given by health professionals	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=44	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Disease Cause	11	25.00	4	28.57	7	23.33	7	41.18	4	14.81	4	25.00	6	31.58	1	11.11
Treatment options	41	93.18	13	92.86	28	93.33	16	94.12	25	92.59	15	93.75	17	89.47	9	100.00
Disease management	26	59.09	6	42.86	20	66.67	11	64.71	15	55.56	9	56.25	11	57.89	6	66.67
Complementary therapies	6	13.64	3	21.43	3	10.00	2	11.76	4	14.81	2	12.50	3	15.79	1	11.11
Interpret test results	6	13.64	3	21.43	3	10.00	3	17.65	3	11.11	1	6.25	4	21.05	1	11.11
Clinical trials	6	13.64	4	28.57	2	6.67	5	29.41	1	3.70	4	25.00	1	5.26	1	11.11
Dietary	11	25.00	4	28.57	7	23.33	2	11.76	9	33.33	3	18.75	5	26.32	3	33.33
Physical activity	20	45.45	7	50.00	13	43.33	8	47.06	12	44.44	8	50.00	9	47.37	3	33.33
Psychological/ social support	20	45.45	6	42.86	14	46.67	7	41.18	13	48.15	9	56.25	8	42.11	3	33.33
Hereditary considerations	30	68.18	9	64.29	21	70.00	11	64.71	19	70.37	12	75.00	15	78.95	3	33.33

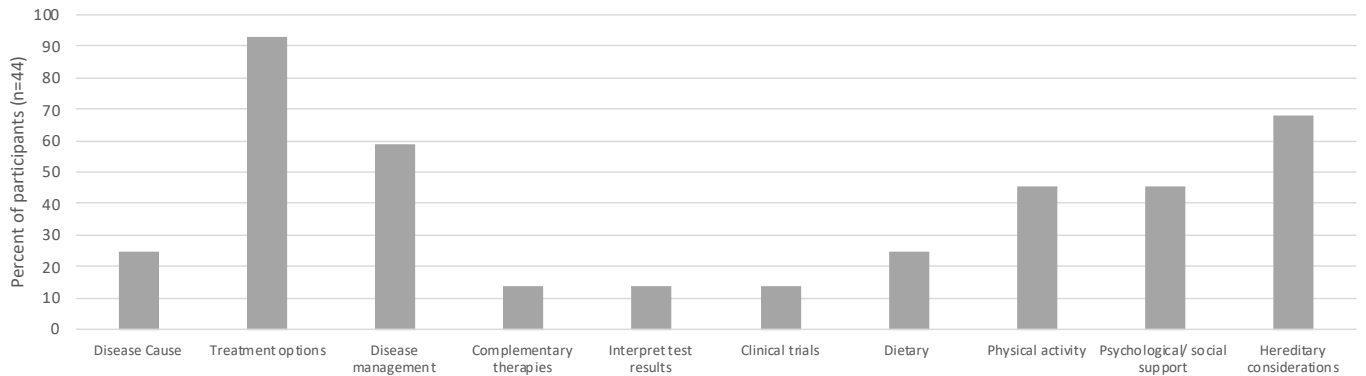


Figure 6.46: Information given by health professionals

Table 6.32: Information given by health professionals – subgroup variations

Information given by health professionals	Less Frequently	More frequently
Disease Cause	Higher status Aged 55 to 74	Mid to low status
Disease management	Early breast cancer Diagnosed in 2020 or 2021 Regional or remote	Advanced breast cancer Diagnosed before 2020
Clinical trials	Poor physical function Regional or remote Mid to low status Aged 25 to 44	
Dietary	Mid to low status	
Physical activity	Early breast cancer Aged 55 to 74	Advanced breast cancer
Psychological/ social support	Aged 55 to 74	Poor physical function Aged 25 to 44
Hereditary considerations	Aged 55 to 74	Aged 45 to 54

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most

frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) were searched for least often (Table 6.33, Figure 6.47).

Subgroup variations of more than 10% are listed in Table 6.34.

Table 6.33: Information searched for independently

Information searched independently	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=44	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Disease Cause	21	47.73	11	55.00	10	41.67	10	52.63	11	44.00	11	50.00	10	45.45	12	57.14	9	39.13
Treatment options	21	47.73	9	45.00	12	50.00	8	42.11	13	52.00	9	40.91	12	54.55	12	57.14	9	39.13
Disease management	21	47.73	6	30.00	15	62.50	10	52.63	11	44.00	8	36.36	13	59.09	13	61.90	8	34.78
Complementary therapies	23	52.27	10	50.00	13	54.17	11	57.89	12	48.00	13	59.09	10	45.45	12	57.14	11	47.83
Interpret test results	28	63.64	12	60.00	16	66.67	11	57.89	17	68.00	14	63.64	14	63.64	13	61.90	15	65.22
Clinical trials	12	27.27	3	15.00	9	37.50	4	21.05	8	32.00	6	27.27	6	27.27	7	33.33	5	21.74
Dietary	17	38.64	12	60.00	5	20.83	9	47.37	8	32.00	10	45.45	7	31.82	6	28.57	11	47.83
Physical activity	19	43.18	10	50.00	9	37.50	8	42.11	11	44.00	11	50.00	8	36.36	6	28.57	13	56.52
Psychological/ social support	13	29.55	7	35.00	6	25.00	8	42.11	5	20.00	7	31.82	6	27.27	5	23.81	8	34.78
Hereditary considerations	18	40.91	8	40.00	10	41.67	6	31.58	12	48.00	8	36.36	10	45.45	8	38.10	10	43.48

Information searched independently	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=44	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Disease Cause	21	47.73	9	64.29	12	40.00	9	52.94	12	44.44	11	68.75	6	31.58	4	44.44
Treatment options	21	47.73	7	50.00	14	46.67	10	58.82	11	40.74	4	25.00	12	63.16	5	55.56
Disease management	21	47.73	7	50.00	14	46.67	11	64.71	10	37.04	5	31.25	10	52.63	6	66.67
Complementary therapies	23	52.27	7	50.00	16	53.33	11	64.71	12	44.44	10	62.50	10	52.63	3	33.33
Interpret test results	28	63.64	11	78.57	17	56.67	12	70.59	16	59.26	10	62.50	15	78.95	3	33.33
Clinical trials	12	27.27	6	42.86	6	20.00	6	35.29	6	22.22	5	31.25	6	31.58	1	11.11
Dietary	17	38.64	8	57.14	9	30.00	9	52.94	8	29.63	6	37.50	8	42.11	3	33.33
Physical activity	19	43.18	8	57.14	11	36.67	8	47.06	11	40.74	7	43.75	9	47.37	3	33.33
Psychological/ social support	13	29.55	3	21.43	10	33.33	5	29.41	8	29.63	7	43.75	3	15.79	3	33.33
Hereditary considerations	18	40.91	7	50.00	11	36.67	8	47.06	10	37.04	5	31.25	9	47.37	4	44.44

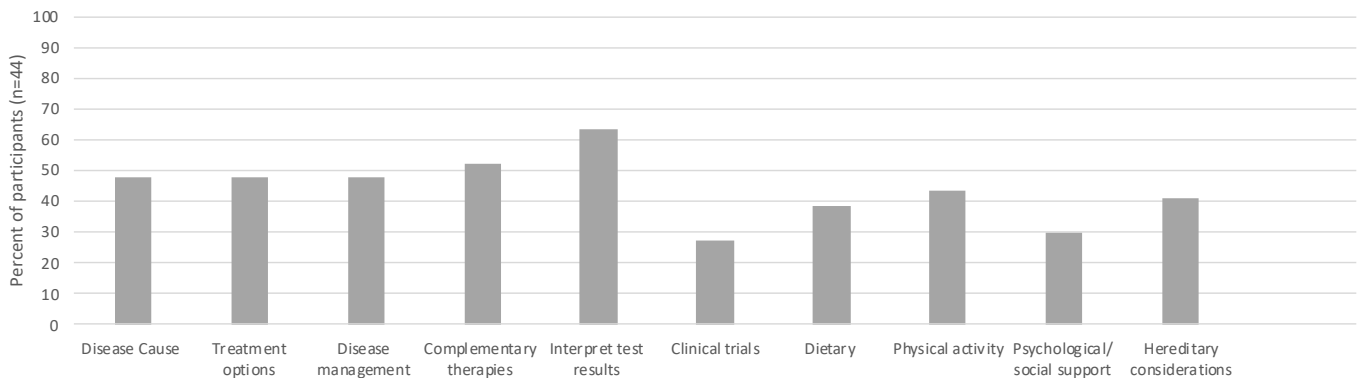


Figure 6.47: Information searched for independently

Table 6.34: Information searched for independently – subgroup variations

Information given by health professionals	Less frequently	More frequently
Disease Cause	Aged 45 to 54	Regional or remote Aged 25 to 44
Treatment options	Aged 25 to 44	Mid to low status Aged 45 to 54
Disease management	Early breast cancer Diagnosed before 2020 University Higher status Aged 25 to 44	Advanced breast cancer Diagnosed in 2020 or 2021 Trade or high school Mid to low status Aged 55 to 74
Complementary therapies	Aged 55 to 74	Mid to low status Aged 25 to 44
Interpret test results	Aged 55 to 74	Regional or remote Aged 45 to 54
Clinical trials	Early breast cancer Aged 55 to 74	Advanced breast cancer Regional or remote
Dietary	Advanced breast cancer Trade or high school	Early breast cancer Regional or remote Mid to low status
Physical activity	Trade or high school	University Regional or remote
Psychological/ social support	Aged 45 to 54	Poor physical function Aged 25 to 44

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were Clinical trials (n = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals

and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Table 6.35: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=44	%	n=44	%	n=44	%	n=44	%
Disease cause	18	40.91	5	11.36	6	13.64	15	34.09
Treatment options	1	2.27	22	50.00	19	43.18	2	4.55
Disease management	10	22.73	13	29.55	13	29.55	8	18.18
Complementary therapies	18	40.91	3	6.82	20	45.45	3	6.82
How to interpret test results	14	31.82	2	4.55	4	9.09	24	54.55
Clinical trials	27	61.36	5	11.36	1	2.27	11	25.00
Dietary information	20	45.45	7	15.91	4	9.09	13	29.55
Physical activity	11	25.00	14	31.82	6	13.64	13	29.55
Psychological/social support	17	38.64	14	31.82	6	13.64	7	15.91
Hereditary considerations	8	18.18	18	40.91	12	27.27	6	13.64

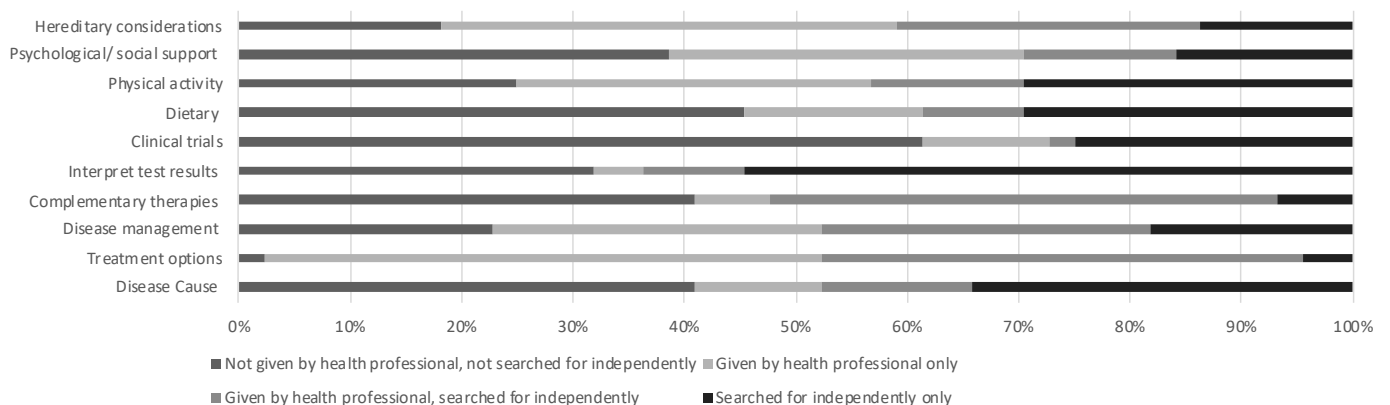


Figure 6.48: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.36 and Figure 6.49. With a weighted ranking, the higher the score, the more accessed the source of information.

Table 6.36: Most accessed information

Information source	Weighted average (n=44)
Non-profit organisations, charity or patient organisations	4.36
Government	3.25
Pharmaceutical companies	1.95
Hospital or clinic I am being treated in	3.11
Medical journals	2.32

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

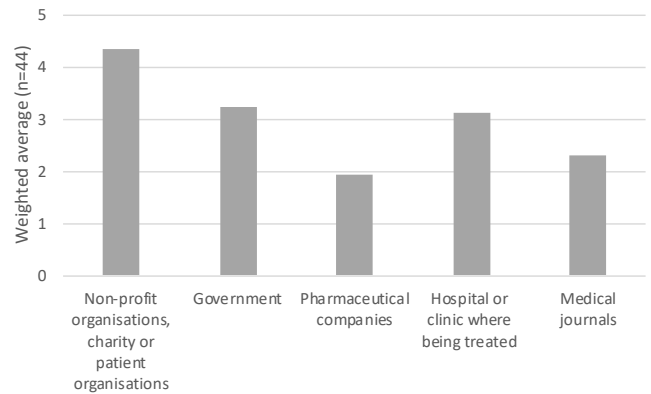


Figure 6.49: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not (Table 6.37. Figure 6.50).

Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good (Table 6.38, Figure 6.51).

Table 6.37: Accessed My Health Record

Accessed "My health record"	Number (n=44)	Percent
Yes	19	43.18
No	21	47.73
Not sure	2	4.55
Doesn't know what 'My Health Record' is	2	4.55

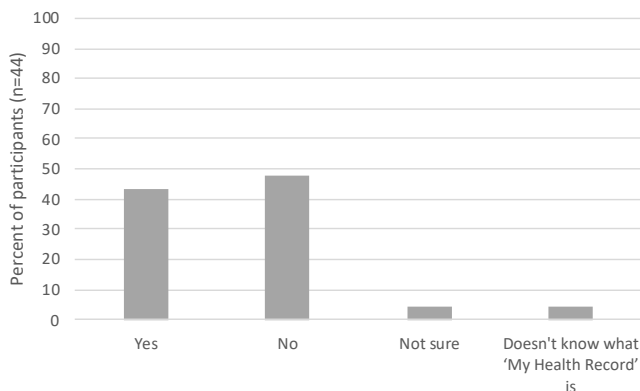


Figure 6.50: Accessed My Health Record

Table 6.38: How useful was My Health Record

How useful was "My health record"	Number (n=19)	Percent
Very poor	4	21.05
Poor	4	26.32
Acceptable	5	21.05
Good	4	10.53
Very good	2	0.00

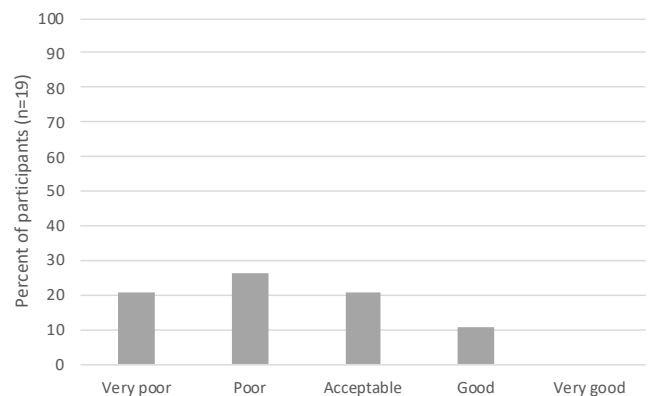


Figure 6.51: How useful was My Health Record