

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 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

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 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and information that is specific to their condition and sub-types (n=5, 9.62%).

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 19 participants (36.54%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 13 participants (25.00%) was other people's experiences. There were eight participants (15.38%) that described other people giving advice or opinions as unhelpful, and the same number that described worst case scenarios and negative information as unhelpful (n=8, 15.38%). Other participants described information from their GP or specialist as unhelpful (n=7, 13.46%), and information from sources that are not credible as not helpful (not evidence-based) (n=6, 11.54%).

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, most participants had a preference for a combination of information sources (n=44, 8.63%), all of these combinations included online information. There were five participants (9.62%) only had a preference for talking to someone, and four participants (7.69%) only had a preference for written (booklets). Participants commonly had a preference for talking to someone plus a written form of information (either app, internet or booklet) (n=33, 63.47%), and a total of 15 participants (n=15, 28.84%) that had a preference for information in the written form only (either app, internet or booklet).

The main reasons for a preference for online information were accessibility, and being able to digest information at their own pace. The main reason for talking to someone as a preference was being able to ask questions, and getting information that was relevant or personalised.

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=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

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=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=17, 32.69%).

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: 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 very good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) 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 treatment options (n=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management (n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) 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 = 37, 71.15%), dietary information (n = 27, 51.92%), complementary therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

The topics that participants were given most information from both healthcare professionals and searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%).

Most accessed information

Across all participants, information from non-profit organisations, charity or patient organisations was most accessed followed by information from the hospital or clinic where being treated. Information from Pharmaceutical companies was least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (23.53%) had accessed My Health Record, 39 participants (76.47%) had not.

Of those that had accessed My Health Record, there were seven participants (58.33%) that found it to be poor or very poor, and four participants (33.33%) that found it acceptable.

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 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

Participant describes accessing information through the internet in general

I'm trying to get the words out. After I was diagnosed, I guess, like most people did, got online. Get on all the different types of chances that you have and treatment that you'd have. Or the usual treatment that you'd be given and general prognosis, I guess. Depending on the stage and all that sort of stuff. Participant 028_2021AUHRP

I haven't accessed much recently, but I used to always be on the internet. Asking any of the physicians or medical people I was seeing what they thought about my understanding of things. Participant 016_2021AUHRP

Oh, lots of googling which everyone tells you not to do that. Probably, at the surgeon with all the results and biopsy and things like that, when we went back, he explained everything, but I don't know. I went home, he gave me the whole report and all the ins and outs of everything, which of course I googled everything. I wanted to know what everything meant and all that sort of thing. Maybe I should have asked more questions at the time, but I probably- a little bit more information from him. I felt that they don't want to overload you with too much information either because they don't want to scare you. You got enough to deal with, but, I guess most of the information that I know now about breast cancer is probably from me doing my own research possibly. If that makes sense. What does my ER/PR+, HER2-negative-- At first, I'm like, well, what's that mean? That's me googling. What does ER/PR+ mean? What does HER2-negative mean? What does all these different, I guess the whole glossary terminology of what. That was me doing that myself. Participant 009_2021AUHRP

Participant describes accessing information from a specific health charity

At the prompting of BreastScreen LOCATION, they told me I should register with BCNA, and so I did that and I found that with a good resource. I also looked through information on reputable sites, reading studies and general information, whether they be Australian, British, American. I knew it was important to make sure it was coming from a well researched -- and I also find it interesting to read the stories of other women, of what they'd experienced and how they access things and what have you. Participant 019_2021AUHRP

Over time, I've found two or three websites that are my go to, so BCNA, the UK breast cancer site and the US breast cancer site. Those tend to be the ones that I will-- The websites that I look at for different things. I've looked up things like types of surgery, risk of lymphedema, side effects of chemo, side effects of radiation, long-term side effects of radiation, short-term side effects, recurrence, risk information, and signs and symptoms of recurrence and metastases, [silence] side effects of hormone therapy. These days as a side effect of hormone therapy, I'm osteopenic. I'm on Prolia, so, looking up different things about that. Participant 023_2021AUHRP

Just mostly about information on on treatment for young women and a lot of stuff about that mental health support and about post tamoxifen inflammation, mostly what I accessed, I went across to Melbourne for conference at the Breast Cancer Network that was pretty good. But yeah, that's really pretty much it. Okay. I tried not to research stuff like, yeah, beyond the extra little bit of support. Because it is like, it's just, it's such a rabbit warren of information that can be read so many different ways. And, you know, I growl at my patients when they Dr. Google stuff, so I've sort of really tried really hard not to be, to follow that path, even though sometimes you just can't help yourself. I have, like, when I was going through treatment, you know, you hear people talking about, oh, you know, will my white cell count was this my neutrophils was that. I purposely didn't sound mine out. Yeah. Cuz I was like, if I need to know, and they're worried about something, you know, they'll tell me. Okay. Participant 033_2021AUHRP

Participant describes primarily accessing information through other patient's experience

So there was just an ad in the paper for the annual sort of fundraiser luncheon in October. And I just went on for the first time, I didn't actually ring you know, and find out what it's about, I just turned up because I just thought that people be standing around for an hour or two, you know, maybe having some nibblies. And when it was a sit down, luncheon, and everyone was in pink, and I turned up in pants and a gray shirt. And was a bit overwhelmed, then I just straightaway obviously knew I was yeah, not, not not Yeah, newbie. And they came up and took me under their wings and had a cry, and yeah, set me down. Yeah. And then and then from then on, like I am still friends with some of them, you know, they just so from them, it was more like than the word of mouth sort of stuff. And that's gold, and you can't, you know, you can't put a price on that. Because they're the people that let me know about the the care plans, you know, the old chronic disease management plans, and things like that, that you didn't know about and what oh, I didn't know about that. And like no that in support, you know, we'd have because I wasn't working, I was going through all my treatment and stuff that has, you know, lunches once a month and have little dress ups and we'd bring a plate each and, and then with all the social things in between. And so, yeah, that was a wealth of information from that group.

Participant 013_2021AUHRP

The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. I get my information from what I consider reputable sources. I'd rather get them from people who know what they're talking about rather than the hearsay.

Participant 037_2021AUHRP

I had a friend who put me in contact with the charity Pink Finns. They've given me a lot of support on a holistic level just with information, support packages, financial support, emotional support, support for the family, support group, just everything. They've really supported me a lot throughout the year. Then, I've also looked at all the support online from Breast Cancer Foundation, Cancer Council, McGraw Foundation, all that stuff. Obviously, looked at all the information from that. I only ever really looked at

reputable sites and then just people's accounts of things, someone shared their experience, I didn't really go looking at random stuff that wasn't reputable. Then I just took people's experiences also with a grain of salt, knowing that everyone's different in how they respond and react. To me, knowledge is power. If I had the information there, then I could adapt it to fit me.

Participant 042_2021AUHRP

Participant describes receiving information from books, pamphlets and newsletters

Well, I've just read the little books that I was sent home with that I got from BreastScreen.

Participant 015_2021AUHRP

I got an information pack at the hospital, from the nurses, before radiation started. There was about seven or eight booklets in it, so it discussed things like your carers, what they go through, and it discussed nutrition, and then just discussed the chemo and the radiation. I read through that. I found that I joined at the Jacaranda Lodge, and I think If COVID hadn't been in it, it would be better. COVID came and it stopped people from meeting face to face. It was done over Zoom, which was fine. I've done that a couple of times, and it was fine. It's good when you go to the hospital and you meet other women who are going through it as well.

Participant 032_2021AUHRP

I had all the information, like the pamphlets and all of those things from Breast Screen. I also got given some more, when I went for the chemotherapy. Then I didn't actually really, like I said, I didn't Google anything, look online, or do any of that stuff. That was it.

Participant 050_2021AUHRP

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

Then, and they had several meetings as well. So they did kind of everything, socialize formal meetings with guest speakers. Then there's also things like the encore program, YWCA encore programs, where that they had guest speakers and people who provided knowledge and information and that we had that exercise Yeah, just simply paying for hospitals and then, things like particular in terms of websites that I've learned, you know, the BCNA in particular have fantastic information, once was sort of put onto them in the first getting the, what they call like the care package was in them send you out a diary and this and that and we can track things that you're going through and lots of good information, lots of good fact sheets about pathology and lymphodema and, and

the care plans. And I found, particularly the bcna to be a lot and Cancer Council, website and booklets and things to be the main go to as incredible and what I needed. And then also Facebook pages that like close Facebook page through bcna, with different the different groups there, which I'm not really on anymore. But at the time, I found it quite helpful. Participant 013_2021AUHRP

I've sought out information on the surgery and its side effects. I've sought information on whether to have a lumpectomy or mastectomy, sought information all about radiation, looked into that. Talked to other women on the breast, on the MyJourney site, I joined that. Talked to other women that had undergone it, just to put my mind at ease about having radiation, looked up everything I could about the hormone drug. Did a lot of research on what to use to stop my skin burning in radiation. Again, I talked to the girls that had already been through all this and they're on MyJourney, what is it like? It's a chat site through the MyJourney thing and you can talk to other girls about everything really, so that's been really helpful. The internet's been really helpful but I've stuck to all the profit.org cancer sites. I haven't looked at-- I ignore the websites that I don't feel look legitimate or real. What else did I look up? I read a lot about chemotherapy and looked all that up before I made my choice, did a lot of reading. A lot of research on practically everything that I had to undergo, I researched it before I gave a yes or no, I went ahead with whatever it was. Participant 035_2021AUHRP

Dr. Google, a lot. [laughs] A lot. I've also, spent a lot of time on Facebook forums, specifically closed ones for stage four breast cancer patients. There's one that's Australia and New Zealand-based. There's one that's international. I've more recently joined one for the older patients and one that's for stage four liver mets-- Breast cancer with liver Mets. Mums with stage four breast cancer, so a fair few different forums. I've got a brain trust of real time experience. That's been really useful. Google's been good. I've been tapping into things like PubMed and the like. The breast care nurse is terrific as well. My oncologist has just wealth of knowledge, and she gives me a lot of times, but I obviously, you don't have them on tap. The breast care nurse has been really great in terms of filling out some information that I think of later on. Participant 051_2021AUHRP

Participant describes receiving information through nursing staff

The hospital provides you with information, seminar type of things. When you first get diagnosed, they sit down with you and talk with you. The breast care nurses are very helpful. Through my dragon boating clubs, dragons of breast, I got information through them. The breast cancer network online. I've accessed a lot of those. I've done a lot of Google researches myself to ask questions. Talking to other people, other cancer survivors, and also Facebook groups have been very helpful. Participant 018_2021AUHRP

You get overwhelmed with it when you first get diagnosed. You get all your information and then you get bombarded by the Breast Care Network. I didn't actually read a lot of it. Does that make me bad? I don't know. If I wanted to look up something I'd look it up on the web or on the books they'd given me or pamphlets or whatever. Or I'd ask the breast care nurse. Participant 024_2021AUHRP

The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. Participant 037_2021AUHRP

Participant describes primarily accessing information through treating clinician

The breast cancer nurse put me on to The Breast Cancer Association, BCNA I want to say. Yes. That was a useful source of information. I had information from my specialist. I did a bit of Googling and I also have access to things like Medline databases, but I tried not to do that too much. Participant 011_2021AUHRP

Dr. Google. Probably just talking to the surgeon or the radiation oncologist or the oncologist. I think of things and make a list to ask them so I don't forget. I'm on a Facebook support group. Participant 014_2021AUHRP

A lot online. Now I know you've got to be very careful about the sources you go to. But there's been a lot through breast cancer network Australia. Just information that I was given through my health providers also tried to look at various PubMed studies. Which, you know, then I discussed with the oncologist. I was happy to ask my oncologist. And I knew that he knew what he was talking about. I guess there's

reading books, or the cancer survivors, and then links then to, you know, things, I guess, groups through social media, other people going through the same things, their stories, what they've tried. Participant 034_2021AUHRP

Participant describes accessing information primarily through journals (research articles)

Okay, um, let's start at the beginning when I was told I had a Phyllodes tumour, the registrar at the hospital who told me wrote down cystosarcoma Phyllodes tumour on a Post-it note, gave it to me and said, that's what you've got. So that is all the information I was given. Everything I have found out about Phyllodes tumours since then, I've done off my own bat. And it's reading research studies, John Hopkins, Mayo Clinic, stuff in The Lancet. So peer reviewed medical journals is where I've been getting most of my information from and also, and also speaking to other women with the same problem. Participant 003_2021AUHRP

Look, mainly I guess internet, only looking things up on the internet, going into certain journals, Lancet

journals. Seeing new studies that are being done, studies that have been done around the world, particularly in regards to tamoxifen and letrozole. Case studies they've done and different groups they've done and the outcome of someone taking this every day versus someone taking it every second day to someone just taking it once a week, what were the outcomes. That's quite interesting. Not much difference which I was quite surprised. Participant 038_2021AUHRP

Well, I pretty much read everything on the internet, and the breast cancer people gave you a lot of books and templates and things. Some of them were a bit out of date. Then because I can get access to some of the medical journals and stuff, the Lancet and things like that, so I can read up specific articles in Google Scholar and things. I can get medical journal articles, and so could have looked at some of them. A lot of it, that stuff was not actually particularly helpful. Then books and blogs and stuff. I've got to the point where I don't really read much anymore. A lot of it is about the same so a bit repetitive. Participant 036_2021AUHRP

Table 6.1: Access to information.

Access to information	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes accessing information through the internet in general	40	76.92	15	78.95	16	76.19	9	75.00	20	68.97	20	86.96	15	78.95	25	75.76
Participant describes accessing information from a specific health charity	29	55.77	9	47.37	14	66.67	6	50.00	14	48.28	15	65.22	12	63.16	17	51.52
Participant describes primarily accessing information through other patient's experience	24	46.15	10	52.63	10	47.62	4	33.33	10	34.48	14	60.87	10	52.63	14	42.42
Participant describes receiving information from books, pamphlets and newsletters	21	40.38	10	52.63	7	33.33	4	33.33	12	41.38	9	39.13	7	36.84	14	42.42
Participant describes accessing information primarily through Facebook and/or social media	17	32.69	9	47.37	4	19.05	4	33.33	8	27.59	9	39.13	7	36.84	10	30.30
Participant describes receiving information through nursing staff	17	32.69	6	31.58	6	28.57	5	41.67	7	24.14	10	43.48	7	36.84	10	30.30
Participant describes primarily accessing information through treating clinician	14	26.92	6	31.58	4	19.05	4	33.33	7	24.14	7	30.43	5	26.32	9	27.27
Participant describes accessing information primarily through journals (research articles)	13	25.00	6	31.58	5	23.81	2	16.67	6	20.69	7	30.43	3	15.79	10	30.30

Access to information	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes accessing information through the internet in general	40	76.92	9	90.00	14	87.50	17	65.38	7	63.64	33	80.49	14	77.78	26	76.47
Participant describes accessing information from a specific health charity	29	55.77	8	80.00	10	62.50	11	42.31	8	72.73	21	51.22	10	55.56	19	55.88
Participant describes primarily accessing information through other patient's experience	24	46.15	6	60.00	8	50.00	10	38.46	6	54.55	18	43.90	9	50.00	15	44.12
Participant describes receiving information from books, pamphlets and newsletters	21	40.38	3	30.00	7	43.75	11	42.31	7	63.64	14	34.15	9	50.00	12	35.29
Participant describes accessing information primarily through Facebook and/or social media	17	32.69	4	40.00	6	37.50	7	26.92	4	36.36	13	31.71	8	44.44	9	26.47
Participant describes receiving information through nursing staff	17	32.69	3	30.00	3	18.75	11	42.31	4	36.36	13	31.71	4	22.22	13	38.24
Participant describes primarily accessing information through treating clinician	14	26.92	0	0.00	4	25.00	10	38.46	3	27.27	11	26.83	3	16.67	11	32.35
Participant describes accessing information primarily through journals (research articles)	13	25.00	3	30.00	5	31.25	5	19.23	3	27.27	10	24.39	6	33.33	7	20.59

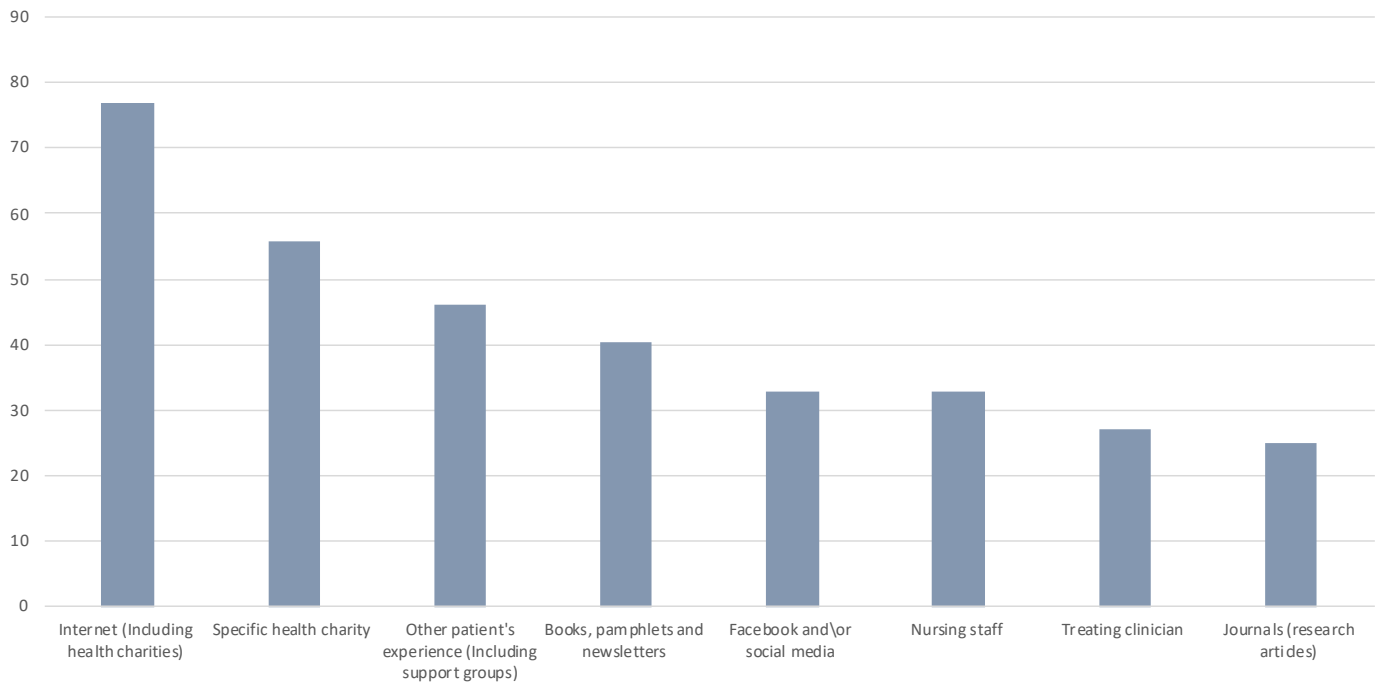


Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Diagnosed in 2020 or 2021 Regional or remote Mid to low status	Diagnosed in 2017 to 2019 Metropolitan
Participant describes accessing information from a specific health charity	Diagnosed in 2020 or 2021 Regional or remote Mid to low status	Diagnosed in 2017 to 2019 Higher status
Participant describes primarily accessing information through other patient's experience	Regional or remote	Aged 55 to 74
Participant describes receiving information from books, pamphlets and newsletters	Stage II Diagnosed in 2016 or before Regional or remote Mid to low status	Stage 0 and I Diagnosed in 2017 to 2019
Participant describes accessing information primarily through Facebook and/or social media	Stage II Regional or remote	Stage 0 and I Diagnosed in 2017 to 2019
Participant describes receiving information through nursing staff	Regional or remote Mid to low status	Stage III and IV Higher status
Participant describes primarily accessing information through treating clinician	Diagnosed in 2016 or before Regional or remote Mid to low status	Stage III and IV
Participant describes accessing information primarily through journals (research articles)		Diagnosed in 2017 to 2019

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 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and information that is specific to their condition and sub-types (n=5, 9.62%).

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

I guess knowing what's going to happen to me as I went through chemo and then radiation. Knowing what to expect. Participant 039_2021AUHRP

Whilst I was going through chemo, the most helpful information I received was from people who'd been through it before, what to expect, what sort of things ease the symptoms. Same with radiation, talking to people who'd been through it and getting information on the things that they do use to reduce the side effects and to get through it. Day-to-day, probably more my oncologist and the information that he

provides me around the expected side effects of the Tamoxifen and how I counteract those and what sort of things will reduce the impacts or reduce the likelihood of the cancer coming back. Participant 037_2021AUHRP

A lot of it was just kind of more under like, you know, the information that gave us an understanding of what to expect and what the process was, you know, from, from where you were, what was the next step? And the step after that so far, so you knew where you're heading and that sort of stuff? Participant 020_2021AUHRP

Participant describes talking to their doctor or specialist as helpful

Probably having it explained to me exactly what the pathology actually meant. That was explained very well to say that the grade of the tumor and how fast it's growing and know what the implications are for having hormone-positive breast cancer as opposed to the negative one. That sort of thing was very helpful from the breast care nurse and the doctor and the oncologist even. They explained things very well. Participant 017_2021AUHRP

I would say actually talking to the oncologists, because I think the stuff that's given to me I think, because I already have medical knowledge it's written for people really with no medical knowledge and it's very thorough, but I know all that stuff. So yeah, so I although it's been good to have it and read it and go yep, yep, yep, yep. Yep, that's what I kind of knew. I haven't found it sort of particularly eye opening or useful. Participant 034_2021AUHRP

Probably the information that, as it's explained to me, either by the doctors or nursing staff, rather than reading it. They're able to provide it in a way that's more interactive, and I can ask follow up questions and things like that. Participant 050_2021AUHRP

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

Actually, I was going to support groups on Facebook and I found that more helpful to me than anything else. It's nice to actually speak to people that were going through it. Whilst, for instance, each breast cancer's obviously different but there are some that are similar and I found that the most helpful, to be honest, than any information written down. Participant 008_2021AUHRP

Honestly, I think a lot of the information that's been best for me is validation of some of my ailments if you like. That no, I'm not the only one that has this, despite the doctor saying, oh, that's not normal. Especially the breast cancer sites on Facebook and through the networks. You talk to other women who are on the same protocols and they'll go, oh yes, I've got that. It's like, "Okay, it's not just me. I'm not being difficult." This is a standard, the joint ache, the lack of being able to sleep, the insomnia is just crazy. All those things are normal. They're all going, "Yes, we've all got that. You're not weird. We're all doing this and this is what we try to do to deal with it." I think it's more about validation than anything else. Participant 018_2021AUHRP

Whilst I was going through chemo, the most helpful information I received was from people who'd been through it before, what to expect, what sort of things ease the symptoms. Same with radiation, talking to people who'd been through it and getting information on the things that they do use to reduce the side effects and to get through it. Day-to-day, probably more my oncologist and the information that he provides me around the expected side effects of the Tamoxifen and how I counteract those and what sort of things will reduce the impacts or reduce the likelihood of the cancer coming back. Participant 037_2021AUHRP

Participant describes health charities information as helpful

The cancer council booklet that I got was good. It was basic. It was to the point and you didn't have to be a rocket scientist to understand it. Actually, that had a glossary in the back of it of terms and wording that might be used and what does it mean. That was probably quite helpful. I don't know. I think it's difficult when you're sitting in front of somebody when you're dealing with. I'd write down questions because I know I'd forget. Sometimes that's why it's good to have somebody else with you because they'll remember things that you don't remember to actually record the conversation. You walk out of there with so much information, so much new information and things that you didn't know anything about before that you think, "Oh, what did he say? Did he say this? Or did he say that? Or did you mean this or did you mean?" Participant 009_2021AUHRP

What's been the most helpful? Yeah, in terms of going through myself, the BCNA fact sheets and booklets. Because you know the pathology gets your pathology, and it's like, you know, reading something in

Japanese, and they don't really I've got some results that they didn't really explain it in detail, or they might have mentioned things. And because you're basically you're in shock. And so you're not absorbing everything because you're still kind of behind on what they just told you. And so even this year, that's the pathology factsheet things that lymphoedema. Like I said, care plans. Fertility, because I'm a young information, hotline that you can ring, you know, they got counselors, they give you financial advice. And then like cancer council for that other more general broader, broader issues, about cancer and things in your community that might help. You know, they've got lots of health and well being things you can do courses, online webinars, all that sort of things. Participant 013_2021AUHRP

It actually depends on what treatment stage I was at. Sometimes, for me, I like- because I've dealt with so many, I felt there's so many different components and it can be so overwhelming that the way I hoped was only just concentrating on if it was my surgery, I'm only looking at the surgery. I'm not even thinking about chemo. I'm not even thinking about radiotherapy. I was just getting to that mindset first. A lot of it, especially like at the start, when they were looking for the diagnosis. The Breast Care Association and so my journey just books, I found a booklet there that I could flip through, look at it, write it. Now, I think they've got an online tool too, but it just asks lots of questions. From that, then I would try and find information. It'd be disadvantages of having a deep surgery compared with having an implant and those types of things. Whether I wanted to have an immediate. There's so many smaller decisions to

make. Whether I wanted an immediate reconstruction or wait till later on. I guess I found that is the basis for that book. That would give me some knowledge that I could ask my health professionals to go from there. Participant 021_2021AUHRP

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

I think it's just the way that-- I'm trying to think, really. How it happens. It's a hormonal one, now I understand what it means. Just the type of cancer it is. I don't know if it's hormonal. Then I need to stay away from things that have high-concentration of progesterone. That kind of information that there was so much information as well so just be careful on what you see sometimes or you just get overwhelmed with it. Participant 040_2021AUHRP

The most helpful was looking at whether or not I should have radiation for the DCIS. Cause with DCIS many women have it, they don't know it. And they die with it, even without ever knowing where head it. And a lot of women with DCIS is over treated. And and, and so that's why I was hesitant in having it that the oncologist gave me the stats that say, Okay, if you don't have it, you've got a 20% chance of coming back. If you have radiation, it's less than 5%. And so in the end had to go with the evidence. And there are international studies, where longitudinal studies where they're tracking women who are not having treatments to try and work out whose DCIS takes off and becomes invasive and who doesn't. And the it's not out yet, they don't know yet. Participant 001_2021AUHRP

Table 6.3: Information that was helpful

Information that was helpful	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	20	38.46	7	36.84	7	33.33	6	50.00	9	31.03	11	47.83	8	42.11	12	36.36
Participant describes talking to their doctor or specialist as helpful	17	32.69	7	36.84	6	28.57	4	33.33	10	34.48	7	30.43	5	26.32	12	36.36
Participant describes other people's experiences as helpful (Peer-to-peer)	11	21.15	5	26.32	3	14.29	3	25.00	5	17.24	6	26.09	3	15.79	8	24.24
Participant describes health charities information as helpful	10	19.23	1	5.26	6	28.57	3	25.00	5	17.24	5	21.74	5	26.32	5	15.15
Participant describes information specific to their condition (and sub-types) as helpful	5	9.62	3	15.79	1	4.76	1	8.33	2	6.90	3	13.04	1	5.26	4	12.12

Information that was helpful	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	20	38.46	5	50.00	7	43.75	8	30.77	4	36.36	16	39.02	8	44.44	12	35.29
Participant describes talking to their doctor or specialist as helpful	17	32.69	4	40.00	3	18.75	10	38.46	6	54.55	11	26.83	6	33.33	11	32.35
Participant describes other people's experiences as helpful (Peer-to-peer)	11	21.15	4	40.00	3	18.75	4	15.38	3	27.27	8	19.51	5	27.78	6	17.65
Participant describes health charities information as helpful	10	19.23	2	20.00	4	25.00	4	15.38	2	18.18	8	19.51	4	22.22	6	17.65
Participant describes information specific to their condition (and sub-types) as helpful	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

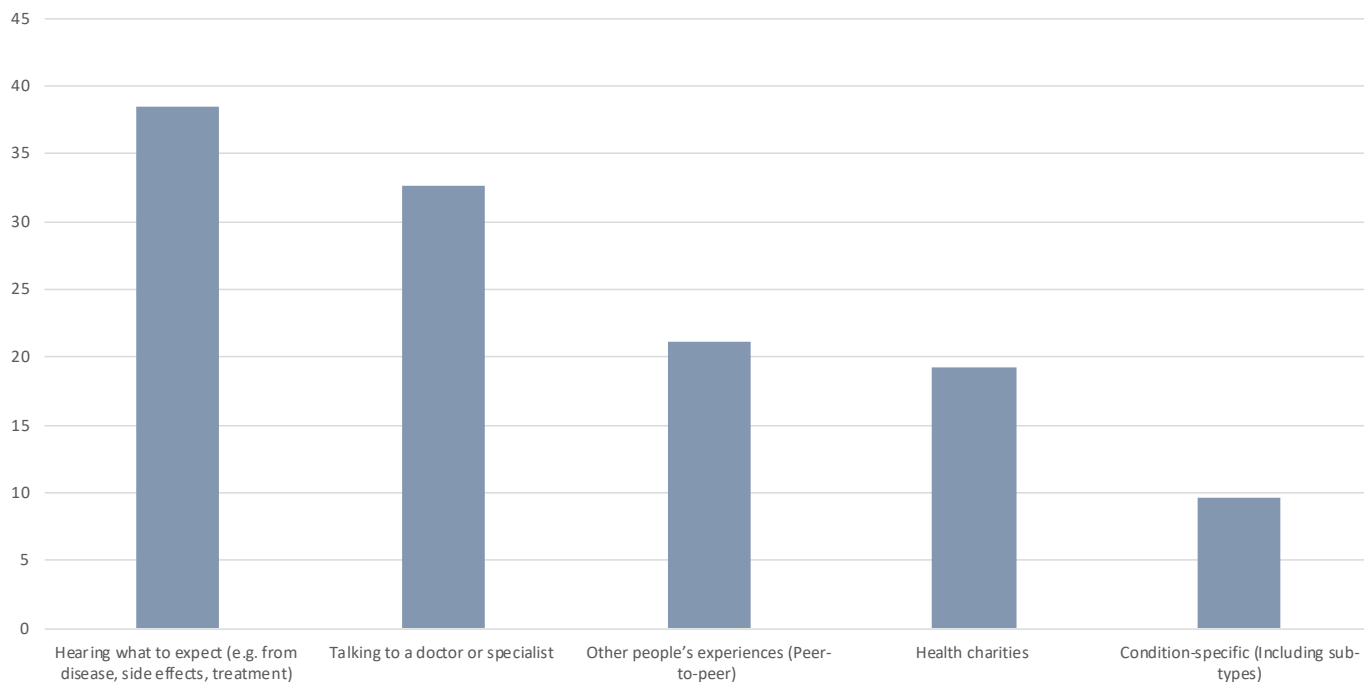


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that was helpful	Reported less frequently	Reported more frequently
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	-	Stage III and IV Diagnosed in 2016 or before
Participant describes talking to their doctor or specialist as helpful	Diagnosed in 2017 to 2019	Regional or remote
Participant describes other people's experiences as helpful (Peer-to-peer)	-	Diagnosed in 2016 or before
Participant describes health charities information as helpful	Stage 0 and I	-

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 19 participants (36.54%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 13 participants (25.00%) was other people's experiences. There were eight participants (15.38%) that described other people giving advice or opinions as unhelpful, and the same number that described worst case scenarios and negative information as unhelpful (n=8, 15.38%). Other participants described information from their GP or specialist as unhelpful (n=7, 13.46%), and information from sources that are not credible as not helpful (not evidence-based) (n=6, 11.54%).

Participant describes no information being not helpful

Not as far as information...not really. Nothing unhelpful, no. Participant 017_2021AUHRP

Not really, like I mean, we were we were given a lot of information at appointments and stuff like that. It

was relevant to what was being discussed, but it wasn't necessarily something that I research further on or something like that. Participant 020_2021AUHRP

Unhelpful? No, no, never been unhelpful. Participant 035_2021AUHRP

Participant describes other people's experiences as being not helpful

They run forums and then you get people constantly saying, "Oh, that made me so sick," or, "That made me," this or that. It's like, "You know, I don't really need to hear all that. I'm just going to go [unintelligible 00:31:42]." I think it can put ideas into your head. There's a medication and I have two injections a year called Prolia for osteoporosis. If you actually go online and read reviews about it, you'd never touch it. You never go within cooe of it because of the side effects. People have just gone on, "Oh, it's killed me," and blah, blah, blah, and it probably did. I gave it a shot anyway and I didn't have any side

effects. I've been on it for two years now. That was an example of going, "Okay, well just don't go onto forums because I don't think that's helpful." Participant 038_2021AUHRP

I will say, like some of the Facebook pages, some of them have been really helpful. Some of them have been very unhelpful as well, just because the people that you get on there, you obviously get some people who are less than helpful. Generally, I'd stay away from undocumented and unsupported sites. It's just not the sort of place that I would go to, to look for information. Participant 037_2021AUHRP

Yes, that Facebook group I joined. So many people had stopped their treatment and they knew this and they were trying this and all these natural things and I thought, "I'm getting out of here." Participant 006_2021AUHRP

Participant describes other people giving their advice or opinions as being not helpful

A lot of people would try and help you with suggestions to different alternative therapy. There are people that try and be supportive by telling you to be positive. Yes, positive energy, it'll make a difference. Yes, it might make a difference emotionally but it's not going to make a difference to the way I respond to my treatment and I guess, in terms of not making...It is sometimes hard to-- Also reading things that are out of date and a lot of what's online is still a few years old these days and a lot of stuff that is freely available. Participant 023_2021AUHRP

The doctors. You probably do way too much reading online in the beginning, and people say don't Google, but you're going to Google. I tend to once I've read things, I can generally discard what I think is stupid information, the stuff that goes, "You're all right, you've got cancer but you need to go, and just going use CBD oil and never see your doctor again." Or, "You just go and don't have any treatment or you become a vegan." Do you know how many times I've been told if I become a vegan, I'd never get cancer again? You've obviously heard that one before? Participant 030_2021AUHRP

"Journey, this journey." I did get upset one day and I said to a really good friend, I said, if you use that word one more time, I'm seriously going to punch you. Well, what do you mean? You're on a journey. I said journey means to me somewhere you go that you want to go, that you're enjoying. I said, "this shit storm is not a

journey." I said, there's no such thing. People that aren't dealing with it, I know they mean well but because they're not there, they throw a throwaway line. "What doesn't kill you makes you stronger." Standard crap like that, I just look can go, yes, you're [unintelligible 00:39:57]. I won't go there because they don't mean it to be unkind, so I'm not about to be mean back. As I said, I just tend to, I'm not wasting my time on that one. I'll leave it alone and I just smile and go. "Yes, okay." Because when you're not in it and you're not doing it, it is hard to relate to. I often say to people now, especially since diagnosis and treatment, when I hear of someone who's-- I've lost a couple of friends in the last 18 months. I'll visit and I'll say to them, "There isn't anything I can say so I'm not going to. I'm just going to give you a hug and tell you I love you." Because there's nothing else you can do. To me, don't say anything if it's really a waste of time to say it, just do something. Tell someone you love them, give them a hug. That means more than a whole lot of words that really don't mean anything. Participant 018_2021AUHRP

Participant describes information about worse case scenarios and negative information as being not helpful

People? Yeah. Yeah. You know, everybody knows somebody who knows somebody who Oh, my God, she died. That's not very helpful. And I had said that to a few people who you know, so yeah, so I would say most of the unhelpful information has come from the general community. Yes. Yeah. So Facebook pages or those, they're always funs aren't they? Then I joined Facebook page for Western Australian breast cancer people and lasted on that for about six months and then went Oh, no more thank you! Participant 033_2021AUHRP

I think reading all about the tamoxifen really got me very upset. There's so many people with different side effects that I actually before I even got on it was just very much like I don't want to take it. I don't want anything to do with it. I've been lucky so far but I would say the rest of it, it had to have the surgery that was no issue. The radiation was very simple for me. It was really around the tamoxifen more than anything. I felt that there's a lot of people posting their experiences which is great but a friend of mine said, people only post a negative, they don't post the positive. Participant 007_2021AUHRP

I guess other people's horror stories. Participant 050_2021AUHRP

Participant describes the GP/specialist as being not helpful

No. I think the only thing that hasn't been helpful is, when you go in for all these tests before your operation, like the sentinel node and the radiation fade, you know, just a bit of a heads up. If they say to you, "Look, this is really an uncomfortable procedure, and maybe you should have a driver with you." The truth is, it took an hour and a half to get down here, you're bawling all the way home because it feels like hell, and you just think, "A heads up would have been nice." Participant 026_2021AUHRP

I mean, probably the main thing I did was ask for, going back to the previous question, was asking for a prophylactic mastectomy and I had to fight tooth and nail for that. Surgeons were more -- and other doctors are more interested in seeing whether I would like reconstruction done, than me wanting to take the risk of a possible reoccurrence in the other breast because

they did find another fibroadenoma. In that one, again, I was not told about it. It was there for four years. And nobody bothers to tell me or my surgeon that I had another one growing in the other breast. So, the moment I found out that I had another fibroadenoma, which could turn nasty, I started fighting for getting mastectomy. Participant 003_2021AUHRP

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

Only with the local oncologist who was just unbelievable. I could not believe how negative he was. Instead of sitting down and explaining things to me as she had done he leaned back against a wall or whatever and says joking, "What do you know about this?" I mean the breast cancer. I was just absolutely gobsmacked. I said, "I thought I was here to be told." Participant 022_2021AUHRP

Table 6.5: Information that was not helpful

Information that was not helpful	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes no information being not helpful	19	36.54	7	36.84	8	38.10	4	33.33	10	34.48	9	39.13	11	57.89	8	24.24
Participant describes other people's experiences as being not helpful	13	25.00	4	21.05	6	28.57	3	25.00	9	31.03	4	17.39	5	26.32	8	24.24
Participant describes other people giving their advice or opinions as being not helpful	8	15.38	2	10.53	4	19.05	2	16.67	3	10.34	5	21.74	3	15.79	5	15.15
Participant describes information about worse case scenarios and negative information as being not helpful	8	15.38	3	15.79	3	14.29	2	16.67	4	13.79	4	17.39	3	15.79	5	15.15
Participant describes the GP/specialist as being not helpful	7	13.46	3	15.79	2	9.52	2	16.67	2	6.90	5	21.74	1	5.26	6	18.18
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	11.54	2	10.53	2	9.52	2	16.67	2	6.90	4	17.39	0	0.00	6	18.18

Information that was not helpful	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes no information being not helpful	19	36.54	3	30.00	7	43.75	9	34.62	4	36.36	15	36.59	5	27.78	14	41.18
Participant describes other people's experiences as being not helpful	13	25.00	3	30.00	6	37.50	4	15.38	4	36.36	9	21.95	7	38.89	6	17.65
Participant describes other people giving their advice or opinions as being not helpful	8	15.38	2	20.00	0	0.00	6	23.08	1	9.09	7	17.07	0	0.00	8	23.53
Participant describes information about worse case scenarios and negative information as being not helpful	8	15.38	1	10.00	2	12.50	5	19.23	4	36.36	4	9.76	4	22.22	4	11.76
Participant describes the GP/specialist as being not helpful	7	13.46	1	10.00	1	6.25	5	19.23	2	18.18	5	12.20	0	0.00	7	20.59
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	11.54	1	10.00	3	18.75	2	7.69	1	9.09	5	12.20	3	16.67	3	8.82

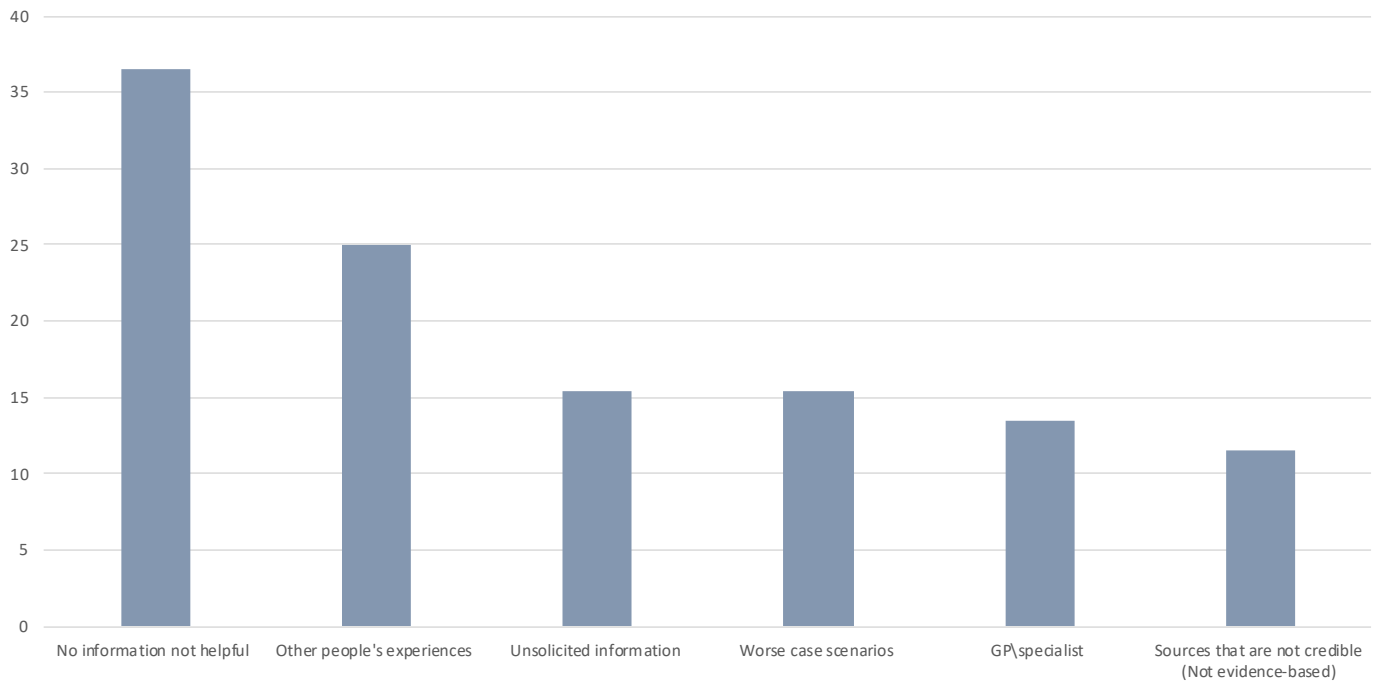


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that was not helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	University	Trade or high school
Participant describes other people's experiences as being not helpful	-	Diagnosed in 2017 to 2019 Regional or remote Mid to low status
Participant describes other people giving their advice or opinions as being not helpful	Diagnosed in 2017 to 2019 Mid to low status	-
Participant describes information about worse case scenarios and negative information as being not helpful	-	Regional or remote
Participant describes the GP/specialist as being not helpful	Mid to low status	-
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Trade or high school	-

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, most participants had a preference for a combination of information sources (n=44, 8.63%), all of these combinations included online information. There were five participants (9.62%) only had a preference for talking to someone, and four participants (7.69%) only had a preference for written (booklets). Participants commonly had a preference for talking to someone plus a written form of information (either app, internet or booklet) (n=33, 63.47%), and a total of 15 participants (n=15, 28.84%) that had a preference for information in the written form only (either app, internet or booklet).

The main reasons for a preference for online information were accessibility, and being able to digest information at their own pace. The main reason for talking to someone as a preference was being able to ask questions, and getting information that was relevant or personalised.

Participant describes a preference for online information

I think online simply because it's right there right when you want it. There'll be times I'd be sitting in my living room and a question would pop in my head. You just walk back and you google it on the computer. Instantaneous information. Participant 007_2021AUHRP

Maybe the online information would be a preference because I said, "Go back and read over it." Read it again and evaluate things from it where if I was talking to somebody on things being personal, I might forget what- or not take in all the information that, like I said, actually maybe ask questions and make sure-- You don't always do- I don't think you always do that. Participant 009_2021AUHRP

Online because it's immediate gratification when you are worried about something, but I'm still old school

and I do like books and booklets. It would be nice to talk to someone, but I don't know who to contact. I'd say that would probably be my first. Well, maybe, first and foremost, online, and then to be able to access to talk to someone. Participant 012_2021AUHRP

Participant describes a preference for booklets/pamphlets/newsletters

I am happy with any sort of information. I'm an avid reader, so yeah booklets or online stuff doesn't bother me. I research that way quite a lot. Talking to other people also helps. So I don't have a preferred method of information. Just information in general in any way, shape or form is good. Yeah. Participant 003_2021AUHRP

Maybe the booklets, because you can pick them up at any time and have a look, and then go back and check something. and have a look, and then go back and check something. Participant 015_2021AUHRP

I don't know, I quite like getting handouts because I can go back to them and reread them rather than searching the internet. It's probably not a good idea for me to search the internet all the time anyhow, you only find out a lot of negative stuff there. Yes, I quite like it when they give you the handouts, the pamphlets. They're very helpful. Participant 017_2021AUHRP

Participant describes a preference for talking to someone

I think talking to someone is probably the best because that you can ask the questions in that information tailored for you. But then having obviously, because you've got so much you might want to find out about having some online resources are always really useful, because then you can obviously follow up on any leads. And I mean, I'm lucky that I've got the ability to do a PubMed search and look at a journal article and understand what studies. So you know, that's obviously going straight to the evidence myself, and I'm more than happy to read a review article as well. And, and have that

evidence summarize. So yeah, so online to me and like in person best, but then some resources online, I can follow up on. Participant 034_2021AUHRP

Certainly, talking to the specialist and the information they gave. Then I did find the network good for some general information. Participant 011_2021AUHRP

I prefer when it comes to my own treatment anyways, face to face. So that when you're processing it, you can ask a question directly and get a response. That's just my personal, and I think that's a generational thing. Participant 018_2021AUHRP

Participant describes a preference for phone apps

Okay, I think a combination. I like things that are written because it allows you to go back over them, and particularly when you're in those first couple of weeks of trying to sort things out. There's a lot of information going round in circles so it's nice to be able to re-read it. Whether that's online or it's an app, I think doesn't matter very much to me, it's much the same. In terms of talking to people, that's always useful but sometimes after you've actually had the opportunity to read and digest the information and then talk to a clinician afterwards. Participant 005_2021AUHRP

I'm attached to the...I like booklets, and I like to have something in my hand I can read and circle or whatever. Apps are always good as well. I think it's having the information and then having that person to talk to you about it. I think it has to be a combination. You're going to come up with questions and then having someone to talk it out and just clear our minds of whatever's going through our head at the time would be very beneficial. Because sometimes you might not see your specialist for a couple of weeks, and then it could be something that's really bothering you, and you haven't been able to get onto a breast care nurse. I loved the service, and the nurse that was working at therapy was fantastic. So many times like when I was going to go into hospital trying to call them for help, they just weren't there. No one answered, and you felt really alone and let down. Participant 048_2021AUHRP

Table 6.7: Information preferences

Information preferences	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes talking to someone plus online information as main preference	15	28.85	7	36.84	5	23.81	3	25.00	7	24.14	8	34.78	3	15.79	12	36.36
Participant describes online plus written information as main preference	10	19.23	1	5.26	7	33.33	2	16.67	6	20.69	4	17.39	5	26.32	5	15.15
Participant describes talking to someone plus online, and written information as main preference	7	13.46	4	21.05	1	4.76	2	16.67	4	13.79	3	13.04	3	15.79	4	12.12
Participant describes talking to someone as main preference	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes talking to someone plus online, and written information, plus apps as main preference	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes talking to someone plus online information as main preference	5	9.62	1	5.26	3	14.29	1	8.33	3	10.34	2	8.70	2	10.53	3	9.09
Participant describes written information as main preference	4	7.69	2	10.53	1	4.76	1	8.33	3	10.34	1	4.35	3	15.79	1	3.03
Participant describes online plus written information as main preference	1	1.92	0	0.00	0	0.00	1	8.33	1	3.45	0	0.00	0	0.00	1	3.03
Participant describes talking to someone plus online information, plus apps as main preference	1	1.92	1	5.26	0	0.00	0	0.00	0	0.00	1	4.35	1	5.26	0	0.00

Information preferences	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes talking to someone plus online information as main preference	15	28.85	3	30.00	4	25.00	8	30.77	4	36.36	11	26.83	3	16.67	12	35.29
Participant describes online plus written information as main preference	10	19.23	2	20.00	4	25.00	4	15.38	3	27.27	7	17.07	3	16.67	7	20.59
Participant describes talking to someone plus online, and written information as main preference	7	13.46	2	20.00	3	18.75	2	7.69	1	9.09	6	14.63	4	22.22	3	8.82
Participant describes talking to someone as main preference	5	9.62	1	10.00	3	18.75	1	3.85	0	0.00	5	12.20	1	5.56	4	11.76
Participant describes talking to someone plus online, and written information, plus apps as main preference	5	9.62	1	10.00	3	18.75	1	3.85	0	0.00	5	12.20	1	5.56	4	11.76
Participant describes talking to someone plus online information as main preference	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	4	22.22	1	2.94
Participant describes written information as main preference	4	7.69	0	0.00	1	6.25	3	11.54	0	0.00	4	9.76	1	5.56	3	8.82
Participant describes online plus written information as main preference	1	1.92	0	0.00	0	0.00	1	3.85	0	0.00	1	2.44	0	0.00	1	2.94
Participant describes talking to someone plus online information, plus apps as main preference	1	1.92	1	10.00	0	0.00	0	0.00	1	9.09	0	0.00	1	5.56	0	0.00

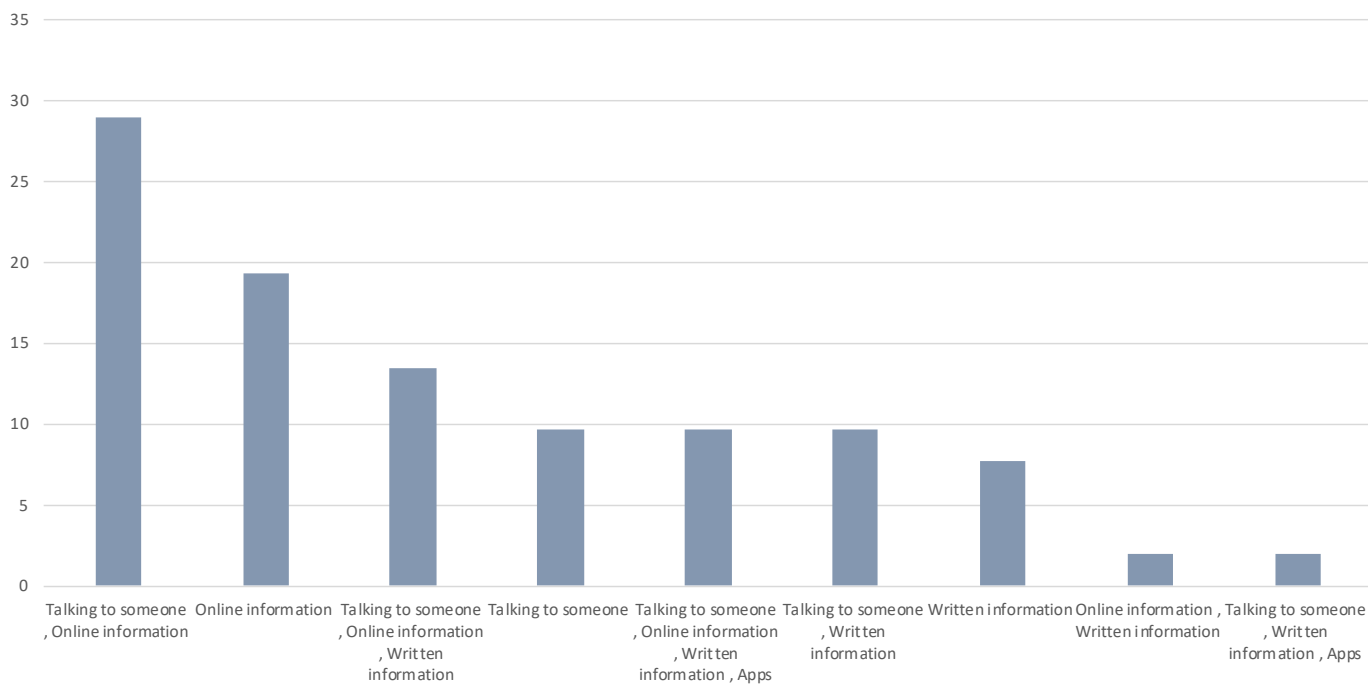


Figure 6.4: Information preferences

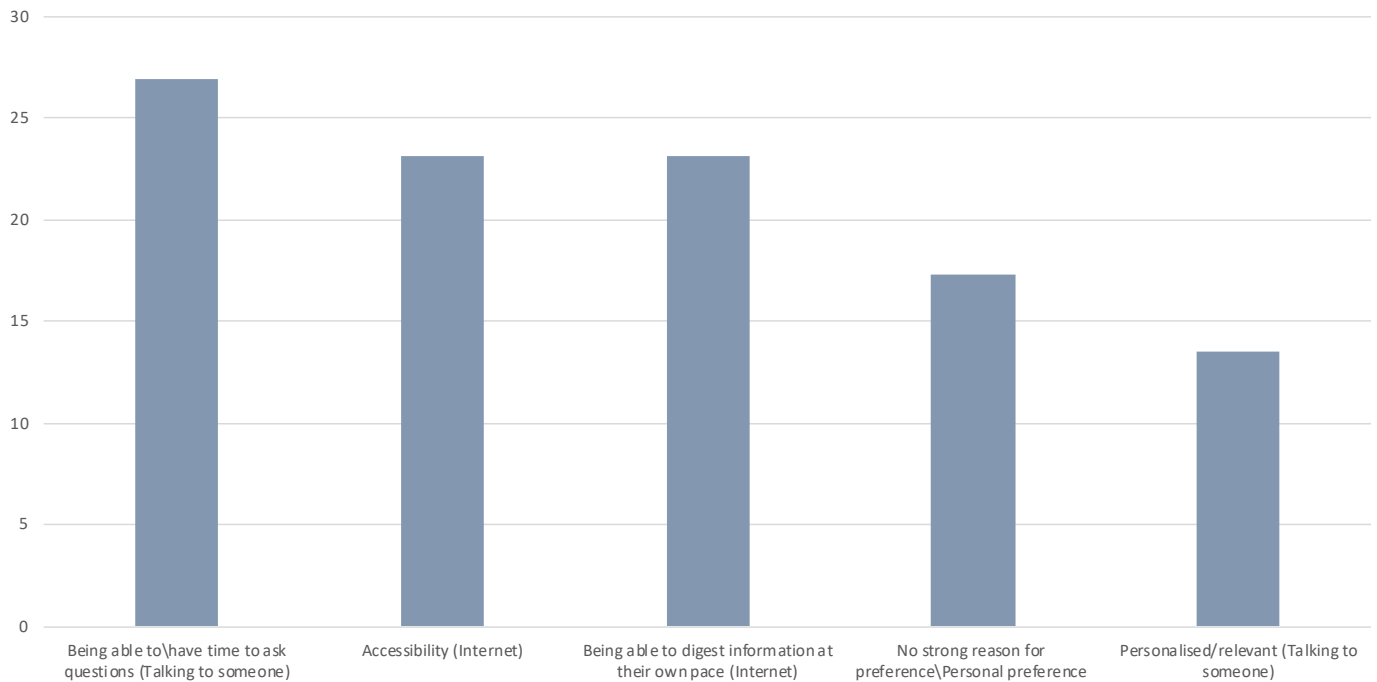


Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone plus online information as main preference	Trade or high school Mid to low status	Stage II
Participant describes online plus written information as main preference	Stage 0 and I	Stage II
Participant describes talking to someone plus online information as main preference		Mid to low status

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=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

Participant describes being receptive from the beginning (diagnosis)

Virtually straight away? I think I cried for maybe about a minute and a half when they told me. And then yeah, basically shook myself off and thought, OK, let's deal with this And that's it. That's the way I am. I don't have -- I don't think I'm more receptive to information now or then, just any information is good. Participant 003_2021AUHRP

Well, even when I first went to the breast clinic, because I'd done a lot of research on the internet and

I was reading the Cancer Council booklets and things, I thought I was pretty okay with what was going to happen, and even the nurse said, "Oh, you've done a lot of research on this as well." I said, "Yes." The signing of the paper about having the surgery and the sentinel node biopsy and then the clearance, I just think that little bit needs to be fully explained more to people. It just seemed to be brushed over when I think back, that's how I felt, it was brushed over. Participant 012_2021AUHRP

I think when I was first diagnosed, I was just soaking up everything and reading everything. I couldn't think of anything else, so I was really reading everything and searching the net, doing all of this stuff. Well, probably I still could-- That's what I do anyway. Yes, so probably at the start for me, and then as things settled down and then I was a bit more selective and able to look at things with a bit more depth and trained a bit more is what I would say. Participant 036_2021AUHRP

Participant describes being receptive to information after the shock of diagnosis

I don't really know. Well, my doctor, on the day of my diagnosis, she gave me a printout but I couldn't look at it. I wasn't ready then. Plus, it was at that stage where I just knew it was breast cancer, nothing much more. I think when I started chemo was when I was more receptive to start receiving the information. Participant 008_2021AUHRP

Um, from the start for me. So I was diagnosed on a Wednesday, and was side-swipped for the Thursday and the Friday from the shock of it and then after that I was just into research, and I don't know, we tend to go, well I did, went into this brave mode for all your family and friends that was in tears and panicking and you know, had already started my research and gone it's not that bad. It's okay, it's early it's fine. And then at the six week mark I think it's finally hit me, it's amazing. After those two days of shock, it was righto, lets do some learning. Participant 014_2021AUHRP

Oh, I guess when you when you really upset. So the initial diagnosis isn't there isn't a good time, because I know that you're just totally triggered, and you're not going to think logically. So I think probably those still, while it's quite raw, that you've had a little bit of time to process and calm down. And you're really, really got loads of questions. And you really, really need to know, I think that's probably the best time because if you leave it too long, people are going to go to the internet and find, you know, find it unhelpful, or certainly what I found, I found it extremely depressing. Participant 034_2021AUHRP

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

As I said before, I had to compartmentalize it. I was most receptive of the different information just before I was going to have the next procedure. Maybe I could finish the other stuff and then I'd go Okay, right. We've got radiotherapy. What do I need to do now? Participant 021_2021AUHRP

Pretty much all the way through because it's part of the journey. There was new information to deal with. Whether it was surgery, whether it was radiation, whether it was medication. All the way through. Participant 038_2021AUHRP

I've probably been quite receptive to receiving information the whole way through being all that, knowledge is power. Any piece of information could

be beneficial to me or, God forbid, I have contact with someone else, it could be beneficial to them. I just generally like to gather as much as I can from everywhere. Participant 042_2021AUHRP

Participant describes being receptive to information after treatment

Probably once, I'd actually had that initial surgery. And once I knew that, this was the plan, like and had, like, lost that first element of absolute fear of what was going on. Once we were on a process of I've had the surgery. And then I've had the appointment, the oncologist and I knew that okays right from this day, this is what's happening. And this is happening for this long, then I was sort of, I feel like my brain was able to slow down a little bit and take stuff in then. Yeah. Whereas when you're initially diagnosed, it's such a whirlwind of information thrown at you in a short period of time. And I guess, as well, I mean, everything that happened to me happened in really quite quick succession. Whereas I've had a couple of girls that I grew up with that got diagnosed at later date. I don't feel like there's, to me, as an outsider, I didn't feel quite as rushed. But, you know, I also had that little bit more knowledge by that point, as well, because it was like already finished treatment and stuff. So watching their journey didn't feel quite as chaotic, as I felt like mine was but yeah, it's the outside looking in thing. Participant 033_2021AUHRP

I think it's a bit overwhelming at the beginning when you get diagnosed. I think probably more after my treatment, I'd be more inclined to go, "Oh, is that what I've--" I think after the treatment is finished then I found I was looking into what I'd actually had a bit more. Does that make sense? Participant 024_2021AUHRP

PARTICIPANT: *Probably, I don't know, that's a hard one. I don't think it's-- I know I couldn't take anything in or read anything for at least a week after I was diagnosed. Following surgery, I just couldn't taste anything for maybe a week following surgery. That was probably the worst time for me, just post-diagnosis and post-surgery.*

INTERVIEWER: *After that, you can do a more effective receiving information?*

PARTICIPANT: *To contemplate reading the information and having it sink into my brain, yes. Participant 035_2021AUHRP*

Table 6.9: Timing of information

Timing of information	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being receptive from the beginning (diagnosis)	20	38.46	11	57.89	5	23.81	4	33.33	12	41.38	8	34.78	6	31.58	14	42.42
Participant describes being receptive to information after the shock of diagnosis	13	25.00	5	26.32	4	19.05	4	33.33	9	31.03	4	17.39	4	21.05	9	27.27
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	17.31	3	15.79	3	14.29	3	25.00	5	17.24	4	17.39	5	26.32	4	12.12
Participant describes being receptive to information after treatment	7	13.46	1	5.26	3	14.29	3	25.00	6	20.69	1	4.35	3	15.79	4	12.12

Timing of information	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being receptive from the beginning (diagnosis)	20	38.46	6	60.00	7	43.75	7	26.92	3	27.27	17	41.46	6	33.33	14	41.18
Participant describes being receptive to information after the shock of diagnosis	13	25.00	0	0.00	6	37.50	7	26.92	2	18.18	11	26.83	3	16.67	10	29.41
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	17.31	0	0.00	5	31.25	4	15.38	0	0.00	9	21.95	4	22.22	5	14.71
Participant describes being receptive to information after treatment	7	13.46	2	20.00	1	6.25	4	15.38	2	18.18	5	12.20	3	16.67	4	11.76

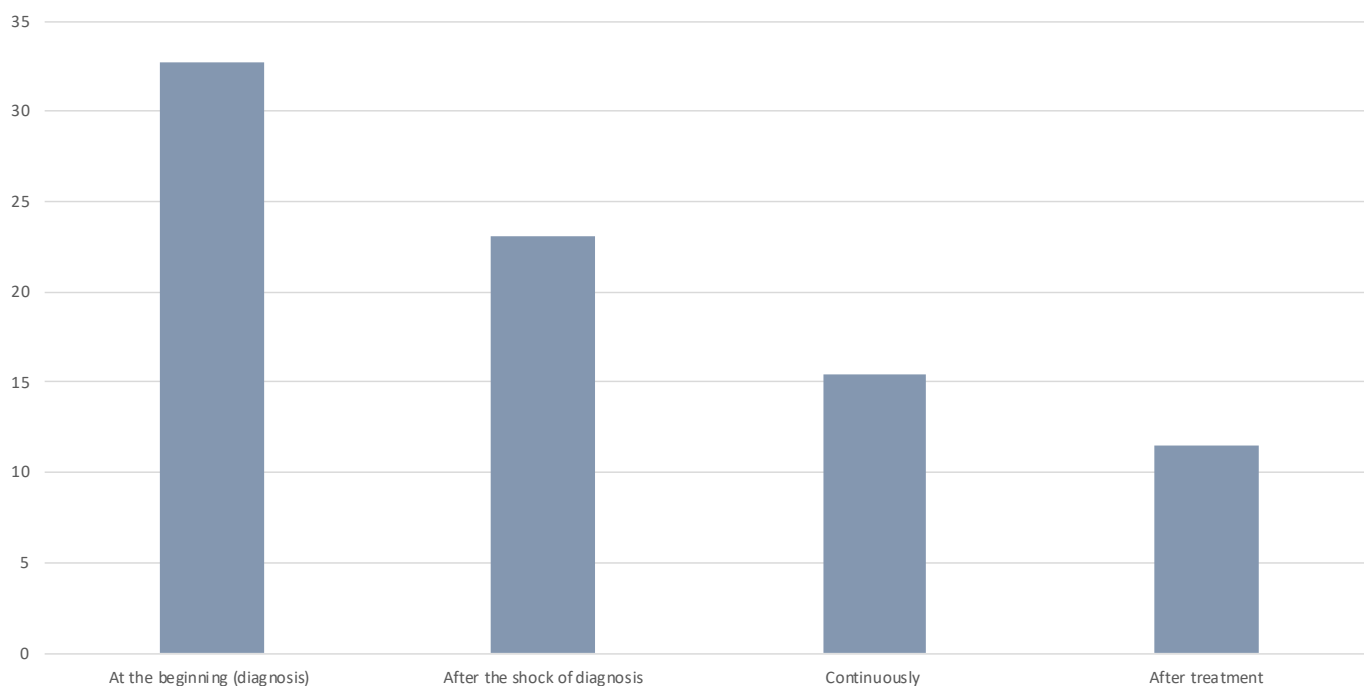


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Stage II Diagnosed in 2020 or 2021 Regional or remote	Stage 0 and I Diagnosed in 2016 or before
Participant describes being receptive to information after the shock of diagnosis	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes being receptive to information after treatment	-	Stage III and IV

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=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

Participant describes health professional communication as overall positive

Really good. I can't fault it. I feel I've been supported well. I've been given good information. I think I've been given plenty of time. Participant 051_2021AUHRP

It's been good. They've been really good. They've shared to me as much information as they can and, obviously, enlighten me to risk factors and possible side effects as best they can, and then they've, obviously, touch base with me and I've been able to share what's been happening. They've been able to help me with those issues as needed so that's been good. Participant 042_2021AUHRP

I've got a really good bunch of health care professionals that I work with. They're all very informative. Whenever I've had a question, it hasn't been like I couldn't pick up the phone and talk to them or email them and ask the questions that I've got. Participant 037_2021AUHRP

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

I think fairly good except for the initial diagnosis that didn't even come to my GP by the receptionist, which was just shocking, absolutely shocking. Overall, the information has been good. Participant 007_2021AUHRP

I've seen a lot. I wish to say that they were all of the more brilliant. A lot of them were. Some of them weren't so brilliant. Some of them, I wish they would have individualized, seeing me as an individual, not like tick the box sort of thing. Participant 021_2021AUHRP

The surgeon was really good. The oncologist was really good. I wasn't so impressed with the radiation oncologist. I've only had one blip with the oncologist, and I think she was just having a bad day. Participant 030_2021AUHRP

Participant describes health professional communication as overall negative

It's been somewhat fraught...I would not say it has been a positive experience with any of them to be honest. Participant 036_2021AUHRP

Good question. Very good question. I have found that it's not always very clear. In fact, I learned to take a good friend with me who is quite skilled at note taking and it also helping me take notes. I don't wish to be disrespectful, but a lot of times things were not very clear. I think that's probably to do with, in terms of me and lots of other patients, our lack of understanding of what's going on and how it all goes together and the pathway and that. I guess there's so much maybe information. I don't feel the communication that's particularly good. Participant 047_2021AUHRP

Well, I just feel like once I've had the surgery and the radiation, that's it, off you go, and then I've been with my GP. He's been looking after me. I don't think there's been any follow-up really that-- I beg your pardon, I've had two phone calls from a medical oncologist, but they were concerned about the numbness on my lips and tongue, but otherwise, she said when I spoke to her, "Normally we would hand you over to your doctor now, but we want to keep a check on this, so we'll have another appointment for you." Maybe I'm expecting too much or not really know what is the norm and help that people should get because I've always been healthy and not had a lot of dealings medically-wise for myself. Participant 012_2021AUHRP

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes health professional communication as overall positive	32	61.54	12	63.16	14	66.67	6	50.00	21	72.41	11	47.83	9	47.37	23	69.70
Participant describes health professional communication as overall positive, with the exception of one or two occasions	16	30.77	5	26.32	6	28.57	5	41.67	6	20.69	10	43.48	9	47.37	7	21.21
Participant describes health professional communication as overall negative	4	7.69	2	10.53	1	4.76	1	8.33	2	6.90	2	8.70	1	5.26	3	9.09
Healthcare professional communication	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes health professional communication as overall positive	32	61.54	6	60.00	11	68.75	15	57.69	6	54.55	26	63.41	11	61.11	21	61.76
Participant describes health professional communication as overall positive, with the exception of one or two occasions	16	30.77	1	10.00	4	25.00	11	42.31	4	36.36	12	29.27	5	27.78	11	32.35
Participant describes health professional communication as overall negative	4	7.69	3	30.00	1	6.25	0	0.00	1	9.09	3	7.32	2	11.11	2	5.88

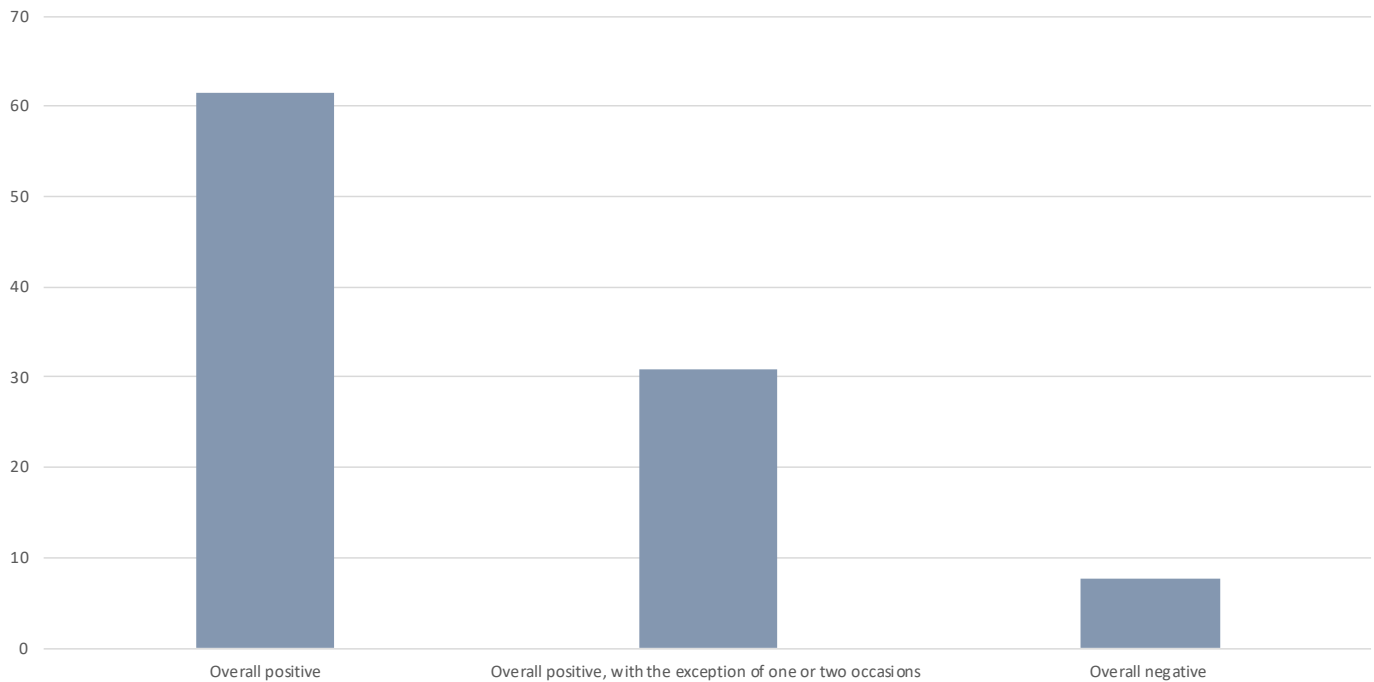


Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes health professional communication as overall positive	Stage III and IV Aged 55 to 74 Trade or high school	Aged 25 to 54
Participant describes health professional communication as overall positive, with the exception of one or two occasions	Aged 25 to 54 Diagnosed in 2016 or before	Stage III and IV Aged 55 to 74 Trade or high school Diagnosed in 2020 or 2021

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 of holistic, two-way, supportive and comprehensive conversations (n=17, 32.69%).

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

If I've had any questions, I have a breast care nurse who's standing there answering questions. I went through, I guess a holistic provider with HOSPITAL. They were very well-practiced in everything that needed to be done. I think that probably was the most helpful having people I've asked the question through. Participant 007_2021AUHRP

Pretty like I have been pretty happy with anything that any doctor that I've seen everything's been

explained in full if I had any questions you know, they'll happy to answer them whether that be during the appointment or later afterwards. I've never really had any issues in terms of that during the course of my treatment. Participant 020_2021AUHRP

My surgeon has always been really open to discussions and answering questions and to a great degree, she has been a go-to and my medical oncologist is also fabulous, in a different way. He is very good at using statistics for and against things to help with decision-making and doesn't push a decision overly in one direction. He'll gently encourage but he's not a you-must-do-this person, it's, "I suggest this because the research shows." My GP, hit and miss. Participant 023_2021AUHRP

Participant described healthcare communication as good, with no particular reason given

The specialists have been very good, each one of them from the surgeon to the oncologist and the radiotherapy. Participant 015_2021AUHRP

Participant 032_2021AUHRP

Mine has been very good. I have nothing negative there at all. Participant 017_2021AUHRP

I found the communication really good. As I said, I wouldn't do any different. It's been fantastic.

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	17	32.69	7	36.84	6	28.57	4	33.33	9	31.03	8	34.78	4	21.05	13	39.39
Participant describes healthcare communication as good, with no particular reason given	15	28.85	5	26.32	7	33.33	3	25.00	10	34.48	5	21.74	7	36.84	8	24.24
Participant describes healthcare communication as good, yet limited in understanding	4	7.69	3	15.79	1	4.76	0	0.00	1	3.45	3	13.04	2	10.53	2	6.06
Participant describes healthcare communication as good, yet limited in time	3	5.77	2	10.53	1	4.76	0	0.00	1	3.45	2	8.70	1	5.26	2	6.06
Participant describes health professional communication as limited in relation to their understanding of the condition	3	5.77	0	0.00	2	9.52	1	8.33	1	3.45	2	8.70	2	10.53	1	3.03
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	5.77	1	5.26	1	4.76	1	8.33	2	6.90	1	4.35	1	5.26	2	6.06

Healthcare professional communication (Rationale for response)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	17	32.69	3	30.00	6	37.50	8	30.77	4	36.36	13	31.71	9	50.00	8	23.53
Participant describes healthcare communication as good, with no particular reason given	15	28.85	2	20.00	3	18.75	10	38.46	4	36.36	11	26.83	4	22.22	11	32.35
Participant describes healthcare communication as good, yet limited in understanding	4	7.69	1	10.00	0	0.00	3	11.54	2	18.18	2	4.88	2	11.11	2	5.88
Participant describes healthcare communication as good, yet limited in time	3	5.77	2	20.00	1	6.25	0	0.00	1	9.09	2	4.88	1	5.56	2	5.88
Participant describes health professional communication as limited in relation to their understanding of the condition	3	5.77	2	20.00	0	0.00	1	3.85	1	9.09	2	4.88	1	5.56	2	5.88
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	5.77	0	0.00	2	12.50	1	3.85	0	0.00	3	7.32	1	5.56	2	5.88

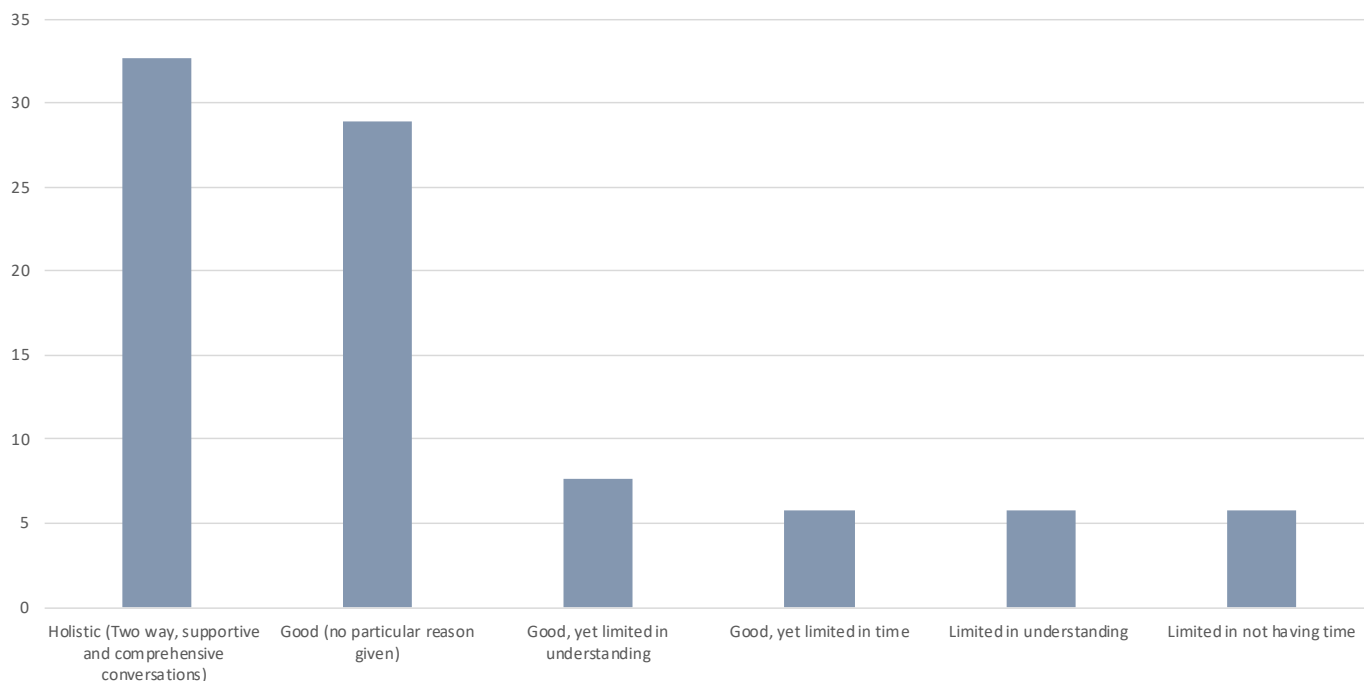


Figure 6.8: Healthcare professional communication (Rationale for response)

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

Healthcare professional communication (Rationale for response)	Reported less frequently	Reported more frequently
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Trade or high school	Mid to low status
Participant describes healthcare communication as good, with no particular reason given	Diagnosed in 2017 to 2019	

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.

Overall, the participants in this PEEK study had an average score for **Partners in health: Knowledge** (median = 29.00, IQR = 5.00), **Partners in health: Recognition and management of symptoms** (median = 21.00, IQR = 3.50), **Partners in health: Adherence to treatment** (median = 15.00, IQR = 2.00), **Partners in health: Total score** (mean = 80.86, SD = 9.38) in the highest quintile indicating very good knowledge, very good recognition and management of symptoms, and very good adherence to treatment.

The average score for the **Partners in health: coping** (median = 18.00, IQR = 9.00), was in the second highest quintile indicating good coping.

Comparisons of Partners in health have been made based on **stage** (Table 6.16, Figures 6.9 to 6.13), **age** (Tables 6.17 to 6.18, Figures 6.14 to 6.18), **education** (Tables 6.19 to 6.20, Figures 6.19 to 6.23), **year of diagnosis**, (Tables 6.21 to 6.22, Figures 6.24 to 6.28), **location** (Tables 6.23 to 6.24, Figures 6.29 to 6.33), and **socioeconomic status** (Tables 6.25 to 6.26, Figures 6.34 to 6.38).

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 very good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	28.00	3.39	29.00	5.00	0 to 32	5
Partners in health: coping	17.22	4.80	18.00	9.00	0 to 24	4
Partners in health: recognition and management of symptoms	20.71	2.85	21.00	3.50	0 to 24	5
Partners in health: adherence to treatment	14.94	1.30	15.00	2.00	0 to 16	5
Partners in health: total score*	80.86	9.38	82.00	10.00	0 to 96	5

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

Partners in health by stage

Comparisons were made by breast cancer **stage**, there were 18 participants (35.29%) with *Stage 0 and I* breast cancer, 21 participants (41.18%) with *Stage II*, and 12 participants (23.53%) with *Stage III and IV*.

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.16).

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

Table 6.16: Partners in health by stage summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	C ²	dF	p-value
Knowledge	Stage 0 and I	18	35.29	27.00	5.00	2.15	2	0.3420
	Stage II	21	41.18	29.00	5.00			
	Stage III and IV	12	23.53	28.00	3.50			
Coping	Stage 0 and I	18	35.29	18.50	8.75	2.24	2	0.3255
	Stage II	21	41.18	19.00	6.00			
	Stage III and IV	12	23.53	15.00	7.50			
Recognition and management of symptoms	Stage 0 and I	18	35.29	21.00	2.75	0.06	2	0.9708
	Stage II	21	41.18	22.00	6.00			
	Stage III and IV	12	23.53	21.50	2.25			
Adherence to treatment	Stage 0 and I	18	35.29	15.50	1.75	1.18	2	0.5543
	Stage II	21	41.18	15.00	2.00			
	Stage III and IV	12	23.53	16.00	2.00			
Total score	Stage 0 and I	18	35.29	80.50	16.00	1.08	2	0.5841
	Stage II	21	41.18	84.00	10.00			
	Stage III and IV	12	23.53	80.00	5.75			

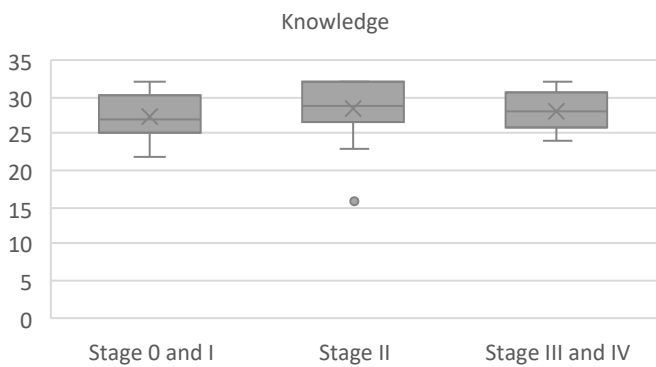


Figure 6.9: Boxplot of Partners in health: knowledge by stage

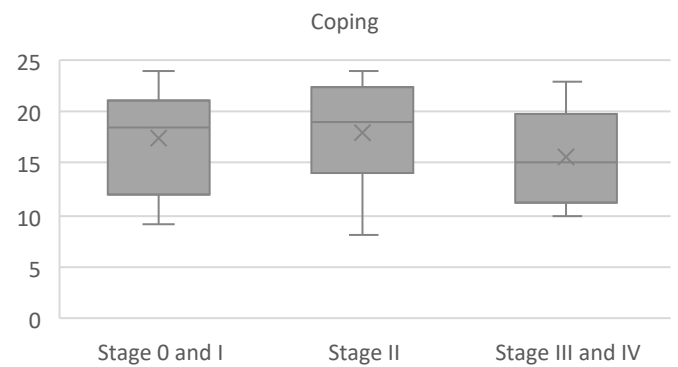


Figure 6.10: Boxplot of Partners in health: coping by stage

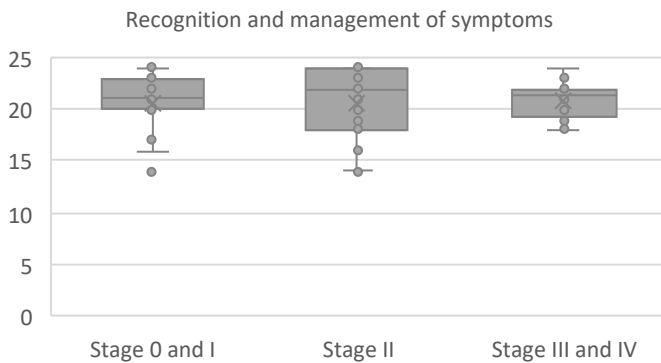


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by stage

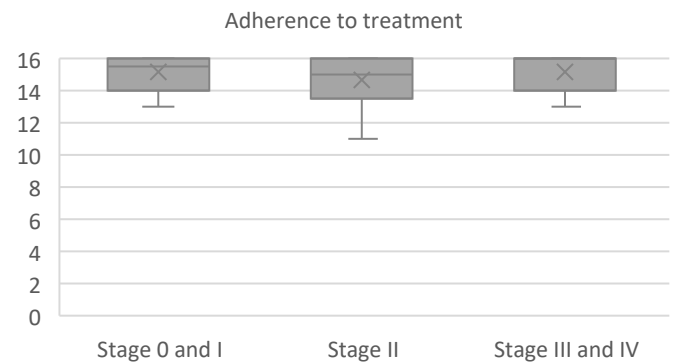


Figure 6.12: Boxplot of Partners in health: adherence to treatment by stage

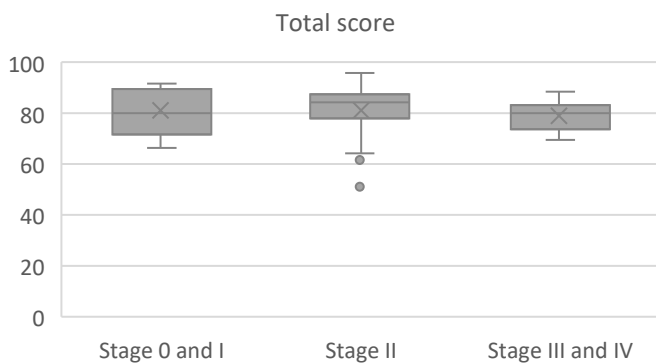


Figure 6.13: Boxplot of Partners in health Total score by stage

Partners in health by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 54* (n=29, 56.86%) and participants *Aged 55 to 74* (n=22, 43.14%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.17), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.18).

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

Table 6.17: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 54	29	56.86	79.83	9.67	-0.90	49	0.3707
	Aged 55 to 74	22	43.14	82.23	9.01			

Table 6.18: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 54	29	56.86	28.00	4.00	320.00	0.9923
	Aged 55 to 74	22	43.14	29.00	5.75		
Coping	Aged 25 to 54	29	56.86	16.00	8.00	240.00	0.1333
	Aged 55 to 74	22	43.14	19.50	5.25		
Recognition and management of symptoms	Aged 25 to 54	29	56.86	21.00	3.00	288.00	0.5574
	Aged 55 to 74	22	43.14	22.00	3.00		
Adherence to treatment	Aged 25 to 54	29	56.86	15.00	2.00	328.50	0.8543
	Aged 55 to 74	22	43.14	15.50	2.00		

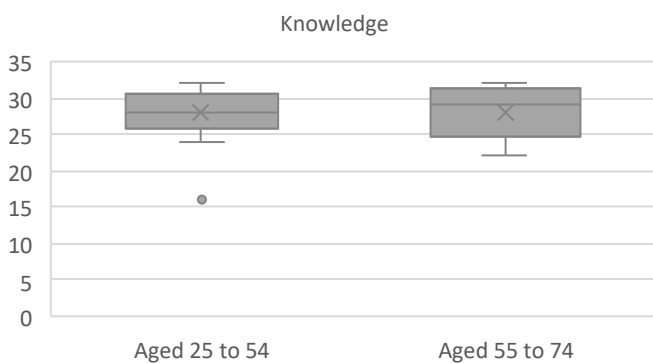


Figure 6.14: Boxplot of Partners in health: knowledge by age

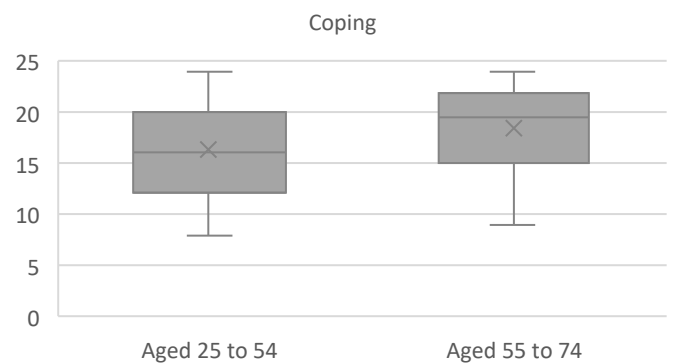


Figure 6.15: Boxplot of Partners in health: coping by age

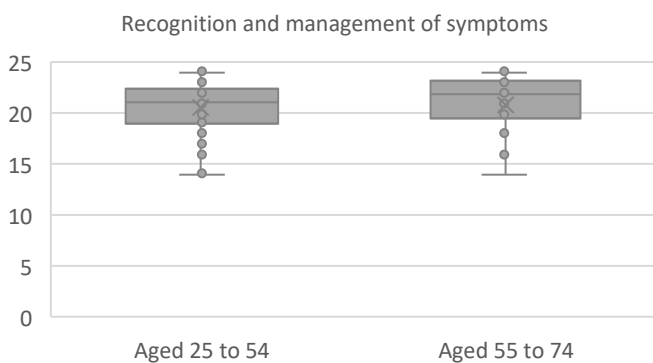


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by age

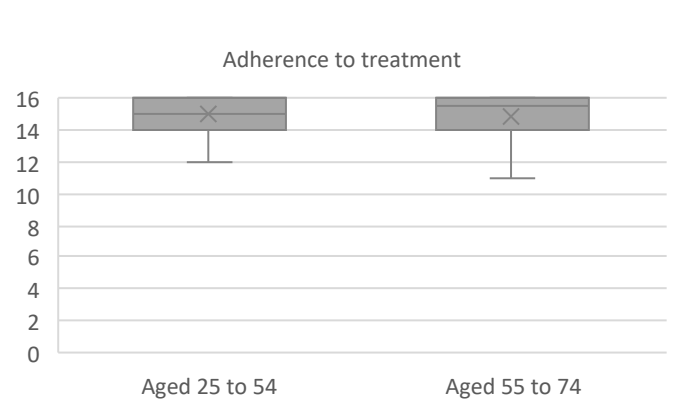


Figure 6.17: Boxplot of Partners in health: adherence to treatment by age

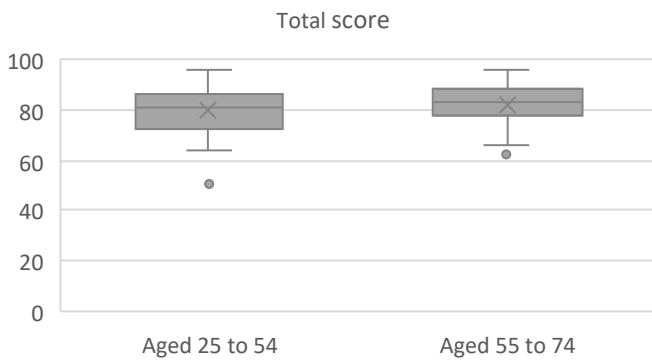


Figure 6.18: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 37.25%), and those with a university qualification, *University* (n= 32, 62.75%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.19), or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.20).

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

Table 6.19: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	19	37.25	16.84	5.49	-0.42	49	0.6730
	University	32	62.75	17.44	4.42			

Table 6.20: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	19	37.25	28.00	6.00	311.50	0.8905
	University	32	62.75	29.00	4.50		
Recognition and management of symptoms	Trade or high school	19	37.25	20.00	6.00	283.50	0.6935
	University	32	62.75	22.00	3.00		
Adherence to treatment	Trade or high school	19	37.25	15.00	2.00	252.50	0.2865
	University	32	62.75	16.00	2.00		
Total score	Trade or high school	19	37.25	79.00	17.50	274.00	0.5646
	University	32	62.75	82.00	10.00		

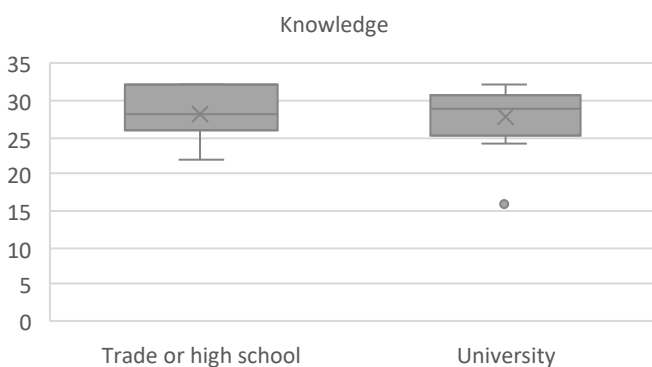


Figure 6.19: Boxplot of Partners in health: knowledge by education

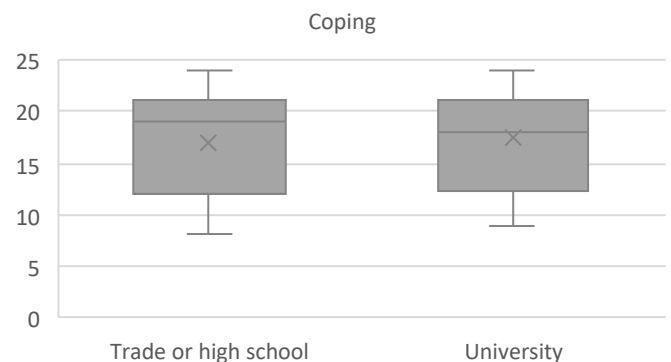


Figure 6.20: Boxplot of Partners in health: coping by education

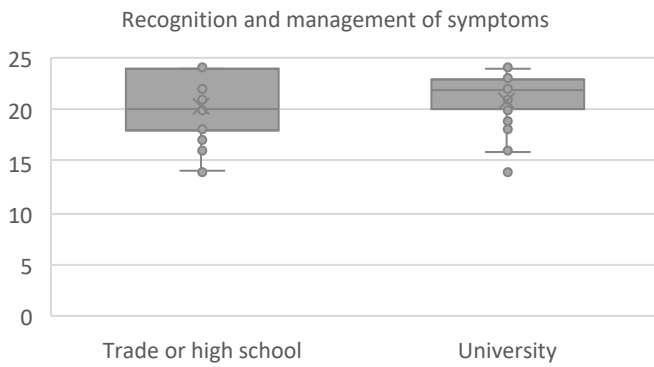


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by education

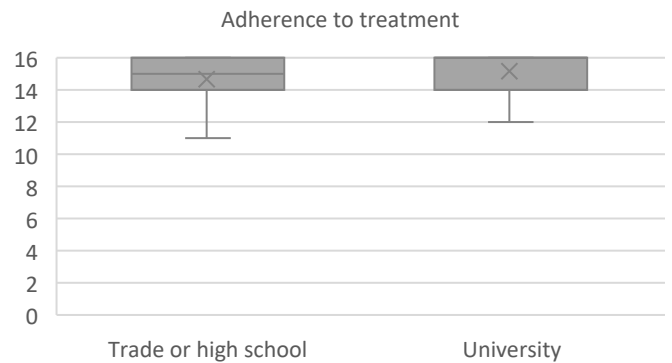


Figure 6.22: Boxplot of Partners in health: adherence to treatment by education

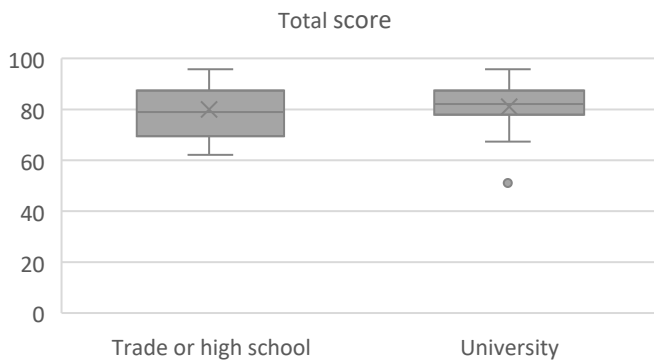


Figure 6.23: Boxplot of Partners in health Total score by education

Partners in health by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 9 participants (17.65%) *Diagnosed in 2016 or before*, 16 participants (31.37%) *Diagnosed in 2017 to 2019*, and 26 participants (50.98%) *Diagnosed in 2020 or 2021*.

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal (Table 6.21). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.22).

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

Table 6.21: Partners in health by year of breast cancer diagnosis summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Diagnosed in 2016 or before	9	17.65	77.56	9.79	Between groups	125	2	62.34	0.701	0.501
	Diagnosed in 2017 to 2019	16	31.37	81.13	10.61	Within groups	4271	48	88.99		
	Diagnosed in 2020 or 2021	26	50.98	81.85	8.52	Total	4396	50			

Table 6.22: Partners in health by year of breast cancer diagnosis summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	C ²	dF	p-value
Knowledge	Diagnosed in 2016 or before	9	17.65	45.00	10.00	1.68	2	0.4314
	Diagnosed in 2017 to 2019	16	31.37	48.50	11.00			
	Diagnosed in 2020 or 2021	26	50.98	46.00	10.50			
Coping	Diagnosed in 2016 or before	9	17.65	24.00	7.00	1.21	2	0.5461
	Diagnosed in 2017 to 2019	16	31.37	28.00	4.25			
	Diagnosed in 2020 or 2021	26	50.98	26.00	5.50			
Recognition and management of symptoms	Diagnosed in 2016 or before	9	17.65	70.00	15.00	1.48	2	0.4763
	Diagnosed in 2017 to 2019	16	31.37	77.00	12.75			
	Diagnosed in 2020 or 2021	26	50.98	73.50	18.50			
Adherence to treatment	Diagnosed in 2016 or before	9	17.65	7.00	3.00	0.41	2	0.8142
	Diagnosed in 2017 to 2019	16	31.37	8.50	1.25			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.00			

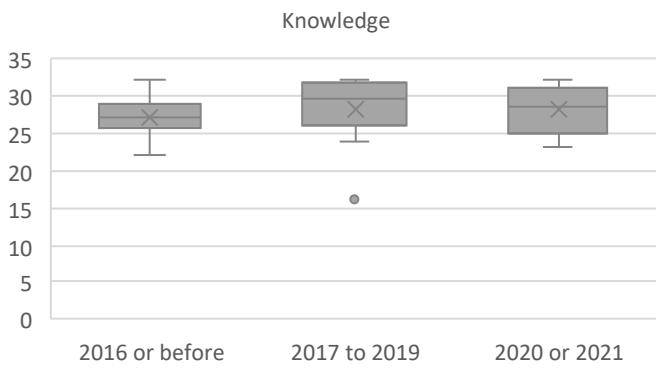


Figure 6.24: Boxplot of Partners in health: knowledge by year of breast cancer diagnosis

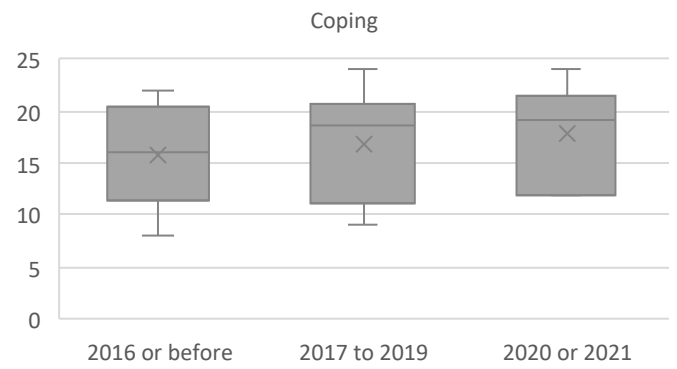


Figure 6.25: Boxplot of Partners in health: coping by year of breast cancer diagnosis

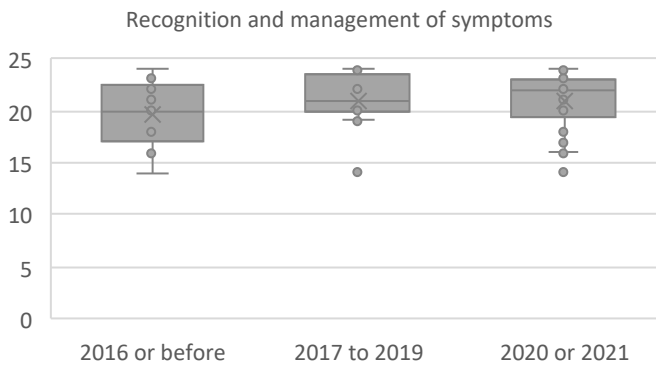


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by year of breast cancer diagnosis

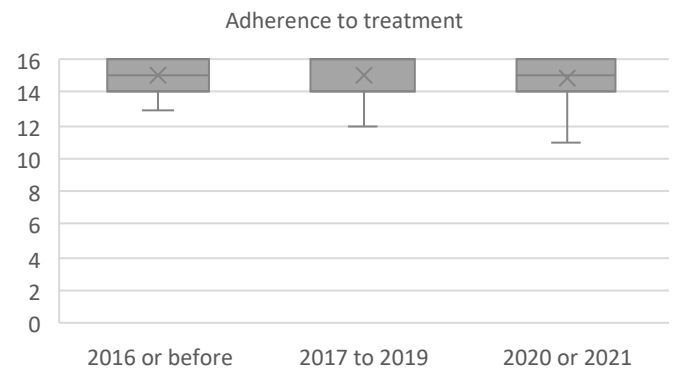


Figure 6.27: Boxplot of Partners in health: adherence to treatment by year of breast cancer diagnosis

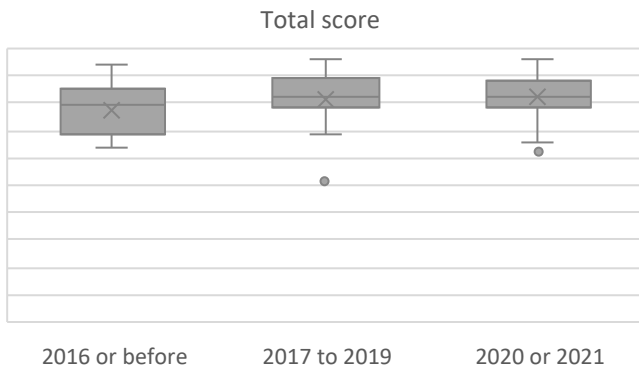


Figure 6.28: Boxplot of Partners in health Total score by year of breast cancer diagnosis

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=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.23), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.24).

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

Table 6.23: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	10	19.61	81.36	9.66	0.20	49	0.8438
	Metropolitan	41	80.39	80.73	9.42			

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

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	10	19.61	28.00	7.00	213.50	0.8897
	Metropolitan	41	80.39	29.00	4.25		
Coping	Regional or remote	10	19.61	18.00	7.50	223.00	0.9541
	Metropolitan	41	80.39	18.50	8.25		
Recognition and management of symptoms	Regional or remote	10	19.61	22.00	5.00	249.50	0.5017
	Metropolitan	41	80.39	21.00	2.50		
Adherence to treatment	Regional or remote	10	19.61	15.00	1.00	235.00	0.7217
	Metropolitan	41	80.39	15.50	2.00		

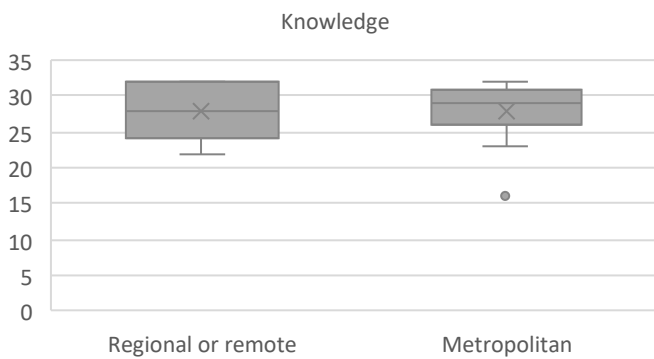


Figure 6.29: Boxplot of Partners in health: knowledge by location

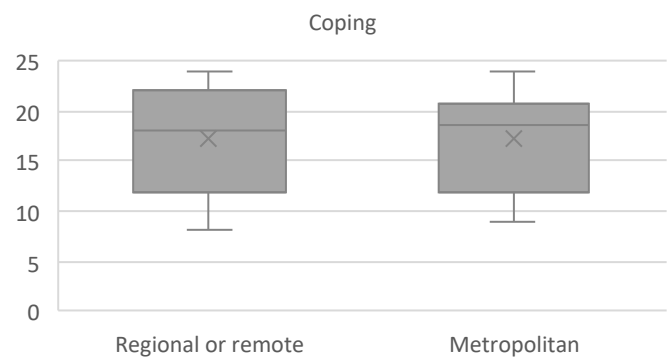


Figure 6.30: Boxplot of Partners in health: coping by location

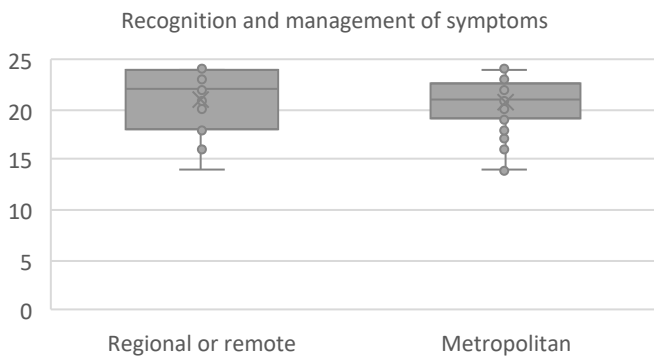


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by location

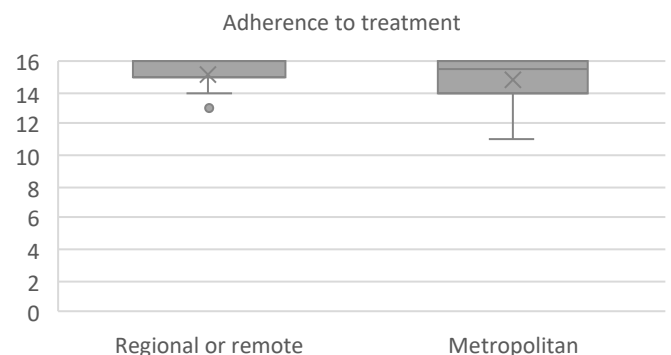


Figure 6.32: Boxplot of Partners in health: adherence to treatment by location

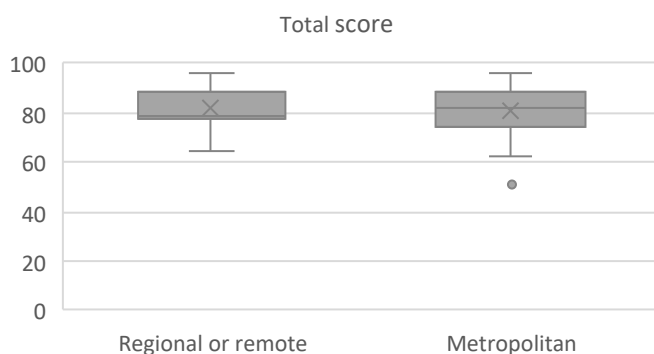


Figure 6.33: Boxplot of Partners in health Total score by location

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=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.25), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.26).

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

Table 6.25: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	17	33.33	80.47	9.29	-0.21	49	0.8352
	Higher status	34	66.67	81.06	9.55			

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

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	17	33.33	28.00	5.00	260.00	0.5655
	Higher status	34	66.67	29.00	5.00		
Coping	Mid to low status	17	33.33	19.00	7.00	284.00	0.9280
	Higher status	34	66.67	18.00	9.00		
Recognition and management of symptoms	Mid to low status	17	33.33	22.00	4.00	312.50	0.6420
	Higher status	34	66.67	21.00	3.75		
Adherence to treatment	Mid to low status	17	33.33	15.00	2.00	256.50	0.4928
	Higher status	34	66.67	16.00	2.00		

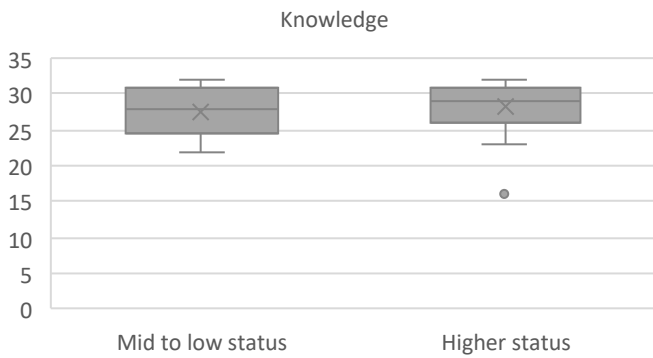


Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic status

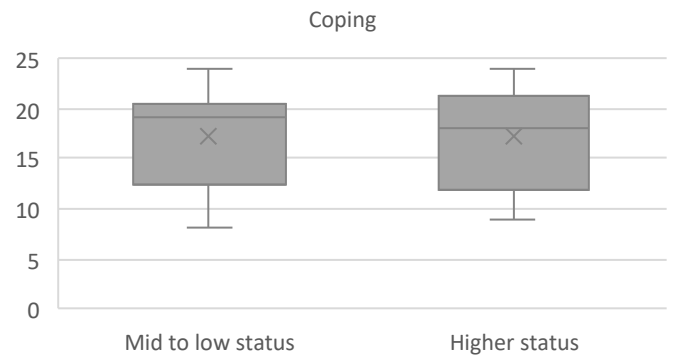


Figure 6.35: Boxplot of Partners in health: coping by socioeconomic status

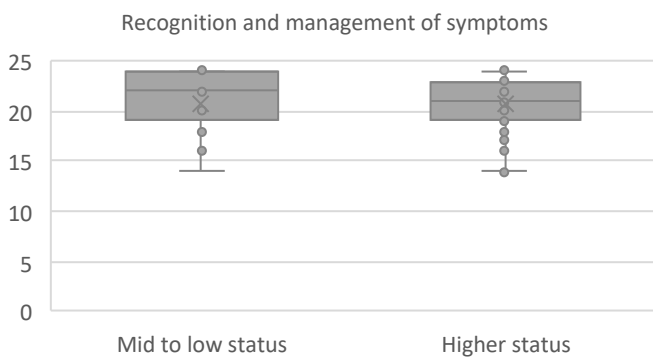


Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

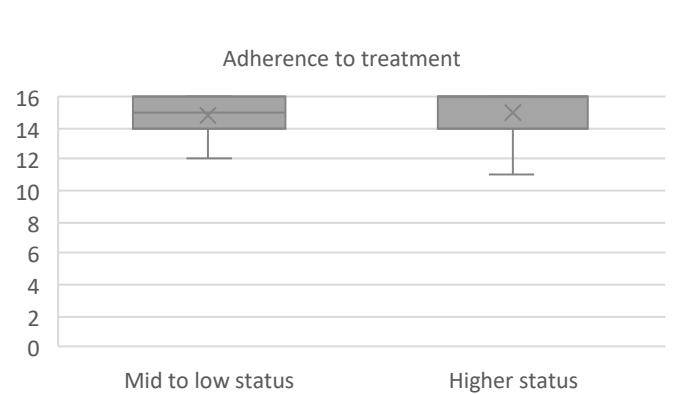


Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic status

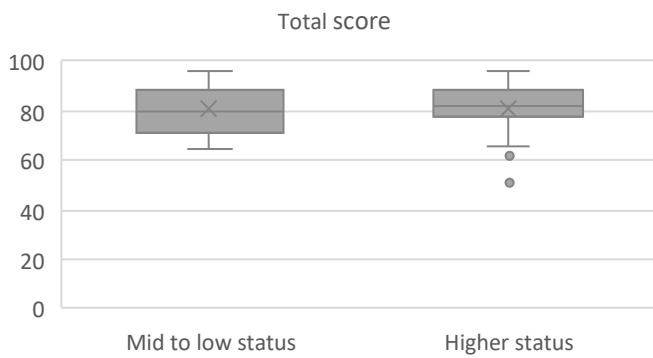


Figure 6.38: Boxplot of Partners in health Total score by socioeconomic status

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 = 32, 62.75%), and 18

participants (35.29%) responded that they took medicines as prescribed most of the time. (Table 6.27, Figure 6.39).

Table 6.27: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=51	%
All of the time	32	62.75
Most of the time	18	35.29
Sometimes	1	1.96
Rarely	0	0.00

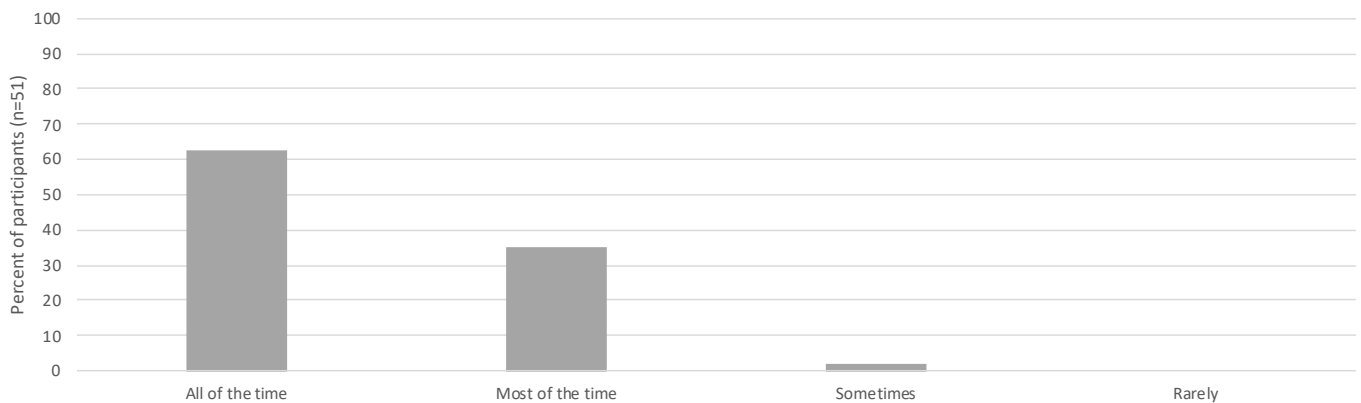


Figure 6.39: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to

interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) were given least often (Table 6.28, Figure 6.40).

Subgroup variations of more than 10% are listed in Table 6.29.

Table 6.28: Information given by health professionals

Information given by health professionals	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Disease Cause	15	28.85	5	26.32	5	23.81	5	41.67	9	31.03	6	26.09	6	31.58	9	27.27
Treatment options	46	88.46	16	84.21	19	90.48	11	91.67	27	93.10	19	82.61	15	78.95	31	93.94
Disease management	25	48.08	8	42.11	13	61.90	4	33.33	14	48.28	11	47.83	8	42.11	17	51.52
Complementary therapies	9	17.31	1	5.26	6	28.57	2	16.67	5	17.24	4	17.39	2	10.53	7	21.21
Interpret test results	10	19.23	6	31.58	4	19.05	0	0.00	6	20.69	4	17.39	2	10.53	8	24.24
Clinical trials	7	13.46	0	0.00	3	14.29	4	33.33	6	20.69	1	4.35	3	15.79	4	12.12
Dietary	12	23.08	1	5.26	8	38.10	3	25.00	9	31.03	3	13.04	2	10.53	10	30.30
Physical activity	26	50.00	7	36.84	14	66.67	5	41.67	16	55.17	10	43.48	7	36.84	19	57.58
Psychological/ social support	19	36.54	5	26.32	9	42.86	5	41.67	15	51.72	4	17.39	5	26.32	14	42.42
Hereditary considerations	22	42.31	5	26.32	7	33.33	10	83.33	16	55.17	6	26.09	7	36.84	15	45.45

Information given by health professionals	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Disease Cause	15	28.85	3	30.00	4	25.00	8	30.77	5	45.45	10	24.39	3	16.67	12	35.29
Treatment options	46	88.46	7	70.00	14	87.50	25	96.15	10	90.91	36	87.80	14	77.78	32	94.12
Disease management	25	48.08	5	50.00	9	56.25	11	42.31	7	63.64	18	43.90	8	44.44	17	50.00
Complementary therapies	9	17.31	2	20.00	5	31.25	2	7.69	1	9.09	8	19.51	2	11.11	7	20.59
Interpret test results	10	19.23	1	10.00	3	18.75	6	23.08	4	36.36	6	14.63	4	22.22	6	17.65
Clinical trials	7	13.46	2	20.00	4	25.00	1	3.85	2	18.18	5	12.20	2	11.11	5	14.71
Dietary	12	23.08	3	30.00	5	31.25	4	15.38	3	27.27	9	21.95	5	27.78	7	20.59
Physical activity	26	50.00	3	30.00	10	62.50	13	50.00	5	45.45	21	51.22	9	50.00	17	50.00
Psychological/ social support	19	36.54	5	50.00	5	31.25	9	34.62	4	36.36	15	36.59	6	33.33	13	38.24
Hereditary considerations	22	42.31	4	40.00	7	43.75	11	42.31	4	36.36	18	43.90	6	33.33	16	47.06

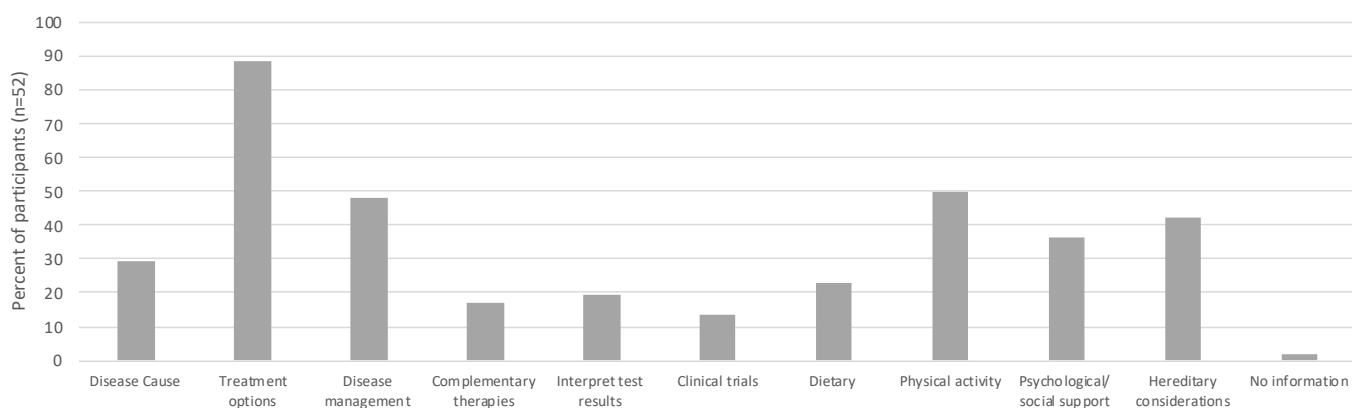


Figure 6.40: Information given by health professionals

Table 6.29: Information given by health professionals – subgroup variations

Information given by health professionals	Less frequently	More frequently
Disease Cause	Mid to low status	Stage III and IV Regional or remote
Treatment options	Diagnosed in 2016 or before Mid to low status	-
Disease management	Stage III and IV	Stage II Regional or remote
Complementary therapies	Stage 0 and I	Stage II Diagnosed in 2017 to 2019
Interpret test results	Stage III and IV	Stage 0 and I Regional or remote
Clinical trials	Stage 0 and I	Stage III and IV Diagnosed in 2017 to 2019
Dietary	Stage 0 and I Aged 55 to 74 Trade or high school	Stage II
Physical activity	Stage 0 and I Trade or high school Diagnosed in 2016 or before	Stage II Diagnosed in 2017 to 2019
Psychological/ social support	Stage 0 and I Aged 55 to 74 Trade or high school	Aged 25 to 54 Diagnosed in 2016 or before
Hereditary considerations	Stage 0 and I Aged 55 to 74	Stage III and IV Aged 25 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 treatment options (n=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management

(n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) were searched for least often (Table 6.30, Figure 6.41).

Subgroup variations of more than 10% are listed in Table 6.31.

Table 6.30: Information searched for independently

Information searched independently	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Disease Cause	24	46.15	7	36.84	11	52.38	6	50.00	12	41.38	12	52.17	8	42.11	16	48.48
Treatment options	29	55.77	10	52.63	12	57.14	7	58.33	16	55.17	13	56.52	11	57.89	18	54.55
Disease management	25	48.08	9	47.37	9	42.86	7	58.33	14	48.28	11	47.83	7	36.84	18	54.55
Complementary therapies	20	38.46	5	26.32	10	47.62	5	41.67	13	44.83	7	30.43	7	36.84	13	39.39
Interpret test results	27	51.92	11	57.89	8	38.10	8	66.67	17	58.62	10	43.48	7	36.84	20	60.61
Clinical trials	10	19.23	4	21.05	3	14.29	3	25.00	4	13.79	6	26.09	5	26.32	5	15.15
Dietary	19	36.54	5	26.32	8	38.10	6	50.00	13	44.83	6	26.09	6	31.58	13	39.39
Physical activity	23	44.23	7	36.84	12	57.14	4	33.33	14	48.28	9	39.13	9	47.37	14	42.42
Psychological/ social support	12	23.08	4	21.05	5	23.81	3	25.00	9	31.03	3	13.04	4	21.05	8	24.24
Hereditary considerations	16	30.77	7	36.84	5	23.81	4	33.33	11	37.93	5	21.74	5	26.32	11	33.33

Information searched independently	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Disease Cause	24	46.15	5	50.00	8	50.00	11	42.31	5	45.45	19	46.34	8	44.44	16	47.06
Treatment options	29	55.77	6	60.00	9	56.25	14	53.85	6	54.55	23	56.10	9	50.00	20	58.82
Disease management	25	48.08	5	50.00	9	56.25	11	42.31	4	36.36	21	51.22	6	33.33	19	55.88
Complementary therapies	20	38.46	6	60.00	8	50.00	6	23.08	4	36.36	16	39.02	10	55.56	10	29.41
Interpret test results	27	51.92	4	40.00	11	68.75	12	46.15	4	36.36	23	56.10	9	50.00	18	52.94
Clinical trials	10	19.23	0	0.00	5	31.25	5	19.23	1	9.09	9	21.95	4	22.22	6	17.65
Dietary	19	36.54	7	70.00	5	31.25	7	26.92	5	45.45	14	34.15	7	38.89	12	35.29
Physical activity	23	44.23	7	70.00	7	43.75	9	34.62	5	45.45	18	43.90	8	44.44	15	44.12
Psychological/ social support	12	23.08	4	40.00	3	18.75	5	19.23	1	9.09	11	26.83	3	16.67	9	26.47
Hereditary considerations	16	30.77	3	30.00	5	31.25	8	30.77	1	9.09	15	36.59	5	27.78	11	32.35

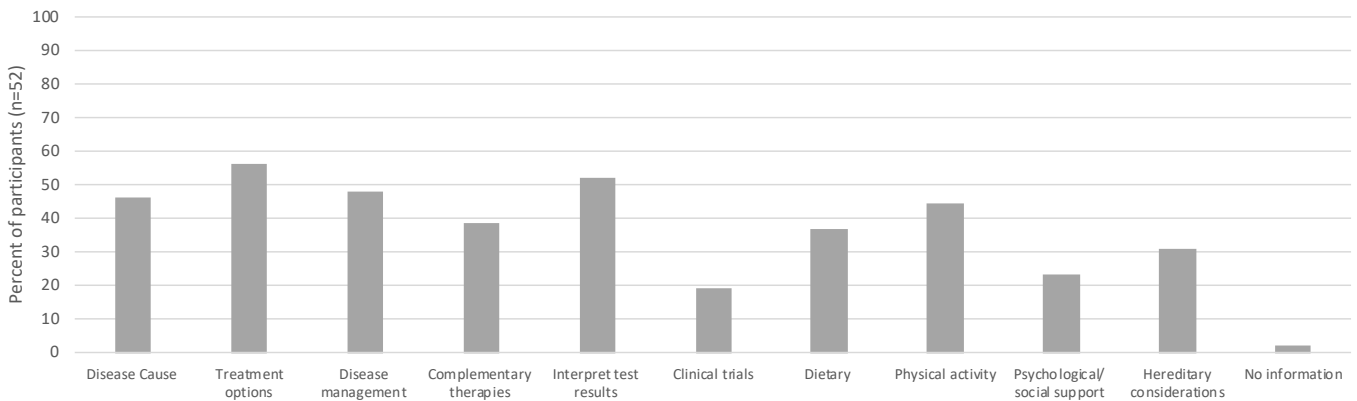


Figure 6.41: Information searched for independently

Table 6.31: Information searched for independently – subgroup variations

Information searched independently	Less frequently	More frequently
Disease management	Trade or high school Regional or remote Mid to low status	Stage III and IV
Complementary therapies	Stage 0 and I Diagnosed in 2020 or 2021	Diagnosed in 2016 or before Diagnosed in 2017 to 2019 Mid to low status
Interpret test results	Stage II Trade or high school Diagnosed in 2016 or before Regional or remote	Stage III and IV Diagnosed in 2017 to 2019
Clinical trials	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Dietary	Stage 0 and I Aged 55 to 74	Stage III and IV Diagnosed in 2016 or before
Physical activity	Stage III and IV	Stage II Diagnosed in 2016 or before
Psychological/ social support	Aged 55 to 74 Regional or remote	Diagnosed in 2016 or before
Hereditary considerations	Regional or remote	-

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for

independently were clinical trials (n = 37, 71.15%), dietary information (n = 27, 51.92%), complementary

therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

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

searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%) (Table 6.32, Figure 6.42).

Table 6.32: 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=52	%	n=52	%	n=52	%	n=52	%
Disease cause	18	34.62	10	19.23	19	36.54	5	9.62
Treatment options	2	3.85	21	40.38	4	7.69	25	48.08
Disease management	14	26.92	13	25.00	13	25.00	12	23.08
Complementary therapies	27	51.92	5	9.62	16	30.77	4	7.69
How to interpret test results	20	38.46	5	9.62	22	42.31	5	9.62
Clinical trials	37	71.15	5	9.62	8	15.38	2	3.85
Dietary information	27	51.92	6	11.54	13	25.00	6	11.54
Physical activity	13	25.00	16	30.77	13	25.00	10	19.23
Psychological/social support	26	50.00	14	26.92	7	13.46	5	9.62
Hereditary considerations	21	40.38	15	28.85	9	17.31	7	13.46

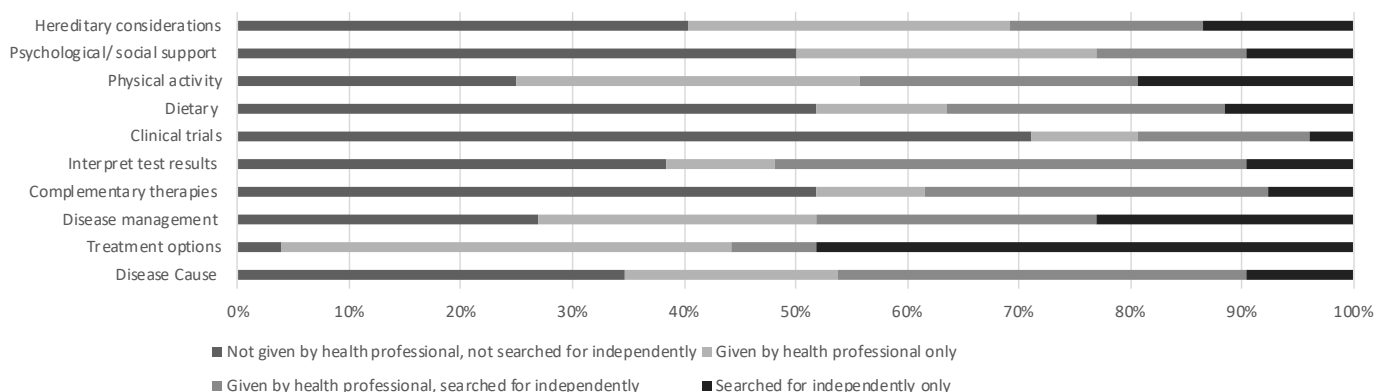


Figure 6.42: Information gaps

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 6.33 and Figure 6.43. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from non-profit organisations, charity or patient organisations was most accessed followed by information from the hospital or clinic where being treated. Information from Pharmaceutical companies was least accessed.

Table 6.33: Most accessed information

Information source	Weighted average (n=51)
Non-profit organisations, charity or patient organisations	3.88
Government	3.20
Pharmaceutical companies	1.94
Hospital or clinic I am being treated in	3.22
Medical journals	2.76

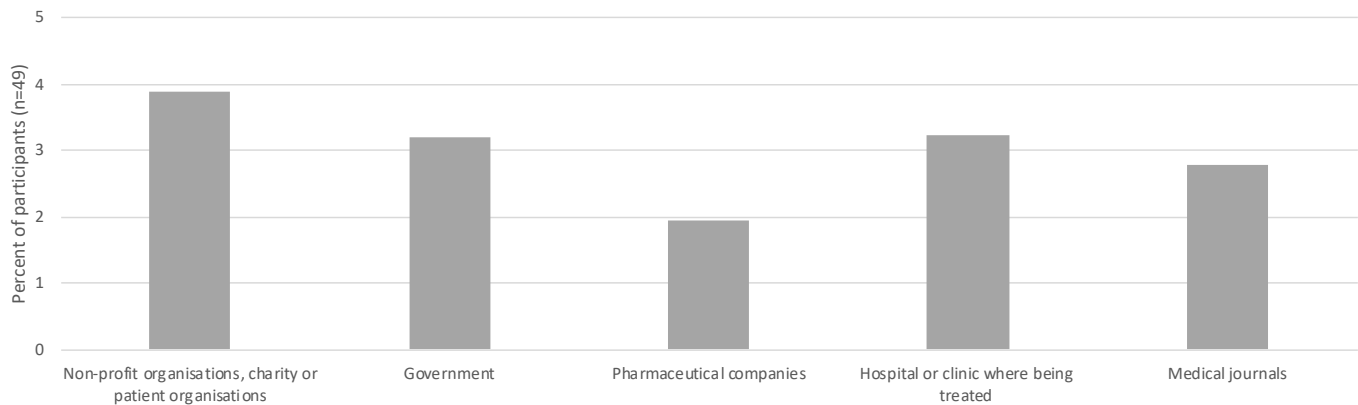


Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (23.53%) had accessed My Health Record, 39 participants (76.47%) had not (Table 6.34. Figure 6.44).

Of those that had accessed My Health Record, there were seven participants (58.33%) that found it to be poor or very poor, and four participants (33.33%) that found it acceptable (Table 6.35, Figure 6.45).

Table 6.34: Accessed My Health Record

Accessed "My health record"	Number (n=51)	Percent
Yes	12	23.53
No	31	60.78
Not sure	6	11.76
Doesn't know what 'My Health Record' is	2	3.92

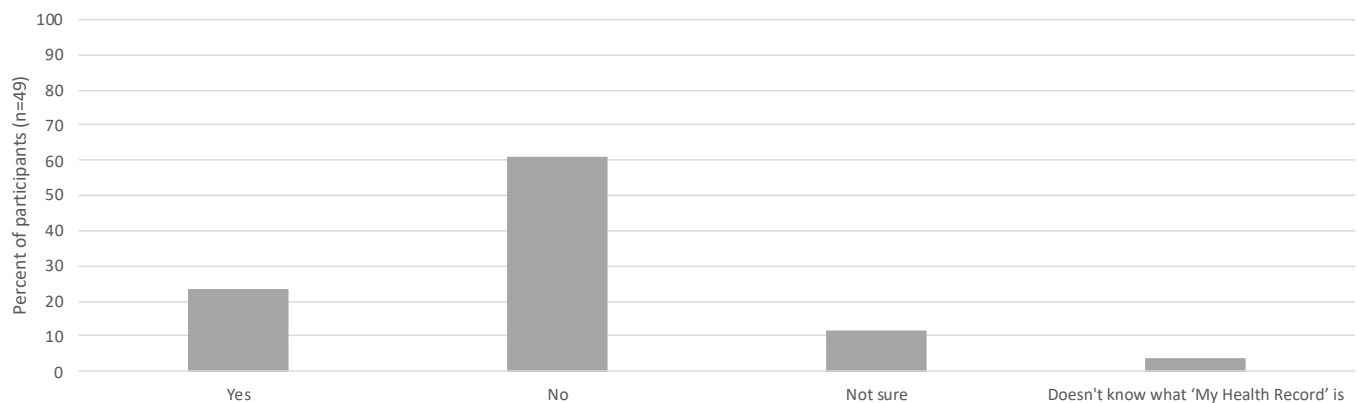


Figure 6.44: Accessed My Health Record

Table 6.35: How useful was My Health Record

How useful was "My health record"	Number (n=12)	Percent
Very poor	4	33.33
Poor	3	25.00
Acceptable	4	33.33
Good	1	8.33
Very good	0	0.00

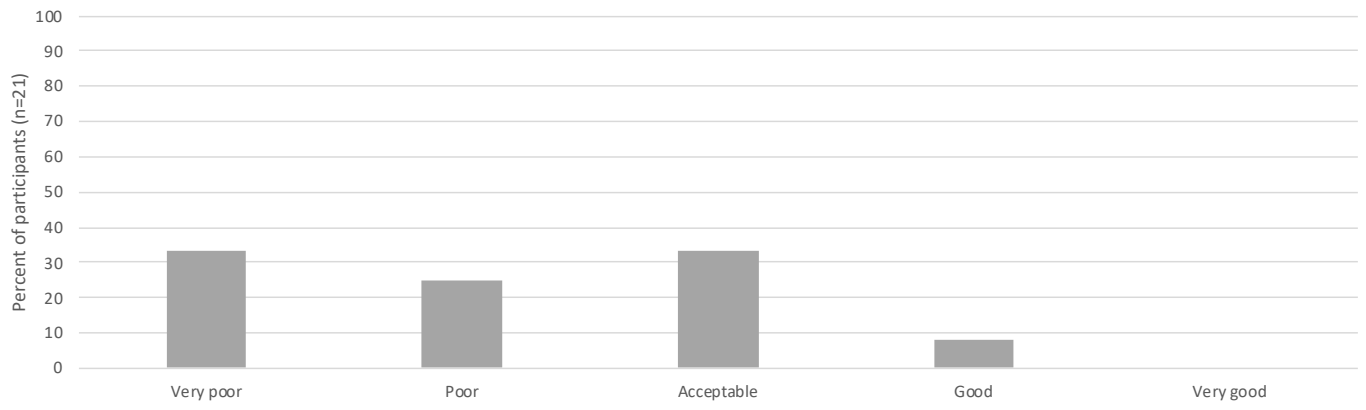


Figure 6.45: How useful was My Health Record