

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%). There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be more accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information available.

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common themes reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments, 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “How personalised the treatment is for me”. The least important were “Ability to follow and stick to a treatment regime” and “The financial costs to me and my family”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n = 28, 63.64%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%).

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?”. There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n = 5, 10.00%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%). There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

Participant describes the expectation that future treatments will have fewer or less intense side effects

I'd love to see people's treatments being individualized because otherwise, you're just battering people with side effects and they could not work. That's probably the biggest one. Treatment at home or something would be great. I found that my oncology team didn't talk much about the side effects and how they might be ongoing. They really, really played them down. I think it's because people experience different things, but also they're just so focused on killing whatever it is.

I don't feel like I was properly prepared for the side effects afterwards. They give you a sheet with them. They go, "You might get tired." When I said, I didn't take much time off work, my oncologist said, "Oh, people who don't take much time off work generally get tired later." She just said it like that not like, "Yes, you'll feel like you've been hit by a truck for like two years." [chuckles] There's not enough even information about side effects. They don't focus that much on side effects. Participant_008

PARTICIPANT: Oh, probably more support for the side effects. I just said it, I totally underestimated it and was too positive in the beginning, I think, and not realistic enough. Then when I got stuck into it and had all the side effects, it was all scrambling around trying to get the support that I needed.

INTERVIEWER: Okay. Your hope's really for future treatment so that side effects are dealt with better.

PARTICIPANT: Definitely. People are more prepared. No one really prepared me for the side effects. I was

given a...not until I asked. I had to ask or speak and call my breast care nurse and said, "Oh, by the way, this is happening," and then she told me about it which was great. In the beginning, the oncology team gave me all the handouts for all the different drugs and the information that's about side effects and whatever but there's not many side effects. Does anyone read those straight away? I don't know. I didn't until I knew that there was something not right then I said "I better look at that this." [chuckles] Maybe a little bit more information right at the beginning. It was there but I had to ask for it. Participant_012

Participant describes the expectation that future treatment will be more effective

OK. Oh, gosh. Well, triple negative is the area that has the least advances in treatment outcomes, poor prognosis. So I guess I would like to see, you know, having ongoing research and trials into triple negative, looking at immunotherapy in particular, you know, combining chemo and that kind of stuff. The treatment that is more effective was basically just I mean, ultimately we can have all the supportive care and all the rest that we like. But a research institute for negative people still going to die to me would be, you know, research or curative to at least, you know, significantly extend a lot of things. Participant_002

That's one thing I would really like to see. I would also really like to see that every person who is diagnosed has a genome test at the beginning, to test their actual tumour, to explore whether or not they are going to benefit from the chemo that they're actually given. To be told, "These are the four chemo that you have to do, and these are the only ones that really potentially will work with your tumour." At the beginning, that's just the blanket. It's what everybody with triple negative breast cancer is really told. These are the blanket chemo, but it's not factored in that, "Well, Taxol might not work for this person the way it works for this person." Side effects will be significantly minimized, in my mind, if that testing's done right at the beginning, to actually help, again, complement your treatment plan. How oncologists should be expected to make a decision when they don't have all the information about a person's body, I don't think it's fair on an oncologist to be quite frank, but also for the patient to have to then go through unnecessary side effects when there are tests there that can be done to help. Those are the two things for me. Participant_015

I'd just like to see new treatments that are more successful with less side effects, more targeted, I guess. More targeted treatments, rather than your whole body getting sick. Participant_037

Participant describes the expectation that future treatment will have less cost burden

Obviously because I was triple-negative, I'd like to see a proper targeted treatment for triple-negative, so that it's not just a case of, "Well, let's just throw everything at it and hope for the best." Definitely, for me, that's a really big thing is finding the reason for triple-negative and why triple-negative happens when it's not a genetic mutation, and having a proper targeted treatment for it. Obviously, having access to the current drugs that we have, that may not necessarily have been created for breast cancer, but now they're finding work on particularly triple-negative, having them added to the PBS and not paying a ridiculous amount out of pocket, and making it within people's financial reach would be really important. Participant_025

I personally think that you shouldn't have to pay for anything. I don't know why some stuff is charged for, and some stuff isn't. I wish the government just funded it. That was something that we found really difficult. We just didn't know if we went if we were going to get a bill for something or not. I wish chemo didn't make them sick, but I don't really think there's anything anybody can tell about that. Participant_043

Cost is a big one. There was a clinical trial that I could've had the immunotherapy for free, but the doctor said it was too risky to wait. It boggles my mind to think about the poor people that couldn't afford to have it and therefore the positive effects that I won't be having for them just because they weren't in a good financial position or have somebody either that could fund it for them or to gather the funding to cover it. I know it can't be offered everywhere, but I've got a friend, she has to travel well over an hour to get treatment for a different kind of cancer from where she lives. Participant_048

Participant describes the expectation that future treatment will informed by more research/advances in treatments

I think my biggest push would be for research into stage four breast cancer. At this point, we don't have anything to cure stage for breast cancer, just life prolonging. And so being that if my cancer was to

come back, it would be a different recurrence, it would be stage four. And at some point I would die for me. I see big and I've also lost a lot of friends in the breast cancer community since being diagnosed myself. For me personally, I would like to see the biggest push for stage for research. Participant_010

Chemo's such a horrific thing to do to your body, so if there were treatments that you could avoid that, that would be amazing. Obviously, researchers are working on that all the time. I don't know. I like the way that chemo was done for me because just being in a room where other people are, where you see familiar faces and all that kind of thing. I think that really was helpful for me, just being in the room where everybody is dealing with something similar. Participant_011

For regional Australia. I would like to see more possibilities, yes. More different treatments if more choices given even for trial things and stuff. Participant_031

Participant describes the expectation that there will be more holistic approach to treatment in the future

I would really like to see oncology work alongside naturopaths so that you can get a combination of what are some good vitamins, minerals, all of those. What are some good things that we can be adding to our body to help prop us up when we're actually then having chemo, I say, destroy your body? That's what it does. An oncologist isn't necessarily going to know the things that a naturopath does, and they both could complement one another. I don't know if that answers. Does that? Participant_015

Look, I thought the chemo nurses were amazing the way they walk you through everything. I can't say anything wrong about any of that. I think what I feel is that people tell you you have to do things to get through it, like exercise, eat healthy, all those sort of things, but they tell you and they don't give you a guide or a plan, or somewhere to go to achieve that. I think you battle through all the chemo and the surgery knowing that you've got to get through that to get rid of the cancer. You just accept that, but it's hard to accept the consequences of everything without a plan. I'm just somebody that likes to plan anyway, so the weight gain and that sort of stuff...Nobody tells you, "Look, expect to gain weight between 5 and 7 kilos." Nobody tells you that, but they all know that you will. Nobody tells you, "At the end of it, this is how we're going to get rid of that 5 or 7 kilos so that you can get

back to being a healthy weight so the cancer won't return." We've got rid of the cancer once and everybody is telling you you've got to be a healthy body weight so that the cancer won't return, but they don't give you the tools to achieve that success.

INTERVIEWER: Okay, so a bit more structure around what to expect and how to approach it, and what you need to do.

PARTICIPANT: Yes. I actually went and saw...and I forgot about this, but now that I'm thinking about it. I went and saw a nutritionist when I was going because I was so concerned about the weight gain. She helps cancer patients with their diets. She gave me some really good tips on-- and this did help because she said, "Do this to try and help with the steroids," and it did. It slowed it down. I went from 1 kilo to 100 grams and stuff like that by eating what she recommended. I think you need a nutritionist at the hospital that sits cancer patients down and tells them-- because everything else is just, "Don't eat this," or, "Don't eat that," but nobody gives you a structure on what to eat or not what. Nobody tells you. Participant_029

It's probably not so much what they are having because there's so many different ways of doing things with breast cancer. I was treated before surgery whereas there's a lot more that probably get surgery and then treatment. In terms of the drugs, my knowledge of them is only what I've been told and then given on paper. I can't see there being a way around what the side effects are or what it's doing to your body. I'd like to see the ability to have more natural therapies in conjunction with the hard toxic drugs....It's really hard to access that. I know that there's naturopaths that have an oncology science behind it that compliments the chemotherapy. Whereas where we are, the oncologists, they're not against the natural therapy side of things. The pharmacists that give you the drugs are. The oncologist, I said to him that I take natural supplements and everything like that. He said, "Look, I want you not to take any while we're doing chemotherapy because it's just counterproductive. Once you've finished your chemo, absolutely get on it, prep for surgery, do all that sort of stuff." There is a bit of an okay about it, but I just wish there was a holistic way of doing it. I didn't have that choice if that makes sense. This probably takes you back to what answer do you want to those questions. There was no choice in the treatment side of things because within getting diagnosed within two weeks I was on chemotherapy. To then try and find someone to do oncology and natural therapies in conjunction, which

I know they are out there, I wouldn't have time.
Participant_030

Participant describes the expectation that there will be changes in the way treatments are given

New treatments. Personally, for me, I struggle with things being injected into me. I think, if I could do something orally, I guess that would be preferred. I realize it's not as an efficient means of getting it into you, but I did struggle with having stuff injected. I don't know, everything did just seem very incredible that we're still doing this stuff. Even though we're such an advanced society, it all just does seem very barbaric to be injecting all these liquids and it's all just disgusting. Something, it's more oral and that still just lets you get on with your day, but at the end of the day, we can only...I don't know where modern medicine is. I don't really follow the changes and things, but I know that there's good things coming. I don't know where they're at with things, I don't really think about that sort of stuff. I can't really answer it very well. Participant_005

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038

Oh, gosh, if there could be a treatment that has no side effects, that would be a miracle. Obviously, if you weren't having cell, you're having IV That would be great because I have come out of treatment at times looking like the walking wounded where they've tried three or four times to hit a vein. Yes, avoiding that would be great. It's really anything that can lessen side effects, and then is more easily administered would be wonderful. Participant_027

I think it would be good if we were given the option to be tested prior to starting a treatment. I didn't know about that test until after I finished my treatment. It would've been good to have that initially. I would have paid for it had I known, but I didn't even know about it. Participant_045

Participant describes the expectation that future treatment will be the same as it is now

But, you know, like the radiation, it's amazing. Like they put music on and stuff for you. So it's really calming and they're pretty amazing. I don't know if I could improve it much more. The hospital was amazing, like when, when I had my surgery. So I don't know if there's a lot that you could improve Participant_006

Right. As I say, I was delighted with the public hospital system. The treatment-- well, I'm still here, so it has obviously worked and they knew what they were doing. I had no issues with costs. They were absolutely marvelous. They used to ring me, just to check on me and everything that the private system didn't do, you were just a number to them. Participant_032

No, you know what? I think I feel that everything was done for a reason, so I don't feel like-- I can't sit there and go that, that needs to change off the top of my head. I'm trying to think, and I can't think of anything like that. I was one of the unfortunate ones with the COVID that I had to do all my chemo on my own. I got to the hospital and the nurses were lovely, but they're also run of their feet a little bit. You would have to sit there by yourself and either read or watch TV. I found that probably at first, a little bit hard because you normally have people with you while you're going through chemo, but I didn't find it as hard as some. I saw a couple of old ladies that were really struggling with that, but that was not their fault, that was not the hospital's fault. That was because it was COVID. I felt like I got quite good care. Participant_035

Participant describes the expectation that future treatment includes preventative measures

That I would really like is to see the preventative measure for gene mutations. So I would like to see something that my daughters could take that will protect them if they have the mutation as well. So that would be the number one thing that I would want for from future treatments is something that will protect my daughters. Participant_001

Well, I've heard a little bit about some things going on in relation to immunotherapy and stuff like that. I guess I hope that No. One, there are less invasive treatments that essentially put poison in your body like chemo. That would be good if also immunotherapies or whatever. The therapy is a cold where apparently the cancer grows because obviously your immune system doesn't realise it's a bad thing that cells. So whatever. I think that's what immunotherapy is. If I understand the basics, just yeah, it is ways of then having that help to also prevent any reduce significantly any likelihood of recurrence to the people. That would be lovely. And I guess I hope that the treatments would get to the point that it is something that hopefully most people don't end up having to lose their life over in the long run. But certainly that's the big, big wish. . And you know, particularly because I think metastasis tastes tend to tends to be the the problem over a long time, a longer term, and hopefully that can somehow be managed, treated. I don't know, pie in the sky hoping now that. Yes, that's kind of the you you sort of ask me a question that led me down there, but yeah. Like ones that seem to be. Yeah, I think, I think I heard you immunotherapy was one that was being looked at, but I don't think it's as widespread for cancer at the moment. Participant_023

Table 9.1: Expectations of future treatment

Expectations of future treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	12	24.00	5	21.74	7	25.93	5	26.32	4	16.00	8	30.77	4	16.67	6	25.00	6	23.08
Participant describes the expectation that future treatment will be more effective	11	22.00	7	30.43	4	14.81	4	21.05	4	16.00	7	26.92	4	16.67	1	4.17	10	38.46
Participant describes the expectation that future treatment will have less cost burden	11	22.00	1	4.35	10	37.04	6	31.58	5	20.00	7	26.92	4	16.67	3	12.50	8	30.77
Participant describes the expectation that future treatment will be informed by more research/advances in treatments	8	16.00	4	17.39	4	14.81	2	10.53	6	24.00	5	19.23	3	12.50	2	8.33	6	23.08
Participant describes the expectation that there will be more holistic approach to treatment in the future	7	14.00	5	21.74	2	7.41	2	10.53	5	20.00	2	7.69	5	20.83	4	16.67	3	11.54
Participant describes the expectation that there will be changes in the way treatments are given	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes the expectation that future treatment will be the same as it is now	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	3	11.54	2	8.33	5	20.83	0	0.00
Participant describes the expectation that future treatment include preventative measures	5	10.00	3	13.04	2	7.41	0	0.00	4	16.00	3	11.54	2	8.33	0	0.00	5	19.23

Expectations of future treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	12	24.00	4	25.00	8	23.53	7	35.00	5	16.67	4	21.05	6	27.27	2	22.22
Participant describes the expectation that future treatment will be more effective	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	5	26.32	5	22.73	1	11.11
Participant describes the expectation that future treatment will have less cost burden	11	22.00	4	25.00	7	20.59	2	10.00	9	30.00	5	26.32	4	18.18	2	22.22
Participant describes the expectation that future treatment will be informed by more research/advances in treatments	8	16.00	3	18.75	5	14.71	3	15.00	5	16.67	2	10.53	5	22.73	1	11.11
Participant describes the expectation that there will be more holistic approach to treatment in the future	7	14.00	2	12.50	5	14.71	1	5.00	6	20.00	2	10.53	3	13.64	2	22.22
Participant describes the expectation that there will be changes in the way treatments are given	7	14.00	1	6.25	6	17.65	4	20.00	3	10.00	4	21.05	2	9.09	1	11.11
Participant describes the expectation that future treatment will be the same as it is now	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	0	0.00	2	9.09	3	33.33
Participant describes the expectation that future treatment include preventative measures	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	4	18.18	0	0.00

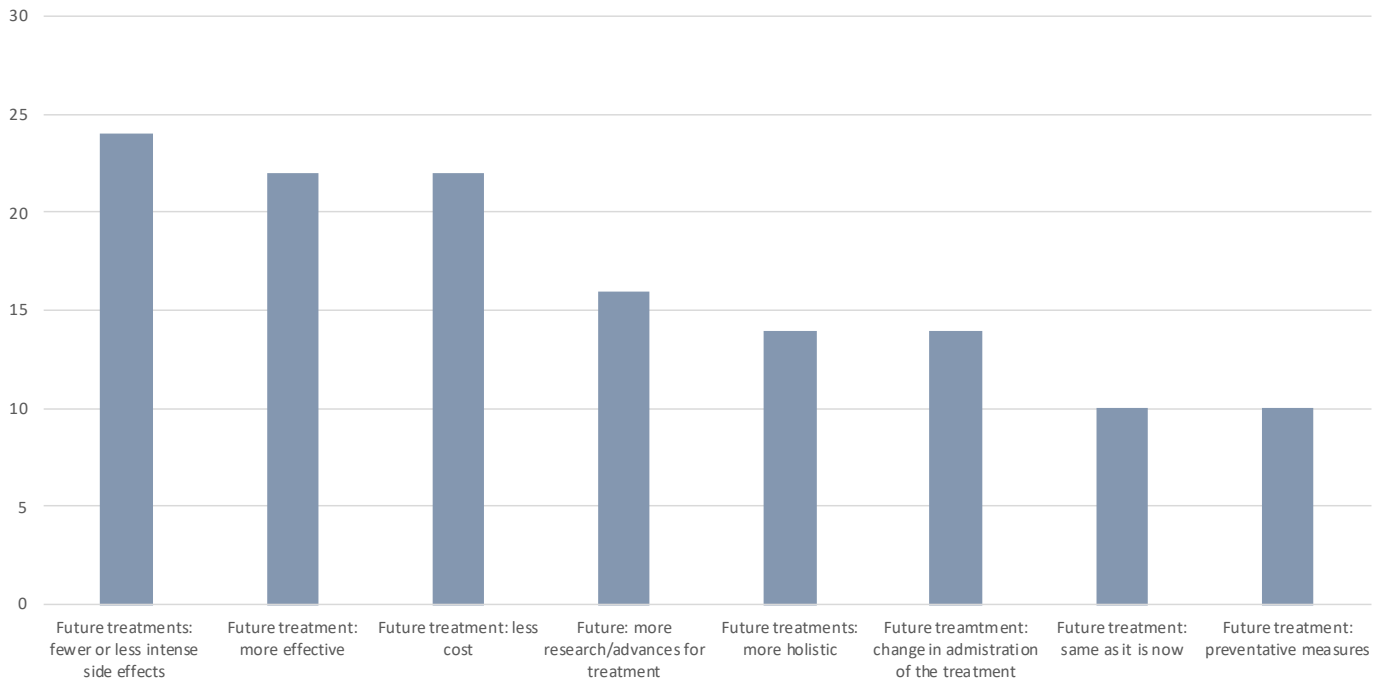


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes the expectation that future treatments will have fewer or less intense side effects	-	Mid to low status
Participant describes the expectation that future treatment will be more effective	Trade or high school Aged 55 to 74	University
Participant describes the expectation that future treatment will have less cost burden	Early breast cancer Mid to low status	Advanced breast cancer
Participant describes the expectation that future treatment will be the same as it is now	-	Trade or high school Aged 55 to 74

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future

information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be more accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information available.

Participant describes the expectation that future information will provide more details about where to find available services

I think what would have been good was like when you have a baby and then they say, oh, here are mother's in your area, would you like to start a mothers group? And you have that sort of peer support where you can meet people in your area and you can just help each other and so you don't feel alone. So maybe having that option that you could opt into that if you want to just said, do you want to talk to people in your area or somehow just link you up, even if it was just to send each other a text, just know that there be other people around you also going through the tough time rather than feeling you're the only person I know. So I guess I was relatively younger because I was 42. So, yes, to link up with sort of your demographic of people would be good. Participant_001

Yes. Even if it was, I don't know, a little pack that you've got towards, I don't know, at some stage in your treatment going, "Hey, these are some of the services that are going to be available to you" whether it's through the health system, whether it's through local community groups." A little information pack, I guess, would be good. Participant_020

I don't know whether it was because I walked into my first appointment with my specialists and I walked into my first appointment with my medical oncologist, and I talked to them about my infertility that we'd been through that it was just assumed, but I felt like at no point did anyone kind of talk to me too much about the infertility side of what chemotherapy can do things to fertility. It was never really talked to me about fertility preservation options because I think it was just assumed I already had a specialist, so I had all of that under control, and I could deal with that myself. I was 37 at the time, and so I think there was that-- I felt like I was too old to be the young patient but too young to be the old patient. I said, given this, I didn't fit in the mode, I suppose, of certain people. I definitely think more inflammation around fertility and the side effects of that would be really good. I also think more information, it was really helpful to see people who've been out of cancer and who were 15 years, 20 years down the track from having their cancer diagnosis. Having information provided to you in the first appointment about...Do you know what? This is really hard One of my biggest pet peeves is that everyone talks about how amazing the National Breast Cancer Foundation is and how amazing the Breast Cancer Network Australia is. I still have actually no idea what they do to help with cancer patients. Having a bit more information about the services that

they offer and what they can do for you, I think would be really useful. If you go into their website, I can find 10 different ways of how I can donate money to them but I can't find what they...They say they support breast cancer patients, but what do they actually do to support breast cancer patients. I think it's really important too to have a local area, information pack. You're having a...You live in LOCATION because there's all of these amazing charities that exist, that you don't know about until someone tells you about them. There's a thing called the OTIS foundation that provides holiday accommodation to breast cancer patients. I think there's a company called Pink Things which is in the LOCATION, there's all of these things. I found and felt that if I had children, there would be way more support information given to me in the first instance. Because I didn't have children, and I had a husband who worked from home, I didn't really get a lot of information about support resources that were available, which is probably why I didn't access any of them because I didn't know they existed. The other thing that would have been really useful to me was actually knowing about...like getting some information on where to go to get a wig, or where to go to get nice scarves. Again, there's all these amazing organizations like Bravery, sews the scarves and real French headbands for some hair things, and all of these things that exist for cancer patients that you really almost need to be in the cancer world and have a secret connection to someone who goes, "Oh, by the way, this exists." When you're first diagnosed with that you don't know about that. Six months down the track, I now know where to go to find a wig, I now know where to go to do this and it's really hard to get those level of-- not the everyday 17 support but then where do I go for a headband? Or where do I go for a headscarf? That level of information would be really good. As I said, I think if it was like a local by region by region thing that was even just a website that had links to all these companies, it would be really good. Interviewer: Yes, that would be fantastic. A lot of these little charities who don't have a big platform people don't know about it and I think a lot of people find out about these little charities through Facebook pages or by word of mouth or things like that. I think if there was some online service to know what you can access in your area...I know it's a huge, big thing to do, and there's probably no money for it and that's probably what prevented a lot of people from doing it because they cost money but it's like, for instance, the cancer council's website, and they have that on their website or just something that you can be told, "This is what you do. This is who you go to," it would be great. Participant_025

Participant describes the expectation that future information will provide more details about treatments

I think information on rehab after a lumpectomy, or a mastectomy, or the lymph nodes removed could be improved. Participant_007

Oh, maybe with choices with treatment. I really wasn't offered any different options and there was no discussion given when they put me on a treatment plan. It was just this is what we're doing. The only other option is not to do it and then that's your choice. There wasn't really that much and I've sort of learned since then that there are other options and there are other paths I could have gone down potentially. Maybe that. I think that's pretty big. Participant_012

It's funny because each time, if you rang me last week there'd probably be other things I've noticed. This week, I've been trying to find information on the optimum time to have surgery after chemo because I'm now at the stage of worrying about tumors returning or growing, or cancer cells growing while I'm waiting for surgery and what's the recommended time, and what's the optimal time. I haven't been able to find that information. I had conflicting information from my oncologist and the surgeon, that didn't help. The oncologist said two to three weeks, the surgeon's saying eight weeks is fine. I'm sitting in the middle thinking, "Well, I don't like this. I want to know." That's what I want this week, but last week it would have been another thing, a different question. I've not been able to find an answer that says, "This is gold standard recommended treatment protocol." I haven't been able to find that. I just have to hope for the best and I don't like that. I like information. Participant_033

Participant describes the expectation that future information will provide more details about mental health and emotional support

Probably, what I've just said. More to do with what else I could do to help myself-- to support me through the treatment alternative therapy-wise or allied health-wise Participant_004.

That's a difficult one because like you say, initially, when you're given the diagnosis, there's so much information that's available, but you just don't take it in initially. It is quite difficult, but I think probably the absolute minimum that I think is having that information about what your treatment is going to

entail. Whether it's, for example, "You have to have chemotherapy," or, "You need to have chemotherapy, what those drugs are, what they do, what the possible side effects are." What I found the most lacking out of all the information I was given was about the long-term effects of the treatment. The thoughts of things that are impacting on my health now, I wasn't aware of until I actually am experiencing it. That information would have been useful to prepare yourself for it. The other thing, I think, is the psychological support. I know, some of the other women in my group who didn't have treatment in the private system. They were actually set up with consults with a clinical psychologist, and they found that very helpful. I think all patients that have that diagnosis should have that option. Some people might need it and might not need an ongoing. I certainly don't think I suffered as a result of that, but I think I believe I would have liked to have maybe had that option. Now, I might have only had one consult and might have been given a lot of useful information. I know that there's other women in my group that still have ongoing psychological issues, and they've either had access to that resource, or they've had to seek it out themselves. I know that I did go to a BCNA conference, and one of the presenters there a clinical cycle psychologists who was excellent has, I think, now been taken on as an ongoing resource for BCNA for conferences. She was very useful, some of her tips were fantastic, very down to earth person and guide very useful information. I think that resource should be mandatory. Participant_013

If I ruled the world and I could have it how I wanted, I guess maybe to have someone like a counselor that you would speak to before you start your treatment just to see where your head's at and make sure the information you're hearing is accurate information. I guess, to have that reassurance at the start that you're on the right plan or whatever. Maybe something like that when you walk in and you know nothing, you have someone to talk you through the process in a non-clinical way. Participant_027

Participant has no recommendations/is satisfied with the information currently available

No, I think it was really good. And I guess once again, being a nurse, I had a greater understanding of the different resources that I could access. And I think we're all different in how much information we want to receive and where we want to receive it from. So I think it's more just continuing to have that broad range of whether it's online videos or pamphlets or, you know, telehealth, those kinds of things. I think

we're all different and we want those different levels and levels of information. So I think that's done well at this point. Participant_010

No. I've always like I said the oncologist and the hospital staff and the breast care nurse has always printed out information to give to me and pointing me in the right direction. I mean the information I received is what [unintelligible] myself so I can-- I would say it's great information. Participant_018

I remember the first thing is giving me information and stuff, so I think it was pretty much readily available and in an easier to read format. Participant_037

Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems

PARTICIPANT: Probably more about holding of-- What do you call it? I guess, yes, relationships, I guess could be one, but more information on that. Well, guess what, sex life went out the window, so more information on that...Yes. The CAT scans obviously provides a little bit of information about that, but there'll probably be more like who you can go to, who you can be referred to to help with that thing. Same with a bit of- I mean, it might be available now- but counseling and that sort of thing for your own general health and well-being. Participant_024

Yes, I think, again, through the networks themselves. One of the hospitals in LOCATION, this is quite a good one, they actually had sexual health information as well, but that wasn't available at the hospital I was at. I think, especially for young couples, information around healthy sexual relationship during and after chemo and things, that would be one thing. Just in general, having better access, having kind oncology nurses, not being treated just as a number, that would be another thing. More on diet would be great. I don't think there's enough information on what you should eat. and stuff on diet. Participant_016

Well, I feel like menopause wasn't really covered...Sexual changes to your body from menopause. My friends weren't even talking about it because they were all too young. It was thanks to that cancer group that I got told a little bit about it. I had to manage that kind of stuff. I still have had to go to about five different doctors to talk about it. The information on how to get treatment and stuff like that, it's so mixed. I don't find that it's very

standardized. That's probably the biggest one. Then side effects, how to deal with that. There's no holistic kind of putting you back together treatment plan afterwards. Participant_008

Participant describes the expectation that future information will provide more general information about the condition

I had to look up a lot of the terminology in terms of what the diagnosis meant. The Cancer Council booklets and all those sorts of things don't really go into the details of what the different diagnoses mean. I guess they probably do that intentionally because I know a lot of doctors prefer to sit with you and go through it rather than you read it yourself. For a person like me, that's the stuff-- I had to Google it and then try and understand it from medical texts which are not always that easy to read. Whereas just having a simple layman's term glossary of what some of that stuff means would be-- I think for someone like me it would be really good just to be able to understand what the difference-- because there's still some things that were on my pathology reports that I've never really been able to find what exactly they mean. Just having more information about that. A lot of the other information was pretty easily available in the booklets and things that were there. When I saw the oncologist before each of the two different types of chemo, they would give me a whole booklet of, "This is what you're about to have. This is all the possible side effects," and all that stuff. They gave us quite a lot of info about everything in that sense as well. Participant_011

I think like I said at the beginning there, I really think that there needs to be-- Your initial point of contact should be with someone that talks to you about your diagnosis, like talk to you about, "Okay, well, you've got breast cancer. This is what breast cancer is. This is what you can expect there or the different types." Then have somebody who actually goes through, "And this is your story. You have triple-negative, or you have estrogen positive. The different types to be able to process it because like I said, I didn't process any of it. I felt like I just had my oncologist talk at me, and I didn't take anything in. I just went with, "Right. Well, okay. You're telling me what I need to do, let's do it." That, I think, needs to happen. Participant_015

Yes. When I was first diagnosed, there probably wasn't a lot on triple-negative and outside of being told don't Google I wasn't given much insight, so I did Google, so I could find my own insight. I think that there needs to be more printed information given to a

patient so that they know exactly what they're dealing with and exactly what it is. Participant_034

Participant describes the expectation that future information will provide more details about symptom and side effect control

I think the I would like more information on what happens after the chemotherapy as far as side effects and what people are left with afterwards. And I'd like to see more follow up from the teams around that to make sure that you are doing OK. Sorry. Have I answer the question that I. Yeah. Participant_038

Menopause 100%. Never pain, nerve damage, chemo side effects afterwards Participant_036

My oncologist just gave me a piece of paper with all the symptoms that I would experience. That could have been a bit prettier, if what I mean, like a little bit less or sear, but he was giving me the most up-to-date information. Participant_040

Participant describes the expectation that future information will be more accessible/easy to find

I think COVID made it extremely difficult for a lot of this because the face-to-faces just aren't there. The information that is given to you is either a booklet or a piece of paper. I'd like to be able to see more in-person stuff. Time is so important to this, whereas when you're in an appointment and there's 500 people waiting to see the same specialist that day, it's all time-poor. That's probably more time, I suppose. Participant_030

It's very hard to get things online I find and that's not blaming anyone else. Maybe I'm just incompetent when it comes to computers.

INTERVIEWER: You found it difficult looking for things online?

PARTICIPANT: I did.

INTERVIEWER: Okay.

PARTICIPANT: Yes. My husband's a computer whiz so he does everything for me. Participant_032

I do think that those drug information sheets should be rewritten. Realistically they're for the doctors, not the patients, but if they are going to be using them for the patients then they need to be different, or they need to develop something else that is more for the patients. Participant_048

Table 9.3: Expectations of future information

Expectations of future information	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future information will provide more details about where to find available services	8	16.00	5	21.74	3	11.11	4	21.05	3	12.00	3	11.54	5	20.83	3	12.50	5	19.23
Participant describes the expectation that future information will provide more details about treatments	7	14.00	6	26.09	1	3.70	6	31.58	0	0.00	3	11.54	4	16.67	2	8.33	5	19.23
Participant describes the expectation that future information will provide more details about mental health and emotional support	7	14.00	3	13.04	4	14.81	1	5.26	5	20.00	5	19.23	2	8.33	4	16.67	3	11.54
Participant has no recommendations/is satisfied with the information currently available	7	14.00	3	13.04	4	14.81	1	5.26	5	20.00	3	11.54	4	16.67	4	16.67	3	11.54
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	12.00	4	17.39	2	7.41	2	10.53	2	8.00	4	15.38	2	8.33	2	8.33	4	15.38
Participant describes the expectation that future information will provide more general information about the condition	6	12.00	2	8.70	4	14.81	2	10.53	3	12.00	1	3.85	5	20.83	1	4.17	5	19.23
Participant describes the expectation that future information will provide more details about symptom and side effect control	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54
Participant describes the expectation that future information will be more accessible/easy to find	5	10.00	0	0.00	5	18.52	4	21.05	1	4.00	3	11.54	2	8.33	4	16.67	1	3.85

Expectations of future information	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes the expectation that future information will provide more details about where to find available services	8	16.00	3	18.75	5	14.71	1	5.00	7	23.33	3	15.79	4	18.18	1	11.11
Participant describes the expectation that future information will provide more details about treatments	7	14.00	5	31.25	2	5.88	4	20.00	3	10.00	3	15.79	3	13.64	1	11.11
Participant describes the expectation that future information will provide more details about mental health and emotional support	7	14.00	3	18.75	4	11.76	4	20.00	3	10.00	2	10.53	2	9.09	3	33.33
Participant has no recommendations/is satisfied with the information currently available	7	14.00	1	6.25	6	17.65	3	15.00	4	13.33	2	10.53	3	13.64	2	22.22
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	5	26.32	1	4.55	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	1	5.26	5	22.73	0	0.00
Participant describes the expectation that future information will provide more details about symptom and side effect control	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	3	15.79	1	4.55	1	11.11
Participant describes the expectation that future information will be more accessible/easy to find	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22

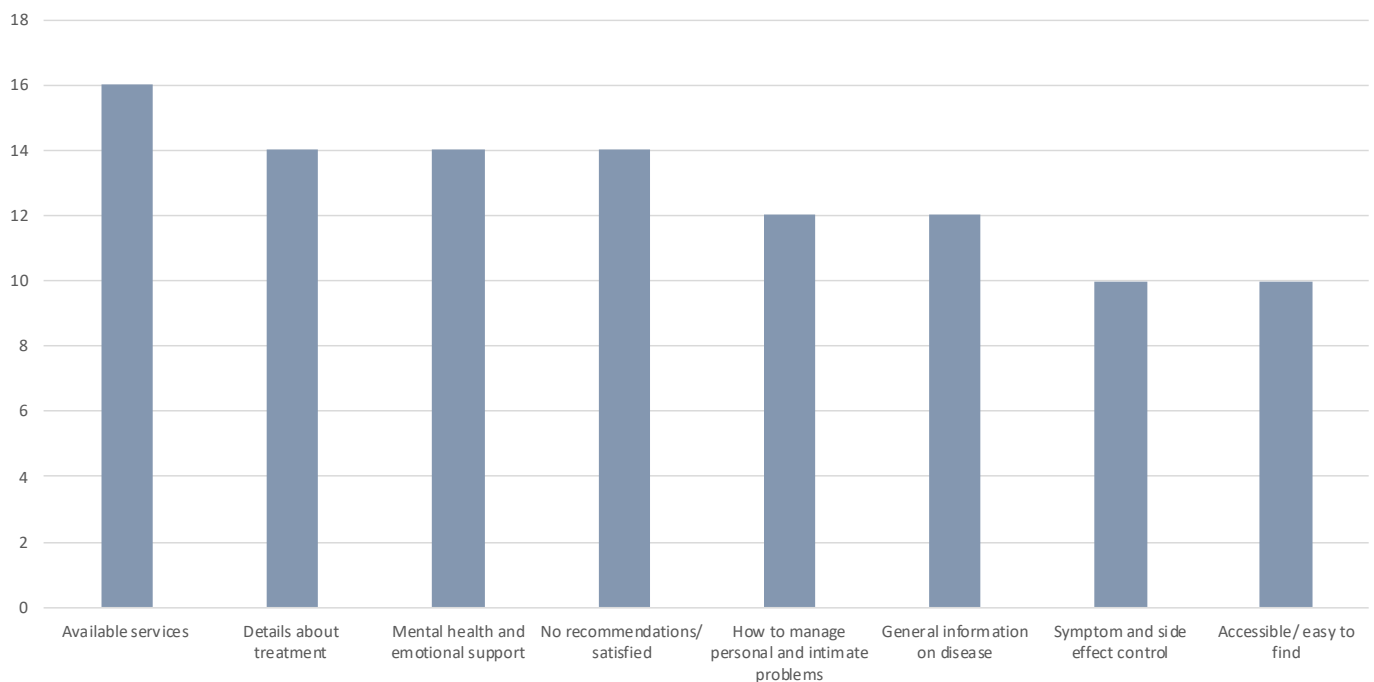


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes the expectation that future information will provide more details about where to find available services	Mid to low status	-
Participant describes the expectation that future information will provide more details about treatments	Advanced breast cancer Good physical function	Early breast cancer Poor physical function Regional or remote
Participant describes the expectation that future information will provide more details about mental health and emotional support	-	Aged 55 to 74
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	Aged 55 to 74	Aged 25 to 44
Participant describes the expectation that future information will provide more general information about the condition	Aged 55 to 74	Aged 45 to 54
Participant describes the expectation that future information will be more accessible/easy to find	-	Poor physical function Aged 55 to 74

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

Participant has no recommendations/experienced good communication

Honestly, I can't complain. It'd be nice if you turned up for a 1:30 PM appointment and you didn't go in at two o'clock, but I'm not going to hold that against anyone. If that's my only complaint, that's not a complaint. That's thinking up something there. I can't fault these cancer nurses. There is no one that's terrible. Participant_007

No. In my case it's been quite good. If I've needed anything extra, I've been able to go to my oncologist and he contacts me straight away, more or less straight away, so not really. It's been good, great. Participant_017

No. I had a very good medical professional who looked after me. I don't have any issues there. Participant_024

Participant describes the expectation that future communication will be more transparent and information more forthcoming

Yes. I actually had a conversation with someone at the hospital one day about this. I guess it's hard for the medical teams to deal with because they're dealing with it all day every day, but sometimes you just feel like a number. For example, at one stage I was doing my radiation, into treatment, and said, "We need you to go and have CT scan." Okay it's as good as you said. No one ever explained to me why I needed to have CT scan. I think that to explain, have someone explain to

you why this has happened or what is happening it's really the only thing that I can think of. Participant_020

They've actually been really good. There's massive gaps I think, in the communication in general, but I don't know if that's in relation to that question. I might answer that and you'll tell me it's not what you're looking for, is not the right time to say that. What I've noticed with the whole journey is how much coordination and organizing you have to do yourself as a cancer patient. There's an expectation that you'll know what to do and where to go and who to talk to and how to do that. Things like contacting surgeons yourself, finding a surgeon, making an arrangement to go there, trying to get scans organized, you have to do all that yourself. Following up things that haven't been done, contacting the oncology rooms because they haven't got back to you about something where you don't know when the next appointment date is. There seems to be an awful lot of things that you need to do yourself to coordinate your own treatment, that I didn't think would be that way. I thought it would be more scheduled, "This is what happened, this is your journey, you need to see this person, this person, and this person." but I felt like that information wasn't given, that wasn't communicated and it's been trying to find out for myself, "Who do I see? Who do I need to see? Where do I go next? Where do I go for scans? Where do I go?" Then you need a heart ultrasound, well, you need to get that done before your chemo next Monday. Where do I go to get that done? Then you find everywhere is booked. You're trying to look at traveling two hours away to try and get an appointment for a scan that you've just been told that you need in the next four days without any information on where to go. That sort of stuff is just not communicated, and that's being really challenging. Participant_033

You have to read the patient. Some of us want to know all the truth, doesn't matter how grim it is, whereas others should be protected from the truth and the partner should be should be made aware. Sorry, I'm such a such a chatterbox. If it wasn't for the PET scan, I would have never known that I had the disease in my bones. Now I know it so now I'm just checking in all the time, so I have extra anxiety. Read your patient, provide all the resources, provide various places where you can go to without judgment. Without judging, yes. Participant_042

Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)

My only miscommunication has only ever been about my annual follow ups, which is sort of easy enough, but is that something they're somehow to, you know, even if it's just to let us three months before your mammograms, do you decide this is what's going to. And that's still current for me, you know, nine, eight, nine years down the track that I, too, would like my doctor three months to put something in your calendar or the reception calendar to say that he needs an email regarding her upcoming mammogram to explain to me still because. Has to hang on. What's going on with them? That's literally my only. And that's always like I said once I stop seeing my oncologist because he gave me that bit of paper every year for three or five years, however long it was. Participant_003

Just being just for them to be upfront and honest? I think they all are. But you're just saying I have to give some more small details of what what we can expect. I mean, when you get diagnosed, you get told you're going on a trip. Yes. I'll tell you about we're going to give you this chemotherapy and it's going to give you the product. But it would be nice to have more information about those side effects. It might not be there, but maybe they could put you on to someone who could help you solve things. So it's just some little information about that. And not just even no one really wants the prognosis, but at the same time, you don't want a prognosis. So having having them been able to to help you with that and to help you cope with it and and knowing what is what, you know, that's what I'm trying to say. But, you know, like I've got a prognosis and and I literally took that and my prognosis know, I had to use to live. Well, I literally took that as I had to use to live for years past that used by date. So it's a little bit hard to sort of grasp, well, how come I'm doing that now? But a little more information on, say, you know, this can happen. This this drug can give you another six, six months of life or whatever, some little bit more information that way. Participant_049

Participant describes the expectation that future communication will include listening to the patient, as they know their body best

Yes, it's definitely not an inclusive process for the patient, I don't feel. I feel like it's very medical-based. It's very much the medical professionals come

together and they talk about the patient, and then you go back to the patient to talk through. It might be, in my case, I feel like I didn't get a choice around things, although they'd probably say differently. That's not necessarily even the medical professionals' fault because there's not a lot of treatment options for triple- negative. I feel like, for the patient to be included in that, for me, my thought process is that I don't have a lot of trust in my medical professionals now, because I just feel like I'm either not being told the whole story, or I'm only being told certain things. When in actual practice, if they just included me in that process right from the outset and given me reasons as to why decisions were made and why things weren't, instead of just telling me, "Well, this is what's happened and this is what we've got to do," I probably would have processed that differently and had a different outlook on just the process in general if that makes sense. Participant_015

I don't think so, because I've actually had-- I think I, fortunately, had a really incredible and supportive experience going through my breast cancer with all of my medical professionals and their communication. I don't think there's really anything that I felt I've missed out on that they could improve on. Sorry, I'd say that. I think for me, the biggest thing that made my communication with my specialists really good was that I didn't go in and go, "Oh, I read this on a forum and this is what you need to be doing," and I never questioned by specialists. Also, I, from the very beginning, because I knew my surgeon had one treatment plan option and my oncologist had a different view, I knew that they were all talking and they were talking to each other about me. I never felt like one person didn't know something about me that the other did. I think as long as people know that they're being supported and that their specialists are communicating with each other and the decisions are being made as a whole not just by one person. I think that would be really important for other people. I had that experience. Participant_025

Whenever I've spoken to anyone, they say they only tell you this much because if they told you everything, perhaps wouldn't go through with it or wouldn't go down the path that they suggest is the best way I feel as though that's a very blanket statement for some people. Myself, I would have dealt better if I knew upfront what I was dealing with. I think it needs to be more individualized to the person. I feel as though that needs to be a discussion with your breast care nurse or your oncologist of how much information you really want to know, do you want to know, like from

here to the end of the process, or do you want to know just what you're dealing with now? I think that would be better dealt with, and explanation of cost would be another one, as what you're in for, for the whole journey, that would be the two things. Participant_036

Participant describes the expectation that future communication will be more empathetic

Oh, it would just be good if maybe it was a bit more rounded and that the emotional well-being was factored in and the families as well, because we were lucky. We were we don't have any family here, but we relied on our friends and the support of friends. But there wasn't any of the emotional support. It was purely this is the treatment. There you go by that was there, that there was there was not even a contact point of if you're having a tough time or your husband or your children. Yeah, I don't know, maybe it's changed. I probably have the hope so. Participant_001

I don't know. I think that I've had fairly good communication with most of my health professionals. As I said, the only one which I've butted heads with has been my surgeon, NAME. I don't know if it's just her as a person. I think it is. She's quite abrupt. The last thing you want is someone who's abrupt dealing with you when you got breast cancer and you tried to make heads and tails of what's going on in your life and being told, this is what you're doing, whether you like it or not, doesn't really sit well with some people. It's like, "How about you give us some options? How about you [unintelligible] yourself a little bit because you're not advocating for me?". Participant_034

Yes, and I actually said this to them one day. I think they'd need to remember that the people they're treating are people and that while for the person

administering the treatment, it might be the one they stabbed that day. The person receiving the treatment it might be the first time they've ever done this, so you just need to explain what's being done and why it's being done. Participant_027

Participant describes the expectation that future communication will include developing a care plan with follow-up

My only miscommunication has only ever been about my annual follow ups, which is sort of easy enough, but is that something they're somehow to, you know, even if it's just to let us three months before your mammograms, do you decide this is what's going to. And that's still current for me, you know, nine, eight, nine years down the track that I, too, would like my doctor three months to put something in your calendar or the reception calendar to say that he needs an email regarding her upcoming mammogram to explain to me still because. Has to hang on. What's going on with them? That's literally my only. And that's always like I said once I stop seeing my oncologist because he gave me that bit of paper every year for three or five years, however long it was. Participant_003.

Yes. I definitely want to see one app that has everything in it. For example, Peter Mac have their own, all your results go in it, your blood tests, your follow-ups, notes from the appointments, everything like that. Whereas in my hometown, my radiation is run by a company called Icon. That's got a separate app. The oncology side of things in Melbourne is done separately. I'd love to see one access point for all of that because everything's so online. Like I said, I file the pieces of paper on everything that they do but I don't want to have a folder for it. I just want one locale for everything. Participant_030

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant has no recommendations/experienced good communication	13	26.00	7	30.43	6	22.22	5	26.32	8	32.00	4	15.38	9	37.50	5	20.83	8	30.77
Participant describes the expectation that future communication will be more transparent and information more forthcoming	13	26.00	6	26.09	7	25.93	6	31.58	4	16.00	8	30.77	5	20.83	7	29.17	6	23.08
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	20.00	8	34.78	2	7.41	2	10.53	5	20.00	6	23.08	4	16.67	7	29.17	3	11.54
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	10	20.00	3	13.04	7	25.93	4	21.05	3	12.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant describes the expectation that future communication will be more empathetic	9	18.00	6	26.09	3	11.11	3	15.79	4	16.00	6	23.08	3	12.50	4	16.67	5	19.23
Participant describes the expectation that future communication will include developing a care plan with follow-up	5	10.00	3	13.04	2	7.41	0	0.00	5	20.00	3	11.54	2	8.33	3	12.50	2	7.69

Expectations of future healthcare professional communication	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant has no recommendations/experienced good communication	13	26.00	5	31.25	8	23.53	6	30.00	7	23.33	4	21.05	7	31.82	2	22.22
Participant describes the expectation that future communication will be more transparent and information more forthcoming	13	26.00	3	18.75	10	29.41	6	30.00	7	23.33	5	26.32	5	22.73	3	33.33
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	20.00	2	12.50	8	23.53	3	15.00	7	23.33	3	15.79	3	13.64	4	44.44
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	10	20.00	4	25.00	6	17.65	5	25.00	5	16.67	4	21.05	5	22.73	1	11.11
Participant describes the expectation that future communication will be more empathetic	9	18.00	4	25.00	5	14.71	4	20.00	5	16.67	3	15.79	4	18.18	2	22.22
Participant describes the expectation that future communication will include developing a care plan with follow-up	5	10.00	2	12.50	3	8.82	1	5.00	4	13.33	2	10.53	2	9.09	1	11.11

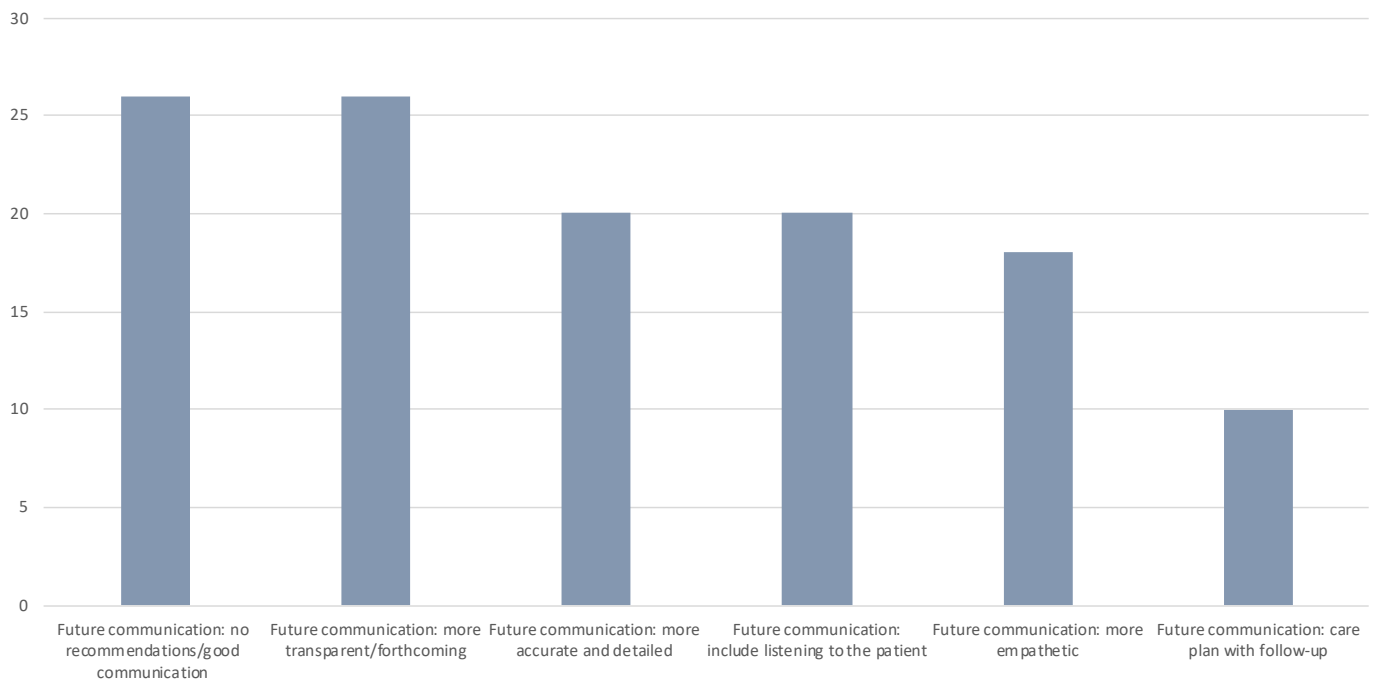


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant has no recommendations/experienced good communication	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	Advanced breast cancer	Early breast cancer Aged 55 to 74

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

Participant describes the expectation that future care and support will include more access to support services

I think that everything along the way is adequate. I think we need to focus on people that have finished treatment, and rehabilitation, physically, and mentally after treatment Participant_007

I don't know. I'd probably get support with doing my housework and all that sort of stuff. I think if there are people like myself who I'm very independent, and God, I hate asking for help. I think if they could maybe have more-- I don't know, maybe sit down and talk to people about their situation more. I could have probably done with, maybe, some help around the house, that sort of stuff. I know, like I said, I got the transport, which is awesome. Participant_028

Maybe in-home support, especially if someone could-- I'm on my own...so I am having to fend for myself with everything and I haven't really had anyone come to me and say, is there anything you might need help with at home? I've had to go looking for it and asking...Yes, just some practical support to help. Participant_014

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who

to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles- Participant_033

Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles-. Participant_033

I would love there to be a one-stop-shop so that you go and somebody is there for your physio, your chiropractic, all the breast care, questions that you have. Yes, just a whole umbrella where it's so hard to - like lymphedema, side effects from chemo, or whatever. Just someone that would deal with all of it. You don't have to run around to so many different professionals and you're constantly-- it's hard to get into appointments as well. Somewhere that just dealt with everything.. Yes. Like a hub for everything. Like you could have your own oncologist in different paths, but this is where you went for everything else. Participant_036

Participant describes the expectation that future care and support will include mental health/emotional support

I'll probably think I have three kids, so maybe something more for them, which we were pointed into canteen's directions which my kids accessed the counselling services for a little bit there. Just something more to help them, take them on [inaudible] At the start, it was a little bit overwhelming for them, and with [unintelligible] charity coming out to take them out for the day or something-- I'm not sure just to help them deal with them.. Participant_018

I think the most important thing is just support and the counselling. For people, specifically breast cancer, having no services there and making sure, like Breast care WA has been awesome for me. If I wasn't here in Perth, I don't know what would have...If I was remote in LOCATION I don't know whether I would have had the same level of support. Participant_017

Psychologists. Cancer psychologists. Participant_042

Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I got a lot out of the Facebook groups. Being able to reach out to survivors, even those ones that have reached stage four or whatever, being able to talk to them and get stuff from their experience. Participant_009

I would like to see support groups or people with similar types of cancer that you have say that you're able to meet other people and talk about your experience with them, because I feel like they understand more like that to me is more beneficial than seeing a psychologist and. So can you repeat the question? Yes, there was something else I had in my head. Participant_038

I believe that the cancer support group, that's just an organization of people going through cancer, that has been very helpful for me. What they're trying to do with the group is to get to people when they're diagnosed because they supply a lot of information that we don't know. You don't know about options about breast surgeons. My GP, who recommended a breast surgeon, he said if his wife had it, he wouldn't send her anywhere else, so I took that as my recommendation, but you've got to make all those decisions and you don't know. Us, as a group together, a list of the surgeons in the area and all that sort of thing and costings and everything like that, but when you're first diagnosed, you're not part of that group because you don't know. It's something that those support groups of people that have gone through it, I think help you more than anything, and getting the information to them. They're putting brochures in the hospitals and things like that to help people. That's the big thing is when you're first diagnosed, you've got so much going on and you don't know. They're saying, "Okay, you got to go and see an oncologist. Who would you like to see?" It's like you never look at - No one doesn't know who an oncologist in the area is if you haven't had to deal with anything like that. It's that information in that crucial time when you're first diagnosed that needs to get to people because you don't know. It's even like, I would have been out-of-pocket \$10,000 for my radiation if I hadn't have gone to the morning tea that the cancer group had and mentioned it to one of the ladies there, and she told me how to get out of paying it. Things like that. It's that crucial time, right at the beginning when you're up in the air, not knowing where you're coming or going, and you're in such a shock and you've got to make all those decisions. Participant_046

Participant has no recommendations/is satisfied with care received

Not that I could think of.
Participant_006

And I think I've been very lucky with the breast nurses and counsellors that I've had, the access I've had to

different activities at different hospitals where I support women and men with cancer. It's just getting that information out. But I think I've been very lucky with that sort of thing. Participant_049

I really can't think of anything. I'm sorry. Participant_020

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future care and support will include more access to support services	24	48.00	9	39.13	15	55.56	7	36.84	12	48.00	9	34.62	15	62.50	9	37.50	15	57.69
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	20.00	1	4.35	9	33.33	5	26.32	5	20.00	5	19.23	5	20.83	6	25.00	4	15.38
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.00	4	17.39	3	11.11	4	21.05	3	12.00	2	7.69	5	20.83	3	12.50	4	15.38
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	6	12.00	4	17.39	2	7.41	2	10.53	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant has no recommendations/is satisfied with care received	5	10.00	3	13.04	2	7.41	3	15.79	2	8.00	4	15.38	1	4.17	4	16.67	1	3.85

Expectations of future care and support	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes the expectation that future care and support will include more access to support services	24	48.00	5	31.25	19	55.88	7	35.00	17	56.67	7	36.84	12	54.55	5	55.56
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	20.00	4	25.00	6	17.65	4	20.00	6	20.00	5	26.32	3	13.64	2	22.22
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.00	3	18.75	4	11.76	1	5.00	6	20.00	3	15.79	4	18.18	0	0.00
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	6	12.00	3	18.75	3	8.82	5	25.00	1	3.33	3	15.79	3	13.64	0	0.00
Participant has no recommendations/is satisfied with care received	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	1	4.55	3	33.33

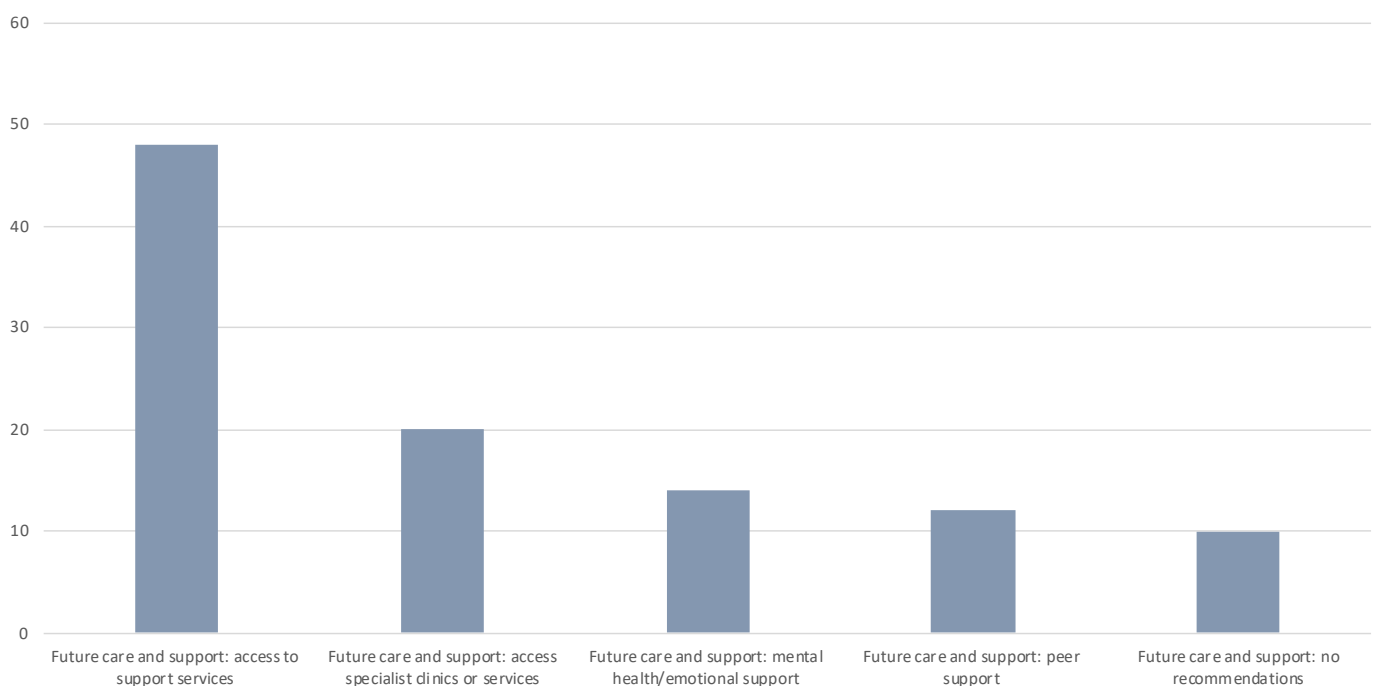


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes the expectation that future care and support will include more access to appropriate, real-world support services	Stage IV Aged 55 to 74 Higher status	Stage III Aged 45 to 54 Regional or remote
Participant describes the expectation that future care and support will include financial help	-	Stage I
Participant describes the expectation that future care and support will include mental health/emotional support	-	Regional or remote
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	-	Stage II Aged 45 to 54
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	-	Stage III Aged 25 to 44

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common themes reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments, 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

Participant is grateful for timely access to treatment

Yes, all of it has been really good. The speed from diagnosis to getting treatment was really quick. It didn't feel it at the time, but I think it was only five weeks from diagnosis to starting chemo. It was quite a quick turnaround. I was able to get appointments with the people I needed to see. The oncologist has been amazing, the breast care nurse has been amazing, the treatment team of the hospital are fantastic. It's all been excellent. There's been no issues at all with the treatment that I've been given. No. Participant_033

Yes. That would be someone's [unintelligible] I was referred straight on to the hospital, and within even though it was over Christmas and New Year period, it was within two weeks of being referred there. All my tests were done, and I was seeing people and it was all happening. I am very grateful and all of my treatment has gone through the public health system and has been free so far. Participant_018

Everything. Everything. I've got relatives in England and I know sometimes they have to wait weeks until they can access stuff. Everything happened within a week. The chemo facilities were lovely. The radiation people were marvellous. Like I said, I was lucky to

have the Mepitel for nothing. Even the chemo, the oral chemo was easy to get and all that kind of stuff. The lumpectomy was very, very smooth, and they make sure everything is good. I think everything in Australia is very, very good, and we're very lucky. Participant_035

Participant is grateful for healthcare staff

Well, having just back to the hospital experiences I had, yes, I am very grateful. My surgeons and my oncologist were just amazing. I. So even though I'm actually terrified of my oncologist and she's maybe doesn't have the greatest bedside manner and so she could be a little bit makes you feel like you stupid sometimes because she's just operating on a different level and she see so many people. But she is fantastic. And her husband, who is a breast surgeon and my plastic surgeon who was at that stage, he was right at the forefront of different techniques for reconstruction. So I was so grateful that I had them also that I had the private health because that just opened up everything. And I'm sure that saved my life as well, being able to get into that private system. Participant_001

Yes, I guess my particular team has just been outstanding. Participant_041

The fantastic doctors. We've got some of the best breast care nurses in the world, and very lucky to have gotten into here and had an exceptional result. I feel as though the team of nurses and everything are all very caring and very loving. The staff, they do amazing things. Participant_036

Participant is grateful for low cost/free medical treatments through the government

Oh, absolutely. Definitely. Like you said, we do have a really good system even financially. Not having to worry about the stresses of paying for treatments. I've seen some horror things through the forums, especially in America, where you've got to rely on insurance to come through to then get certain treatments, and this is life-saving treatments. Absolutely, I think the financial side, the medicare side of things, we are so fortunate, so fortunate here because here you don't have to worry. You can just do the treatment. The ability, the availability of tests and scans, and things like that. Participant_015

Well, when I was going through chemo and radiation and it was completely free, I was so grateful that the level of care was there. I must say, even though those doctors-- when I'm saying the doctors, anything that I've said is not against the doctors or the nurses that I dealt with because they've all been amazing, the level of care, caring people, but they're busy and that's not their fault. I would never say that it's their fault because they've all been very caring and concerned, and lovely people. No, I felt grateful that I lived in Australia [chuckles] and had that level of hospital care. Participant_029

The fact that I can receive Palbociclib, the CDK4/6 inhibitor on the PBS for \$40 a month is absolutely life-changing because I would be much, much sicker without it. I strongly believe it's responsible for my metastasis disappearing. I know that it's not available in many countries, not accessible and hugely expensive in others. Participant_050

Participant is grateful for the entire health system

I think honestly looking at the whole thing, grateful that the system is there, and just can go into action almost straight away to help you. Very grateful for the whole system really and that it appears to work and different specialists can work together to get you through it medically. Participant_004

I am eternally grateful I live in Australia and we have the health care system we have. The fact that I could go through the treatment I had to go through and not the out-of-pocket other than the surgery, I will be eternally grateful for. My ex-husband who is American and he has often said to me, "If we were living in America, we couldn't afford to be treated."

Yes. I feel that we're truly blessed to have the healthcare system we have in this country. Participant_027

Medicare, definitely. I used to bring home the injections at no cost, and they had \$1,000 something written on the box. I'd be like, "Whoa. I wouldn't be able to have this treatment at all if it wasn't for Medicare." Hugely, hugely grateful for Medicare. Just really grateful to be in Australia because our healthcare system is pretty good. I grew up in OVERSEAS. If this had happened to me there, I could have had a very, very different outcome because the cost and everything would have been exorbitant. The health system there would have been at that time overrun with COVID, so it could've been a very scary time to be in hospital. I guess if I had to pick one thing, Medicare, for sure. Participant_011

Participant is grateful for low cost/free medical care through the government

So I'm so grateful, so lucky if I'm really lucky to be able to access all those minimal costs through Medicare. Actually pay my taxes every year until I have my money. So having a public health system that provides at least some level of equity, I'm very grateful for that. I'm very grateful for the quality of care I got in a regional area. I think it has been every bit as good as Melbourne. And in fact, I would say things better than the public system because I've had consistent clinicians. I'm grateful for all of it being able to get psychological care. The White House. Participant_002

I'm grateful for all of it. I mean, I know that that needle that got poked in my stomach after each chemo was apparently like a 2000 dollar needle. Like if we had to pay for those things, that would just crush people. Yet, you know, had something in my body that could have killed me. But because of our system, I'm still here. And it didn't it's not even like we had to take out a small loan to, you know, like it didn't even cost us five grand or ten grand or twenty grand. It cost us nothing. You know, when people get their taxes done and complain about the Medicare levy, don't. Yes, it is an amazing thing. Participant_003

I'm just very thankful of that our town rallied for a cancer center down here, so I didn't have to travel to get my treatment. The only thing I went through is surgery, so chemo and radiation was all done in my hometown, which is 10 minutes away. I'm probably

thankful for the fact that it costs minimal. That we're not having to pay and remortgage houses for the treatment. [laughs] That's probably the biggest thing I've had with it. Participant_030

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant is grateful for timely access to treatment	17	34.00	8	34.78	9	33.33	7	36.84	9	36.00	10	38.46	7	29.17	5	20.83	12	46.15
Participant is grateful for healthcare staff	16	32.00	8	34.78	8	29.63	9	47.37	5	20.00	8	30.77	8	33.33	8	33.33	8	30.77
Participant is grateful for low cost/free medical treatments through the government	12	24.00	7	30.43	5	18.52	2	10.53	8	32.00	6	23.08	6	25.00	5	20.83	7	26.92
Participant is grateful for the entire health system	10	20.00	5	21.74	5	18.52	2	10.53	7	28.00	2	7.69	8	33.33	4	16.67	6	23.08
Participant is grateful for low cost/free medical care through the government	9	18.00	6	26.09	3	11.11	2	10.53	7	28.00	6	23.08	3	12.50	3	12.50	6	23.08

What participants are grateful for in the health system	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant is grateful for timely access to treatment	17	34.00	9	56.25	8	23.53	5	25.00	12	40.00	8	42.11	6	27.27	3	33.33
Participant is grateful for healthcare staff	16	32.00	6	37.50	10	29.41	7	35.00	9	30.00	4	21.05	8	36.36	4	44.44
Participant is grateful for low cost/free medical treatments through the government	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	5	26.32	5	22.73	2	22.22
Participant is grateful for the entire health system	10	20.00	2	12.50	8	23.53	4	20.00	6	20.00	3	15.79	5	22.73	2	22.22
Participant is grateful for low cost/free medical care through the government	9	18.00	3	18.75	6	17.65	2	10.00	7	23.33	3	15.79	5	22.73	1	11.11

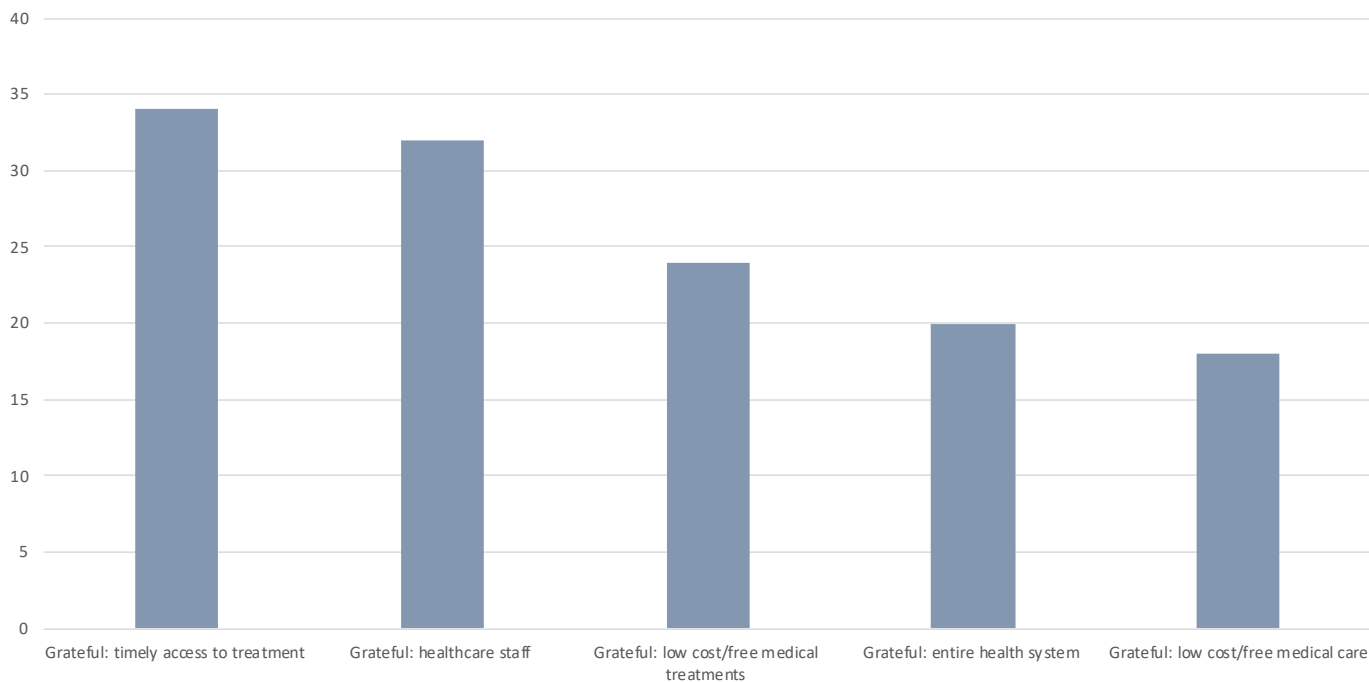


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant is grateful for timely access to treatment	Trade or high school Metropolitan	University Regional or remote
Participant is grateful for healthcare staff	Good physical function Aged 25 to 44	Poor physical function Aged 55 to 74
Participant is grateful for low cost/free medical treatments through the government	Poor physical function	-
Participant is grateful for the entire health system	Diagnosed before 2020	Diagnosed in 2020 or 2021

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.11, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Table 9.11: Symptoms and aspects of quality of life

Symptom	Weighted average (n=44)
Fatigue Pain	10.35
Lymphoedema	5.30
Fertility	1.65
Menopause and menopausal symptoms	4.17
Anxiety and depression	6.78
Body image	3.87
Sexual difficulties	3.91
Problems with movement and strength	7.09
Heart problems	7.78
Memory loss and cognitive function ("chemo brain")	7.61
Effects on bones and joints	7.48

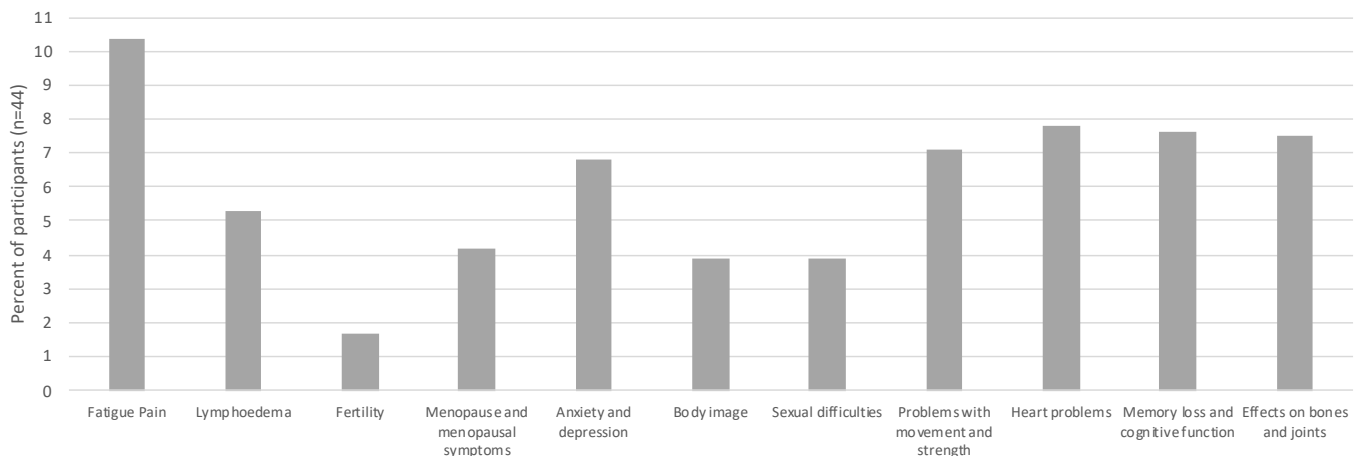


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "How personalised the treatment is for me". The least important were "Ability to follow and stick to a treatment regime" and "The financial costs to me and my family".

Table 9.12: Values in making decisions

Values when making decisions	Weighted average (n=44)
How safe the medication is and weighing up the risks and benefits	6.25
The severity of the side effects	5.55
Time impact of the treatment on my quality of life	4.84
How the treatment is administered	3.25
How personalised the treatment is for me	5.61
The ability to include my family in making treatment decisions	3.82
Ability to follow and stick to a treatment regime	3.11
The financial costs to me and my family	3.57

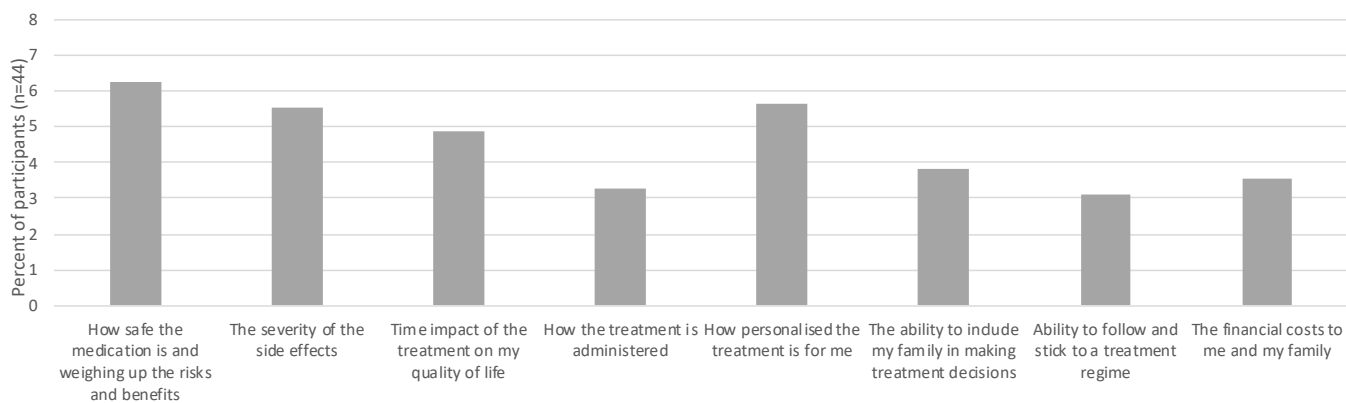


Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=44)
Economic value to government and tax payers	1.27
Economic value to patients and their families	2.68
Quality of life for patients	3.80
Compassion	3.16
All patients being able to access all available treatments and services	4.09

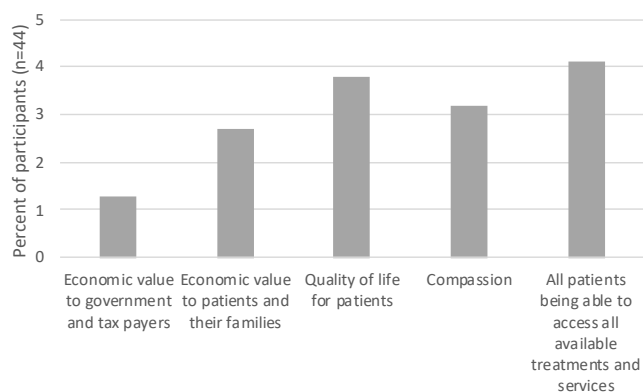


Figure 9.8: Values for decision makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The majority of participants (n = 28, 63.64%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=44)	Percent
Less than 1 year	1	2.27
1 to 5 years	10	22.73
5 to 10 years	5	11.36
More than 10 years	28	63.64

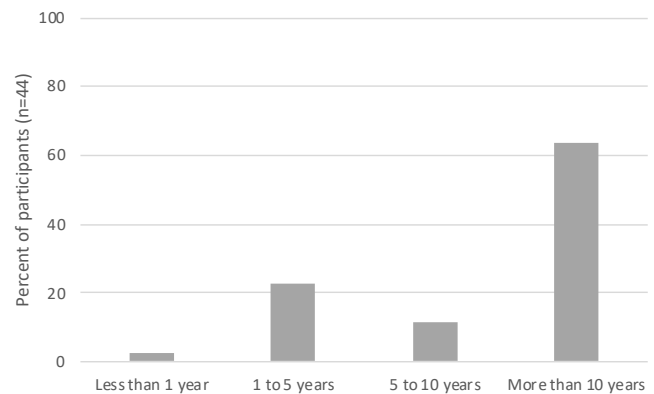


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%) (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Number (n=44)	Percent
IV form (through a drip in hospital)	15	34.09
In a pill form that can be taken at home	0	0.00
Equally effective	16	36.36
Not sure	13	29.55

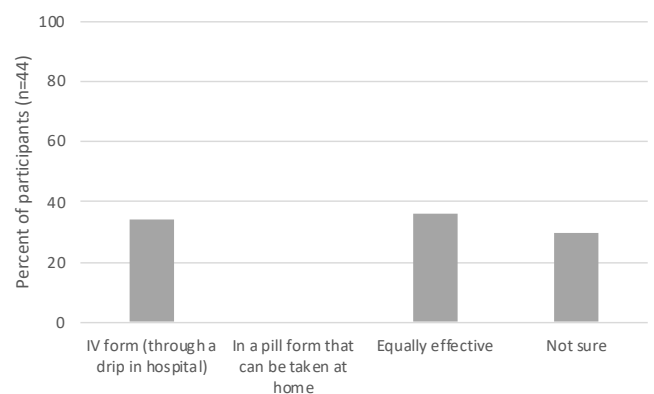


Figure 9.10: Most effective form of medicine

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?". There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n= 5, 10.00%).

Participant's message is to improve access to support and care (including treatment)

I know that there's lots of treatments that could help some people with breast cancer that they don't have access to...some people with more advanced breast cancer than I had don't have access to and possibly other types of cancer have access to. I just think that something needs to be done about speeding up access to possibly helpful drugs for people because I know that some of them are horrifically expensive. Participant_004

Oh God, I don't know. I'd have to think about this one. It would probably have to be with more access to the support from the side effects of it all. For instance, with my physio and lymphatic massage, a lot of it I've had to spend out of my own pocket and organize myself and source for myself where that could have been dealt with as part of my treatment plan from the get-go knowing what I know they know. They knew more than I did at that stage and a lot of the issues could have been dealt with initially, so I'd probably say that. I'd probably say that there needs to be more funding for them to-- Not just the treatment but the side effects of the treatment. Participant_012

That's a difficult one, but I would say I think that people like the breast care nurse, those liaison nurses need to be supported more fully. I specifically think in our region, that FTE could be increased. I think the more that you're able to access treatment resources for cancer in regional areas, obviously, makes less impact on that person emotionally, financially when they're receiving treatment. The more money that's put into getting those treatments locally, the better. I

understand that sometimes that's not always possible. The health budget is not a finite budget, but however, for those people, setting up some local treatment centres, I think from a standpoint of people not having to travel great distances to receive their treatments, must be more financially and emotionally beneficial. Also looking at those trial drugs that you see lots of different information about putting medications onto the PBS that people can access that may improve quality of life. While we argue over that, it should just be a given. Participant_013

Participant's message is to understand the financial implications (and provide financial support)

I would say that, "It's great, and thank you." I think we just need to be looking at some of the costs associated with the ongoing monitoring and maintenance because while I can afford it and there's lots of people who would struggle with that yearly maintenance. Sometimes when I found random weirdness in my boobs, I've had to go and have appointments that again have cost hundreds of dollars that I wasn't really factoring in. Just having some sort of system to manage that. Obviously, everything just cost money and money and money. It'd be nice if that sort of thing could be bulk billed or further reduced than just the standard fee for some other person who comes in and does it that doesn't even have a long-standing condition. Participant_005

Look, I think it's to make sure everyone's informed and know they have choices and not feel alone, but make sure they know of all the options, not just what that specific oncologist normally deals with or that specific surgeon. I think the cost. I read a lot of forums, and people were paying for a lot of other scans and stuff, even in Australia. I find, like I said, other than my surgery and IVF, which really threw us, I didn't pay another cent. That was one big thing because it's one less worry, one really big less worry, especially if you're not able to work. I think finance is a big-- Not everyone's in a position to go private or things like that. That's one thing that will keep you awake at night. It's my life, but I can't afford to save it. Participant_021

I think the radiation, it's a big thing for treatment, the costings and all that sort of thing. Even though I go Private Health, the out-of-pocket is ridiculous. If you pay into a health fund, you shouldn't have to pay any out-of-pocket for anything, I believe. With the

radiation, I would have had to travel an hour there and an hour back each day, if I wanted to go somewhere where I had bulk-billed radiation. Anyone in this area, it's an hour travel there and back, and you'd have to get someone to take you because you don't feel like driving afterwards. It's something that's a bit tough if you can't get to the public radiation places. They should be able to provide some assistance through the others, but like I said, you can, and you don't know those things unless you have people that will tell you those things beforehand. Participant_046

Participant's message is that tailored care plans are needed

I think for me, my message would be that it's not a one size fits all treatment for everybody. Your treatment plan has to be unique and individualized to you specifically. The only way to do that and to make informed decisions about that is to have access to the test. The resources that are available in the world, and Australia should be catching up with-- Doing these things more regularly not just relying on the way it's always happened, if that makes sense, just jumping straight into chemo. Having the test available so that informed decisions can be made about treatment plans and also access to treatment too, and ensuring the availability of that and that it doesn't cost a fortune to access that if it's going to save your life. One patient may have access to a specific type of chemotherapy that for, I don't know, bowel cancer, but if you got breast cancer it's going to cost you \$10,000. Having a little bit more appreciation to the fact that everybody's case is different, so that's why I think the genomic testing would help right in the beginning. It could save money along the way, too. Because you're not having to then go down a path of engaging in different chemos that aren't going to work, and so forth. Also on the health system, I mean, I've had access to hospital system numerous times because of my side effects from neuropathy and possible infection, and things like that that really, I might not have that if we've gone down a different path and had other things available so yes [unintelligible] where I'd go. Participant_015

This is a discussion on my Facebook page that not all cancer is the same. Even though my cancer was triple-negative, all cancers mutate differently and some respond to chemo and some don't. A lot of people go through chemotherapy to find out that after six months of chemo, that it actually hasn't responded greatly to their cancer at all. It would be to have better

access, to get out cancer genetically tested for different mutations. Participant_018

I know that there's lots of treatments that could help some people with breast cancer that they don't have access to-- some people with more advanced breast cancer than I had don't have access to and possibly other types of cancer have access to. I just think that something needs to be done about speeding up access to possibly helpful drugs for people because I know that some of them are horrifically expensive. Participant_004

Participant's message is to invest in research (including to find new treatments)

They just need to have a lot more trials available and they need to get a lot more of the immunotherapies and that sort of thing are expensive. It's proven to work, but we can't access it. That's just ridiculous. It doesn't affect you the way chemotherapy does. Participant_009

First thing I'd tell him is that all of the nurses need a pay raise, huge, huge pay raise, for what they do, for what they go through, for the care they give. I guess I'd just want to make sure that we were putting as much time and effort and money as possible into researching new ways of treating breast cancer, any cancer, different medications that could potentially be used, different types of treatment. Participant_020

I haven't really thought of something like that. I know that there's a lot of courses out there that are pushing more money, obviously is one and that's generally to support. If we could have a couple of extra breast care nurses in our hometown, I think the things that I've got concerns about would be answered. It's getting more bodies in there to then create that access. Yes, and just generally pour more money to research, get it done. The amount of money going into cancer research and stuff like that and to not have, we can get a COVID vaccine for crying out loud. [crosstalk] We can't get something to cancer why? But, anyway. Participant_030

Participant's message is to invest in specialised health professionals, especially nurses.

Breast care nurses. We need more breast care nurses, 24 hours, 7 days a week. We need that resource. I was going through treatment and one of the nurses was telling me that they had their hours cut at the hospital. I just thought, "How can they cut their hours? It's just crazy." I go to Gold Coast Uni and there was hundreds of cancer patients through there at the time. I think they did a bit of a petition too. I was telling somebody in one of the Facebook groups, and I think they all petitioned to see if we can get more hours for the breast care nurses. They're so underrated and their assistance is amazing. Participant_029

First thing I'd tell him is that all of the nurses need a pay raise, huge, huge pay raise, for what they do, for what they go through, for the care they give. I guess I'd just want to make sure that we were putting as much time and effort and money as possible into researching new ways of treating breast cancer, any cancer, different medications that could potentially be used, different types of treatment. Participant_020

I think, look, me personally, would have liked to have had a little bit more emotional support. Someone who talked to me about your feelings and what you're going through. Not at the time when you're going through it. I feel like I finished my lumpectomy and I haven't heard from that breast care nurse then. I was still going through radiation. I was still going through chemo and I was very, very lucky that I have sisters and I have older daughters that I can talk to about it because I feel if you didn't have that, there were times where you want to bash your head because you're just not feeling 100%. Like I said, at times I've-- The friend that I know who had breast cancer a year before me and said, if you found someone you can talk to. She said you've got to ring this number and that number. Otherwise, you've got to pay for it. I think that needs to be a little bit more clear for patients. The help that you can get faster, to be more clear. I feel like I finished and apart from when I see my oncologist who is very, very great, who does-- He's very caring and stuff. It would be nice to have someone just check up on you every now and again and say, "How you doing?" I feel like the breast care nurse was supposed to do that, but because of everything with COVID, she never really got to get a rapport going with all the patients. I think we need care after-- We need a little bit of aftercare to make sure that we're doing okay after it because I think a lot of your friends tend to think, "Oh, you've finished treatment. You're back

normal." They don't realize that you're still fatigued and your bones are still hurting and you're still not sleeping at night. I think they just think, "Oh, the treatment's over and you're back to normal." type of thing. Participant_035

Participant's message is that the health system they are satisfied with their care, that it should stay the same

You know what? Just to put a spanner on it on you, I actually think that breast cancer is really one of the more well-funded-- it gets a lot of attention already. My mum had uterine cancer and a fairly rare kind. They don't even have a protocol. They use the ovarian cancer protocol. It's those rare cancers that worry me more because I think breast cancer gets a lot of attention, and big names put a lot of fundraising and support into it. I felt fortunate because -- It's so much more treatable now than it used to be. So many women are surviving it really well. For me, the concern is more those other cancers that are getting forgotten. Participant_011

Oh, goodness. Just don't change it. Participant_014

I'm eternally grateful for the treatment that's available to me to get a chance at beating this. I know that in other countries I may not be so fortunate. I believe that the treatments I'm getting are the gold standard treatments for triple-negative breast cancer. I believe that the dose-dense chemo, everything that's available that I'm able to access pretty much immediately, 10 minutes down the road from my house, is phenomenal, and I'm very, very grateful. That's what I'd be telling him. It's fantastic the treatment that is available and I have no issues with that whatsoever. Just knowing that it's all available on our doorstep is pretty cool. Participant_033

Participant's message is that treatments need to be holistic

Well, I think for breast cancer, I think we're actually really lucky, I think, because there's a lot of focus on breast cancer. I think that some of the other types are neglected. But I would say more funding for the holistic emotional support because your mental state is so crucial to your recovery. And so I don't think it can be neglected and just go to the purely functional, cut it out, whack the drugs and off you go. So there's so much more to a person. So I think the doctors and nurses that they're just all doing their best. So much more funding round. Participant_001

They also need to make treatment more affordable, that sort of thing. That has to change. Just because you don't have a lot of money and, say, can't afford to pay hundreds of thousands of dollars for treatment, doesn't mean you should be punished for it. We should all be able to access the treatment, especially if we can see that it's working. Basically more, unfortunately, more money needs to be spent on curing cancer or cancer treatments. I don't know if that's ever going to happen. I don't know how much they're going to be able to perfect it, but I can see that it is starting to happen. They also need to do something with regards to the impact that it has on a person's mental health as well. It's still a lot that needs to be done. Participant_038

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. I also think I would be telling him that there needs to be more care given in terms of, I guess if you said holistic. There needs to be more access to physios and psychologists and things like that as part of a government rollout. Participant_036.

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant's message is to improve access to support and care	22	44.00	11	47.83	11	40.74	7	36.84	10	40.00	11	42.31	11	45.83	8	33.33	14	53.85
Participant's message is to understand the financial implications (and provide financial support)	16	32.00	8	34.78	8	29.63	6	31.58	7	28.00	10	38.46	6	25.00	7	29.17	9	34.62
Participant's message is that tailored care plans are needed	11	22.00	5	21.74	6	22.22	7	36.84	3	12.00	4	15.38	7	29.17	7	29.17	4	15.38
Participant's message is to invest in research (including to find new treatments)	7	14.00	4	17.39	3	11.11	2	10.53	4	16.00	3	11.54	4	16.67	4	16.67	3	11.54
Participant's message is to invest in specialist health professionals, especially nurses	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	2	7.69	5	20.83	5	20.83	2	7.69
Participant's message is that the health system they are satisfied with their care, that it should stay the same	5	10.00	4	17.39	1	3.70	2	10.53	3	12.00	2	7.69	3	12.50	2	8.33	3	11.54
Participant's message is that treatments need to be holistic	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	2	7.69	3	12.50	3	12.50	2	7.69

Message to decision-makers	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant's message is to improve access to support and care	22	44.00	9	56.25	13	38.24	7	35.00	15	50.00	9	47.37	8	36.36	5	55.56
Participant's message is to understand the financial implications (and provide financial support)	16	32.00	5	31.25	11	32.35	9	45.00	7	23.33	7	36.84	8	36.36	1	11.11
Participant's message is that tailored care plans are needed	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	4	21.05	5	22.73	2	22.22
Participant's message is to invest in research (including to find new treatments)	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	4	21.05	3	13.64	0	0.00
Participant's message is to invest in specialist health professionals, especially nurses	7	14.00	2	12.50	5	14.71	2	10.00	5	16.67	3	15.79	1	4.55	3	33.33
Participant's message is that the health system they are satisfied with their care, that it should stay the same	5	10.00	2	12.50	3	8.82	4	20.00	1	3.33	0	0.00	4	18.18	1	11.11
Participant's message is that treatments need to be holistic	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	1	5.26	3	13.64	1	11.11

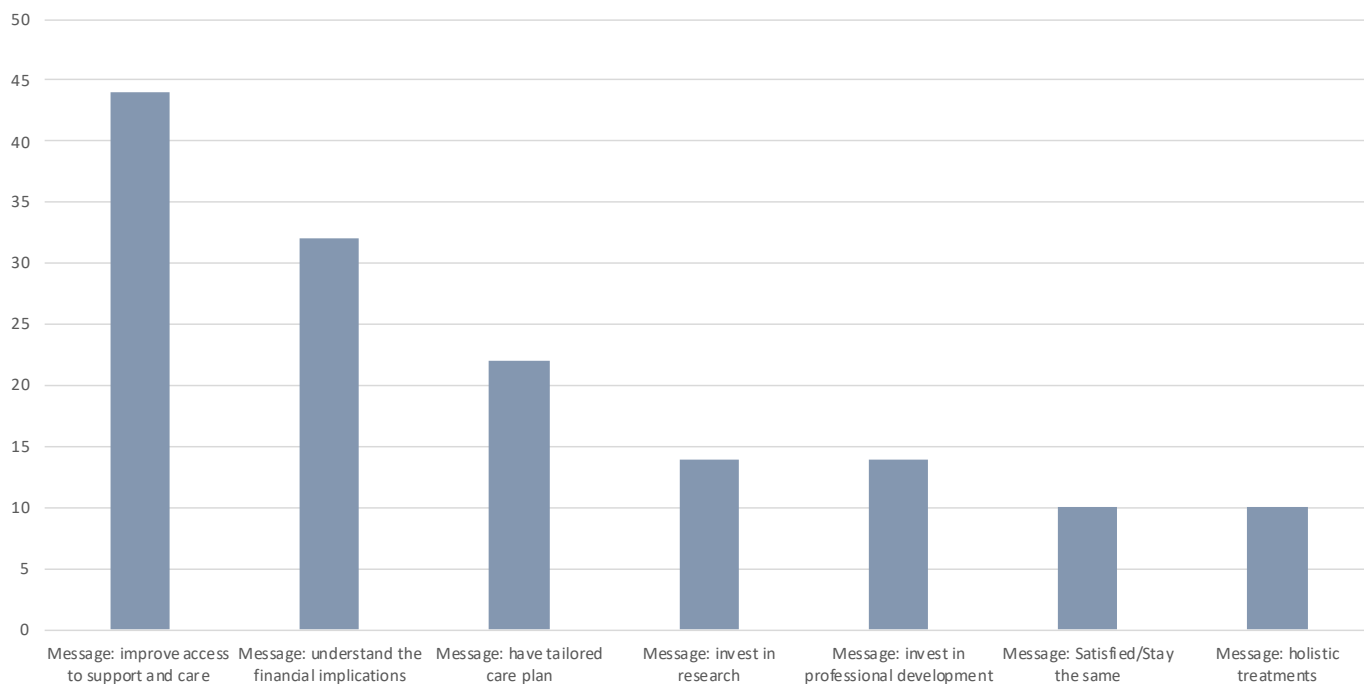


Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant's message is to improve access to support and care	Trade or high school	Regional or remote Aged 55 to 74
Participant's message is to understand the financial implications (and provide financial support)	Aged 55 to 74	Mid to low status
Participant's message is that tailored care plans are needed	-	Poor physical function
Participant's message is to invest in research (including to find new treatments)	Aged 55 to 74	-
Participant's message is to invest in professional development so that clinicians understand the condition	-	Aged 55 to 74