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 theme was that future treatments that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

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. The most common theme was the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently 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 theme was that participants had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

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. The most common theme was that future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

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 were that participants were grateful for the healthcare staff (n=17, 32.77%), and the entire health system (Includes having access to good healthcare and having options) (n=16, 30.77%). Other participants were grateful for access to private healthcare/private insurance (n=15, 28.85%), timely access to treatment (n=13, 25.00%), low cost treatment and medical care through the government (n=12, 23.08%), and timely access to diagnostics (n=6, 11.54%).

Symptoms and aspects of quality of life

The most important aspects reported were memory loss and cognitive function, fatigue, pain problems with movement and strength, and effects on bones and joints. The least important was fertility.

Values for decision makers

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”.

Values in making decisions

The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important were “The ability to include my family in making treatment decisions” and “The financial costs to me and my family”.

Time taking medication to improve quality of life

Almost half of participants (n = 25, 49.02%) 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 most commonly responded that they thought that IV and pill were equally effective (n = 21, 41.18%), followed by not being sure.

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?” The most common messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

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

I guess, the holy grail would be the hormone blocker that didn't cause menopause in the rest of the body. The true breast specific hormone blocker would be fantastic because it would just reduce the side effects and not leave you with that decision to make between maintaining your future health and given your cancer. Participant 005_2021AUHRP

They probably do need to look at the medication that they want you on for the next five years and how to make that much better for women. I feel sorry for some of the younger women though they got to be pushed into early menopause and all of that stuff at least I don't have to do that. Really been there done that sort of thing. Participant 030_2021AUHRP

I don't think anyone should have to pay in Australia for health care of that nature. Because I think it puts a value on people's lives, that is unrealistic because you know you can't do that assess that someone's life is more valuable than someone else's or someone else's can afford it more than someone else. I think it should all be free or you know covered like with Medicare. As far as treatment something other than chemo would be fantastic that doesn't mush your brain and puts you in a perpetual state of old ladyness. No offense to old ladies but I would have liked to go up there naturally and then um you know if there are side effects you know what work harder on getting treatments for it not to say well you know suck it up because like like like I have realized recently that we are living longer which means they're living longer with the side effects. I you know, you need to have a good quality of life not just enough just to live because you might last five years or whatever. I'm gonna live a long life hopefully. Participant 045_2021AUHRP

Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover

There would be some women out there that had the benefit from a treatment that just clearly can't afford it, so that would be helpful. In terms of their special stuff, they know their stuff, and I wouldn't want to change anything with them. Let me explain that a little bit better. If they say that I need Tamera or whatever medication I need, then I need that, otherwise, this cancer is going to come back, so I have a choice. I either take the medication, and I've got a life, or I don't take the medication because I can't stand the side effects, and then, well, I take my chances. Every individual has to make that decision themselves, but I'll put up with the side effects to give myself the best possible chance of surviving. Participant 004_2021AUHRP

Oh, definitely. I think the side effects and the impact on the day-to-day loss, because you often have your treatment away, you don't actually know what impact that's going to have on your day-to-day life until you return to work or you return home and you start care of resuming your role as a wife or a mom. That's probably a big thing. The cost, yes, definitely. Participant 031_2021AUHRP

For new treatments? I think we need to be quicker in getting things funded on the PBS, the new treatments, or new protocols. For instance, an MRI isn't standard scanning for my type of cancer, although in the States, I know they've got a different approach to funding and stuff like that but it isn't. Let's get a bit quicker around the funding that's available. With regards to reconstruction, like really looking at some of the second phase stuff that happens around reconstruction. I think for DX, which is seen as the gold standard in reconstruction, really starting to open that up as being more available to people, particularly on public because there's such a long waiting list for it. Participant 043_2021AUHRP

Participant describes the expectation that future treatment will be more effective

I am disappointed at my tissue loss in my breast because of the hook, or I would I really wish there was a more sophisticated clinical way to get to that tumour without removing as much tissue as I experience. And from my interpretation of things that when you have dense breasts and you got fatty tissue, that the risk of losing is a very real risk. And, you know, it occurs to me twice and I know that when the hook was replaced in situ and they were quite in situ and things like that, and I did nothing at all to kind of move them or that I wish I wish that there was a better technique of seeing them removing the tumour. Participant 019_2021AUHRP

I mean, ultimately, it'd be nice to have a cure for at the very least a treatment that what didn't have the side effects, I guess. It is what it is. And yeah. Participant 020_2021AUHRP

Now I consider that not only the fact that I have fought breast cancer, but now it's all these other things that are going to go along with it. I think that that needs to improve in more understanding and more, I don't know, surely there is something that they can do to that is going to target better or I don't know. You try to get through one thing, but now you have just jeopardized a whole lot of other body systems. Participant 048_2021AUHRP

Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)

I think the accessibility to treatments is really important, that cost shouldn't be a barrier. With any area, I think there's ongoing work towards improving outcomes and reducing side effects. That's always a good thing. That's what we strive for.
Participant 011_2021AUHRP

I just think that because of the distances in Australia they could do a lot more with setting up clinics outside of the main hospitals. Main public hospitals. The public hospital system here needs to do a little bit more I think because if you live a long way away you've got to come in and drive in and you've got to drive distances and in my view, I just think the geographic side of where these hospitals are based and they're too far apart. Participant 032_2021AUHRP

Could I have none of that stuff, no cost, no side effects? That'd be awesome. It's interesting that where it's been administered does impact. I feel like an absolute winger to say that the trial just being in LOCATION went on both in LOCATION, that was-- I wouldn't say problematic, but it was more impactful than the ones at my closer hospital, which is only within 10, 15 minutes, as different to half an hour, 45 minutes drive. Having to wait six weeks for a specialist appointment rather than get in in a timely fashion, when you know things are hanging in the balance, that's really a relief when that stuff comes through. Obviously, it'd be nice if things were reasonably priced, but I think just having availability is the first and most important thing. Sure, I don't want side effects, but damn I want availability of stuff if it's going to make a difference. Participant 051_2021AUHRP

Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways

The cost of the core biopsy, I think, needs to be looked at. I think people need to be given more information at the time when they're told if they've got breast cancer. I know it's probably a shock to a lot of people, but I think I knew what I was getting into anyway. I think I knew it was already cancer. Yes, I just think people need to-- because it's the nurse's job, they just do it automatically. I don't think-- because I had an experience with the radiation, one of the nurses there, and I didn't think she was at all had any empathy. She was quite cold. I think they need to realize that they know it, but they've got to pass that information on. They can't just slide over it if you already know. Do you know what I'm trying to say? Participant 012_2021AUHRP

Probably, I had to find some of the services myself, things like Breast Cancer Care and Solaris. Once you've been diagnosed and going, maybe looking at things to help you maybe for those community process to be introduced to the patient early on maybe through a breast cancer nurse or something like that, or if there's a website or something that would give you all this information of where you can access more services. Participant 049_2021AUHRP

I don't know if this fits in here, but I would like there to be more communication. I didn't have an experience of having, I didn't feel I had a team of people who were looking after me in relation to my treatment, so I would like a more coordinated, in the sense of a, team. I think it's important that people are offering treatments that there's some coordination between them. The other thing is that for me, I'm sorry if I'm not, it's just difficult to sometimes to think of what I've got to say. I'd like them to be clearer about dealing with the side effects. It wasn't really clear to me who was going to manage because I didn't think ask, I just assumed that, say, the radiation therapist would manage the side effects related to that. That wasn't my experience at all. In terms of managing side effects, knowing who was going to manage that, who do I go to, to manage that? Participant 047_2021AUHRP

Table 9.1: Expectations of future treatment

Expectations of future treatment	**All participants**		**Stages 0 and I**		**Stage II**		**Stages III and IV**		**Aged 25 to 54**		**Aged 55 to 74**		**Trade or high school**		**University**	
	n=52	**%**	**n=19**	**%**	**n=21**	**%**	**n=12**	**%**	**n=29**	**%**	**n=23**	**%**	**n=19**	**%**	**n=33**	**%**
Participant describes the expectation that future treatments will have fewer or less intense side effects	27	51.92	9	47.37	13	61.90	5	**41.67**	17	58.62	10	43.48	7	**36.84**	20	60.61
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	17	32.69	6	31.58	6	28.57	5	41.67	11	37.93	6	26.09	8	42.11	9	27.27
Participant describes the expectation that future treatment will be more effective	14	26.92	6	31.58	5	23.81	3	25.00	5	17.24	9	**39.13**	5	26.32	9	27.27
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	15.38	3	15.79	2	9.52	3	25.00	3	10.34	5	21.74	3	15.79	5	15.15
Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways	8	15.38	3	15.79	3	14.29	2	16.67	4	13.79	4	17.39	4	21.05	4	12.12

Expectations of future treatment	**All participants**		**Diagnosed in 2016 or before**		**Diagnosed in 2017 to 2019**		**Diagnosed in 2020 or 2021**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=52	**%**	**n=10**	**%**	**n=16**	**%**	**n=26**	**%**	**n=11**	**%**	**n=41**	**%**	**n=18**	**%**	**n=34**	**%**
Participant describes the expectation that future treatments will have fewer or less intense side effects	27	51.92	5	50.00	8	50.00	14	53.85	6	54.55	21	51.22	11	61.11	16	47.06
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	17	32.69	5	**50.00**	6	37.50	6	23.08	3	27.27	14	34.15	5	27.78	12	35.29
Participant describes the expectation that future treatment will be more effective	14	26.92	4	**40.00**	4	25.00	6	23.08	2	18.18	12	29.27	6	33.33	8	23.53
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	15.38	2	20.00	3	18.75	3	11.54	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways	8	15.38	2	20.00	4	25.00	2	7.69	2	18.18	6	14.63	3	16.67	5	14.71

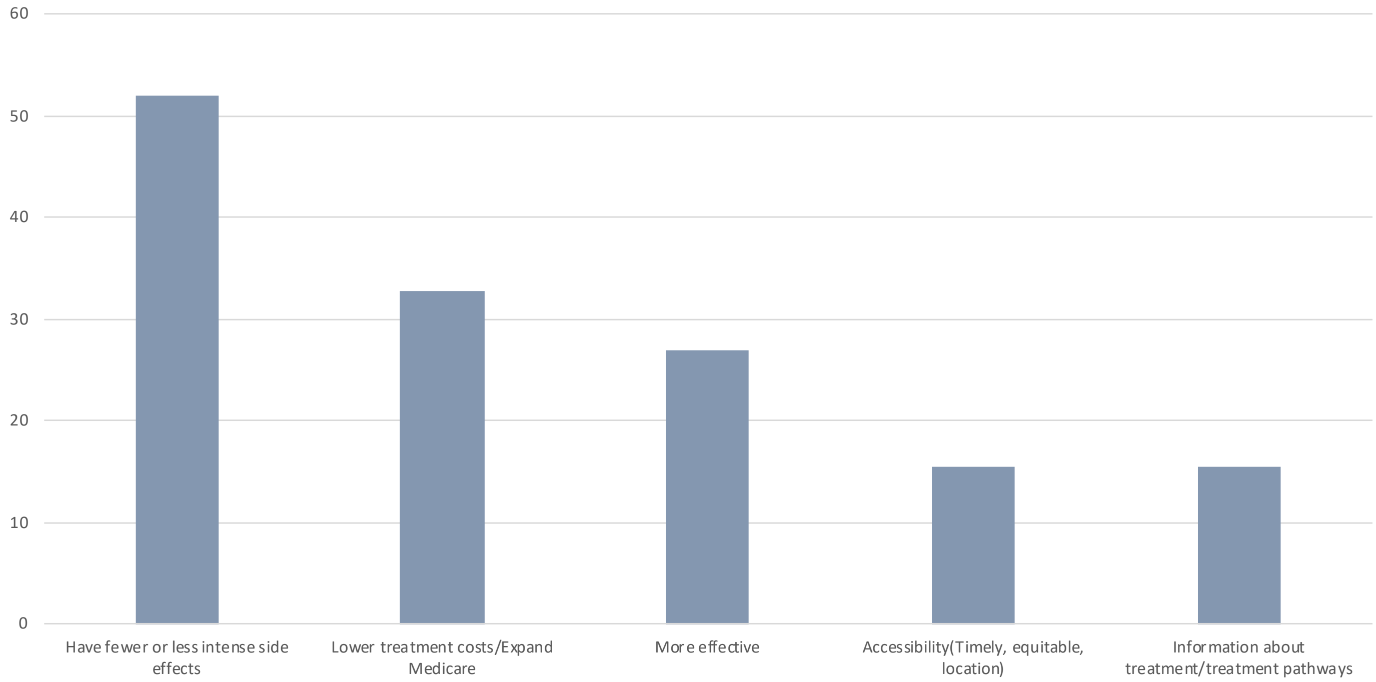

Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatment	**Reported less frequently**	**Reported more frequently**
Participant describes the expectation that future treatments will have fewer or less intense side effects	Stage III and IV Trade or high school	-
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	-	Diagnosed in 2016 or before
Participant describes the expectation that future treatment will be more effective	-	Aged 55 to 74 Diagnosed in 2016 or before

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. The most common theme was the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently available.

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

Probably more of menopause, because I went straight into that. I wish someone would've warned me what menopause was like. Participant 006_2021AUHRP

I think probably the issue with the nerve. The nerve pain that you actually get, but not everybody gets. That's something I had no idea about. Even with all my 40 years nursing experience, I had never heard anybody say anything about the nerve pain, and maybe that's because mostly it doesn't happen until you actually leave hospital. It wasn't actually until I'd got home and been home for a day or two that it started. That may be because of the local anesthetics and all that that are put in when you have the surgery maybe, and you don't feel it. That's probably something that people should be told about and given ways to deal with it, rather than-- It was a week later before I actually-- When I went and saw the breast care nurse a week later, and she told me what had to be done to relieve it, which was basically massaging it, which was excruciating. Participant 017_2021AUHRP

Maybe a little bit more explanation about the radiation. When they were doing the planning and everything, they said, "Look, if you can, we'd like you to hold your breath for 30 seconds." I couldn't do it and because each time-- I had to do it six or seven times, but they said, "That's fine." At the end of it, it was one of the reasons you've got radiation pneumonitis is probably because you weren't holding your breath. Maybe if that had been spelled out a little bit more, I'd asked some more questions and worked a way around minimizing that risk.
Participant 039_2021AUHRP

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

Well, I did a project of my own me absence of other things. So in actually, just before I was diagnosed, the second time, I just did my own grassroots project where I got money from local cancer care and groups, too. And I put together a booklet, which are called the Breast Cancer Resource Guide for the LOCATION or something I helped the LOCATION breast groups do they already had this similar thing, and then I updated theirs while I was going through all my cancer as a way of saying thank you for the help. They did. Put together a booklet for, you know, services in the LOCATION. But not just about people going through breast cancer, but also support and services available to their partners, their children, friends, and pulled all sorts of information from places like the BCNA think about lymphedema, like the holistic view of going through treatments that were literally you know, books that you could pop in your handbag and go okay, I've heard about that things about you know, if you go through you know, you're not well enough in how do I get to the hospital for my treatment? Well, you know, what is that might be not community transport, but things like yeah, they Cancer Council have a transport service and things like that would be great to have more, you know, perhaps in each local health district around the state that it really does is something that has to be updated and can get out of date quickly Participant 013_2021AUHRP

I don't think there's anything that wasn't covered that I saw. I mean, everyone's going to be different, but in my situation, everything was pretty well covered. I suppose as technology goes on, maybe it could be done digitally as an app with different, obviously different states would require different contact information. You could make it relevant to the state or even to the hospitals that it's through, which would give you all the numbers that you'd need in an emergency and things like that. I know when I was going through chemo, I had like a card from the hospital and had my name and my hospital number on *it, and it had the numbers on there, and it was a card that if you got a fever, you just showed this card at the hospital, and you were admitted pretty quickly, and what I did was I took a photo of it with my phone and had it as my lock screen. Participant 025_2021AUHRP*

I think that's support. The direct link of this is what you need to fill out. This is how you're going to get that financial support and someone directly there to help you and take out all that time. I spent I don't even know how long on hold, waiting for letters, waiting for support, getting turned around from person to person. Like a ridiculous RSM. I spent a good 20 hours on the phone for them trying to get the support to then fill out all the documents and be told no because we've done something wrong, and then to resubmit it. Then by the time we resubmit it, we had to get the accountant involved, just that sort of thing. That really needs to change. Participant 042_2021AUHRP

Life after cancer, I think. We are in a country that is top for success in treatment for breast cancer. Via that, you have more women who have fabulously that kind of surviving through it. It can feel like you've fallen off a cliff once you finish treatment because you've had such amazing care, this nest of support that's been around you. What happens after? Actually, on Instagram, it's one of the real-- Even on the Facebook groups, it's one of the real questions, and real--People are not sure how to navigate it, what to do after post-treatment. I think there's an amazing amount of support and care around in treatment. I think we need to be looking at post-treatment, because what we want is more women to be surviving this. If that is the case, then the post-treatment breast cancer community is just going to grow and get bigger. What are we going to do to be able to support that, whether that's through allied health or through getting some of these networks in place so that people just don't feel abandoned? Because that's what you hear. A lot of the abandonment feeds into the mental health issues that surround it.
Participant 043_2021AUHRP

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

Well, I honestly think you can source any amount of information you like through Dr. Google however, is it really accurate? Being able to access breast care psychiatrists or psychologists or whatever they call them and that most of that's free of charge. I think that's important to have and that's accessible so that's fine. I don't know. Participant 010_2021AUHRP

As I said, I've had to find lots of other-- I think, after finding like a face group work, which is basically women, that was probably-- It shows how much topics that aren't covered through what these women are discussing? Participant 021_2021AUHRP

I think the exercise business is really important, and I think things have changed since I was diagnosed. I've noticed other groups have set up. Whether or not that's in the information you get when you first get it. Definitely, things like, I can't get over that no arm exercises were mentioned. The ones I picked out, I would have thought they'd have something diagrammatically, just as I found them, to be-- The help was unbelievable on them, and yet, I can't believe there's not a standard booklet for it. Participant 022_2021AUHRP

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

Not really. Obviously, when you're in the radiation, they've got every single pamphlet about every type of cancer on the wall. I think I had the information that I needed. Participant 007_2021AUHRP

PARTICIPANT: No, not really, because I did that workshop and that went from nutrition to exercise to all sorts of different topics. I was going when- was postponed at one time because of COVID but it was twice a week. That covered the exercise program then you'd have the talk afterwards.
INTERVIEWER: Sounded really valuable
PARTICIPANT: Yes. Participant 015_2021AUHRP

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

Yeah, yeah. So I think as I sort of alluded to with the medical oncologist, just the availability of potentially complementary alternative, integrative kind of options, just to let people know that they're out there, because they are people that won't go and look, and they just throw all their trust in the doctor and that oncologist, and maybe I think, you know, to be honest, having brother and sister in law, who were, you know, nice interests, and whatever, as well, I think the medical profession is extremely arrogant. And I'm not saying they're not caring, but I think it's the way they taught. They, you know, they kind of, you know, turn their nose up at anything that's, you know, like, the chiropractor or, you know, they, it's not traditional medicine, they seem to sort of discount. And I think that's a, that's a really dangerous concept. Participant 034_2021AUHRP

I don't know. I just think of food, nutrition. Then again, they did provide me with making an appointment with a nutritionist, so that was me not taking advantage of it. Participant 040_2021AUHRP

I think for me personally, I'd like to see the medical profession, maybe be a little bit more open to alternative options and not so cut and dried about no, don't go there. Participant 047_2021AUHRP

Participant describes the expectation that future information will be specific to type/stage

Yes, I think the one thing that would be useful would be to start to really see breast cancer as multiple diseases, which of course it is, and to try and really separate out what we're talking about because sometimes that's the hard bit to split-- even in the big clinical trials, it can be really hard to work out even what were the age of the participants?
Participant 005_2021AUHRP

One of my son's friend's mothers had a relapse after 10 years or more, and very aggressive disease. She's been through the wringer. We're talking to them. She's doing well now, which is good. Talking to them, and also talking to them about [unintelligible 00:50:39]. One of the things I said to them was, "You can tell people. If you say to people mum's got breast cancer, some people may react like I'm dying. I'm not dying." and they trust us and believe us. Yes. The information and stuff for them, I thought, could have been a bit better. Participant 011_2021AUHRP

Participant describes the expectation that future information will include personalised records of diagnosis and treatments

Probably not because luckily my husband was able to be there as the support person at the time and just sort of, i don't know, you just don't hear everything anyway. So the bits that I didn't hear he seemed to hear. But don't think I could have taken in much more information at the time but think then, the support person can't go in any where with you for the COVID so that's hard this additional thing that you don't have anyone to confirm it with. Most of my problems are COVID related. Participant 014_2021AUHRP

Participant describes the expectation that future information will be more targeted to a specific age group

Okay. This is actually one's that I do have an interest in, in not so much perhaps what the information is, but the way that we as consumers comprehend especially those initial appointments. The hospital where I now work does have a policy around recording appointments. I actually think that there should be a lot more of it, it will both protect the clinician and provide the consumer, patient, whatever you want to call everyone with-- They can go home and listen back and go, oh, I didn't actually pick up on that during the appointment. It's actually something that lots of people on the BCNA forum talk about that suppose I heard about it. I actually think that to protect themselves hospitals probably need, to look at recording all outpatient appointments and providing the client, the patient with a copy of it. I think that in terms of that way, they've got proof of what information was provided, not just for what's written, but what can be actually heard. As I said, the patient can listen back and go on. "I missed that, I've got to ask about that the next time I'm there, so the way of that side of communications, in terms of the way things are delivered, I'm very happy with verbal communication, being given links to websites, but paper-based still needs to be provided for people that don't have access to the internet, your elderly population. Participant 023_2021AUHRP

Yes, I think-- I think-- There seems to be a bit of a connection with menopausal women and getting older, and as I said in my group I've got younger women but from around about 45. A lot of the women I know are 45 or older. Whether there's a connection with menopause but I would like to see women here being encouraged to see an endocrinologist or whatever about hormones. From where that plays a part in it. Participant 032_2021AUHRP

I definitely think we need more information for young women with breast cancer. Like. And, you know, and making it more accessible. And I guess that, you know, like, I haven't, you know, asked my oncologist, that question, you know, about, you know, whereas she might have more information about that now, but because I'm so far down the track, the conversation we had, but, you know, being able to, you know, ask about how is how are all the medications going to affect me what happens when I come off them, you know, that access to other women who had similar age? You know, I know that there. There are definitely Young Women support groups out there now. But there they weren't when I was first diagnosed, there was like one that was up in LOCATION. And that was it. And I was like, Well, I can't get to that, because it's really far away. And so now, like, you know, you know, needing support doesn't necessarily go away. But now I'm like, 12 years down the track, and at a completely different stage, to those people that are accessing the support groups are sort of, like I still can't accept them, because it's not the same. You know, and so that's, I think, especially, that's why I looked at, looked at the online support through Facebook page and stuff and got annoyed with people because writing dumb stuff, so I was tapping out of that. Participant 033_2021AUHRP

Table 9.3: Expectations of future information

Expectations of future information	**All participants**		**Stages 0 and I**		**Stage II**		**Stages III and IV**		**Aged 25 to 54**		**Aged 55 to 74**		**Trade or high school**		**University**	
	n=52	**%**	**n=19**	**%**	**n=21**	**%**	**n=12**	**%**	**n=29**	**%**	**n=23**	**%**	**n=19**	**%**	**n=33**	**%**
Participant describes the expectation that future information will provide more details about symptom and side effect control	16	30.77	**8**	**42.11**	6	28.57	**2**	**16.67**	**5**	**17.24**	**11**	**47.83**	**8**	**42.11**	8	24.24
Participant describes the expectation that future information will provide more details about where to find available services	13	25.00	5	26.32	6	28.57	2	16.67	7	24.14	6	26.09	4	21.05	9	27.27
Participant describes the expectation that future information will be more accessible/easy to find	11	21.15	3	15.79	5	23.81	3	25.00	4	13.79	7	30.43	**6**	**31.58**	5	15.15
Participant has no recommendations/is satisfied with the information currently available	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	3	15.79	4	12.12
Participant describes the expectation that future information will provide more details about holistic treatments	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	2	10.53	4	12.12
Participant describes the expectation that future information will be specific to type/stage	6	11.54	2	10.53	2	9.52	2	16.67	4	13.79	2	8.70	1	5.26	5	15.15
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	6	11.54	1	5.26	3	14.29	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant describes the expectation that future information will be more targeted to a specific age group	5	9.62	**4**	**21.05**	1	4.76	0	0.00	2	6.90	3	13.04	3	15.79	2	6.06

Expectations of future information	**All participants**		**Diagnosed in 2016 or before**		**Diagnosed in 2017 to 2019**		**Diagnosed in 2020 or 2021**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=52	**%**	**n=10**	**%**	**n=16**	**%**	**n=26**	**%**	**n=11**	**%**	**n=41**	**%**	**n=18**	**%**	**n=34**	**%**
Participant describes the expectation that future information will provide more details about symptom and side effect control	16	30.77	3	30.00	5	31.25	8	30.77	**5**	**45.45**	11	26.83	**9**	**50.00**	**7**	**20.59**
Participant describes the expectation that future information will provide more details about where to find available services	13	25.00	2	20.00	5	31.25	6	23.08	3	27.27	10	24.39	4	22.22	9	26.47
Participant describes the expectation that future information will be more accessible/easy to find	11	21.15	3	30.00	2	12.50	6	23.08	**5**	**45.45**	6	14.63	**2**	**11.11**	9	26.47
Participant has no recommendations/is satisfied with the information currently available	7	13.46	1	10.00	2	12.50	4	15.38	**0**	**0.00**	7	17.07	1	5.56	6	17.65
Participant describes the expectation that future information will provide more details about holistic treatments	6	11.54	**3**	**30.00**	1	6.25	2	7.69	**4**	**36.36**	2	4.88	**4**	**22.22**	2	5.88
Participant describes the expectation that future information will be specific to type/stage	6	11.54	1	10.00	3	18.75	2	7.69	1	9.09	5	12.20	2	11.11	4	11.76
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	6	11.54	**0**	**0.00**	1	6.25	5	19.23	1	9.09	5	12.20	1	5.56	5	14.71
Participant describes the expectation that future information will be more targeted to a specific age group	5	9.62	1	10.00	1	6.25	3	11.54	**3**	**27.27**	2	4.88	2	11.11	3	8.82

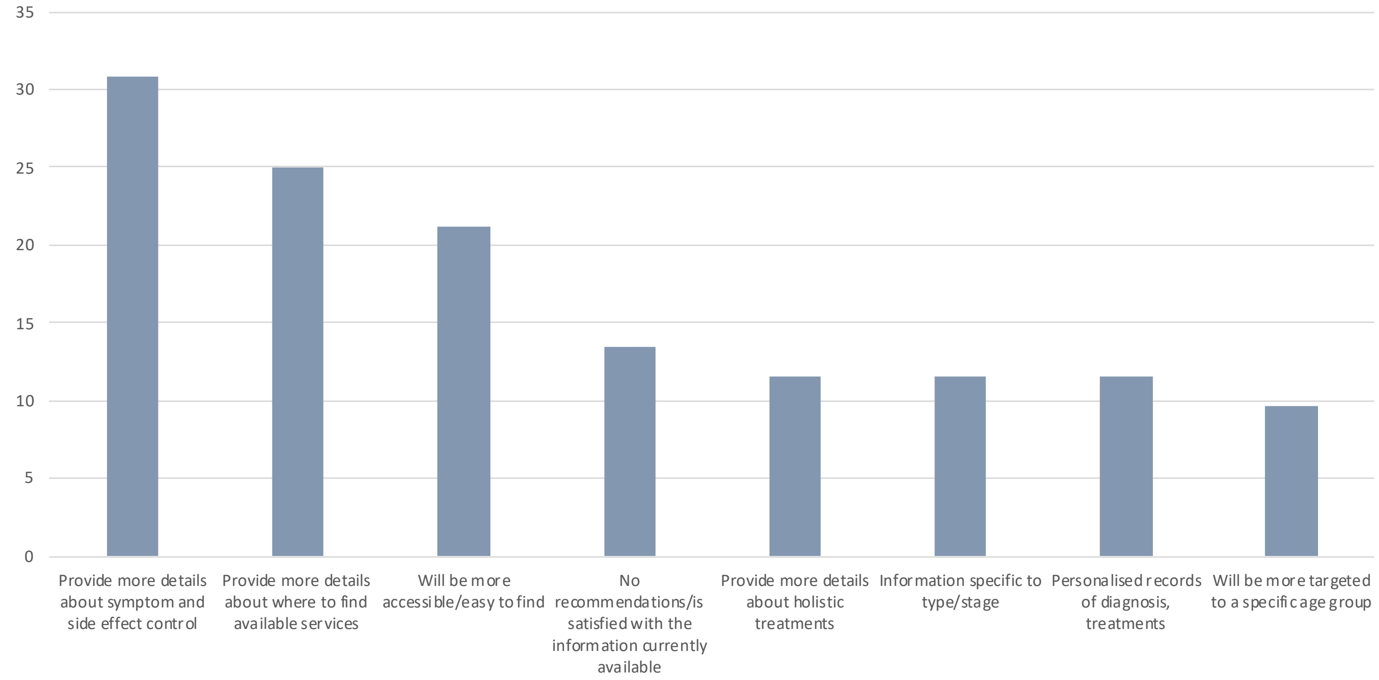

Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
Participant describes the expectation that future information will provide more details about symptom and side effect control	Stage III and IV Aged 25 to 54 Higher status	Stage 0 and I Aged 55 to 74 Trade or high school Regional or remote Mid to low status
Participant describes the expectation that future information will be more accessible/easy to find	Mid to low status	Trade or high school Regional or remote
Participant has no recommendations/is satisfied with the information currently available	Regional or remote	-
Participant describes the expectation that future information will provide more details about holistic treatments		Diagnosed in 2016 or before Regional or remote Mid to low status
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	Diagnosed in 2016 or before	-
Participant describes the expectation that future information will be more targeted to a specific age group	-	Stage 0 and I Regional or remote

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 theme was that participants had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

Participant has no recommendations/experienced good communication

No, I think mine has been very good. They've been very clear in what they say, I can't fault any of them, really. I've just been very, very lucky with the surgeon and the oncologist that I've got and I have a good rapport with my GP. Participant 004_2021AUHRP

No, I don't think so. I had a very good experience with all of my health professionals. I think they all worked really hard to meet me where I was at, rather than where the average kind of thing. If you asked for more information they gave it. It's very hard to always immediately picture that's exactly the right amount of information because nobody wants to know as well which is hard. Some people want to know almost nothing. Just tell me what to do, and other people want to know everything, but I think they all do very well to try and match me. Participant 005_2021AUHRP

No. I think they're pretty understanding. I felt well cared for and compassionate to what we're going through, I think. I think in general the people I came in contact with were like that. Even from having the PET scans and the MRIs and things like that before I had the surgery, everyone was very compassionate and understanding. Participant 009_2021AUHRP

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

Yes, as I said, once again, I think they need to be more open and more honest about the whole process. Look, I understand that everything's a learning curve even for these guys, but they've been doing it long enough now to know what the realities are and I think that transparency and honesty has to be the key. It just has to be because without it, it makes it difficult for us to process what we're going through because a lot of what we go through is not being validated. It really isn't being validated. It's being brushed aside as, "You're in a small minority," when the reality is no, I'm not. Participant 018_2021AUHRP

I can't fault the women really. Look, the other two were so appalling, I can't find words to describe them. It's this business of answering a question, and not feeling threatened by the questions they've asked and accepting the fact there wouldn't be a person alive today who wouldn't look things up on the internet, and to accept that and not see it as a threat. They need the training way back in medical school and be mentored when they're doing their residency and so on. Participant 022_2021AUHRP

I think they need to learn that people going through cancer generally, it's their first time so they don't really know what's going on. Don't assume people know what's going on and don't assume that we're all alike because everybody's got their own stuff going on. As I said, I come from a healthcare background so a lot of people that don't, would be terrified. Really, even at this stage, I don't know what my prognosis is. I hope that I'm cancer-free but I don't know. Who knows? If I get to five years, well, that's terrific but we don't really know. It always sits in the back of your head. Participant 038_2021AUHRP

Participant describes the expectation that future communication will be more empathetic

Yes! Empathy goes a wonderfully long way. I mean, can you imagine being told you have cancer and then having a piece of paper thrusted you saying go and do your own research? That's not good. Being told that on a Check-Up after a mastectomy. Well, it's not like it was cancer, because I had read somewhere that over 60% of these things are benign and you have 30% that are borderline and then you have 10% like me that are malignant. Participant 003_2021AUHRP

I think the only really negative experience was when the receptionist called me. It was literally a one-minute conversation of your tumours are not benign, you need to see a surgeon. In my mind, benign means non-cancer but not non-cancerous, and this call came at six o'clock on a Thursday night. Again, it was a receptionist. I could not marry that up in my mind. Now, I had an appointment with my GP the next morning at 11:00. When I got her on the phone, it seemed very disconnected because she was like, "Hello, how can I help you today?" I'm like, "Well, I got a call last night and I wanted to get my results." She had to break it to me over the phone, "You have cancer." That was the only negative experience I really had. I could not believe that somebody would call me and then in a one-minute conversation tell me I have cancer. Participant 007_2021AUHRP

She was absolutely couldn't believe it. If that's what's happening with somebody who has a lot of contact with breast cancer patients, we've got a lot of work to do. Similarly with the fellow who said to me, "As long as your MRI doesn't come up with like a Christmas tree, then you'll go and have them done any other." That's like no, that is not acceptable.
Participant 043_2021AUHRP

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant has no recommendations/experienced good communication	29	55.77	11	57.89	12	57.14	6	50.00	18	62.07	11	47.83	10	52.63	19	57.58
Participant describes the expectation that future communication will be more transparent and information more forthcoming	16	30.77	**10**	**52.63**	**4**	**19.05**	**2**	**16.67**	9	31.03	7	30.43	7	36.84	9	27.27
Participant describes the expectation that future communication will be more empathetic	11	21.15	3	15.79	5	23.81	3	25.00	5	17.24	6	26.09	**1**	**5.26**	10	30.30

Expectations of future healthcare professional communication	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant has no recommendations/experienced good communication	29	55.77	5	50.00	8	50.00	16	61.54	6	54.55	23	56.10	**8**	**44.44**	21	61.76
Participant describes the expectation that future communication will be more transparent and information more forthcoming	16	30.77	4	40.00	**3**	**18.75**	9	34.62	**5**	**45.45**	11	26.83	**8**	**44.44**	8	23.53
Participant describes the expectation that future communication will be more empathetic	11	21.15	**1**	**10.00**	4	25.00	6	23.08	**1**	**9.09**	10	24.39	3	16.67	8	23.53

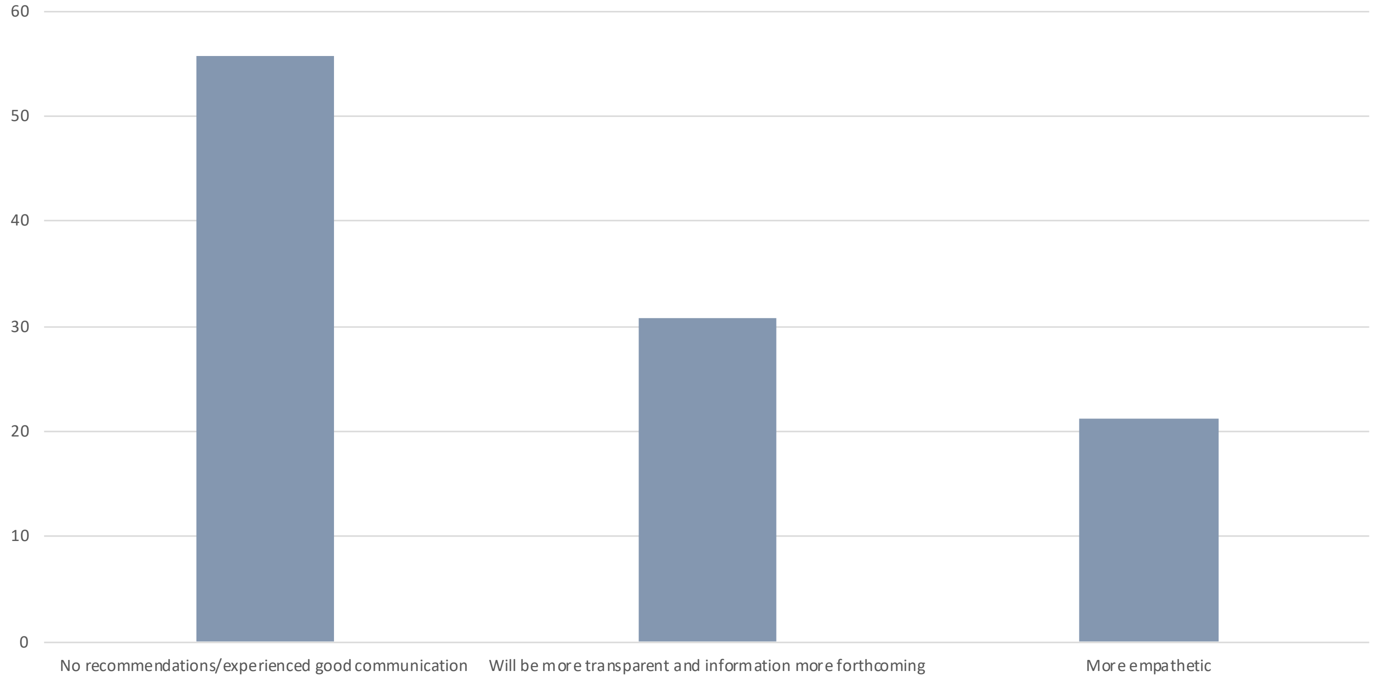

Figure 9.3: Expectations of future healthcare professional communication

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

Expectations of future healthcare professional communication	Reported less frequently	Reported more frequently
Participant has no recommendations/experienced good communication	Mid to low status	-
Participant describes the expectation that future communication will be more transparent and information more forthcoming	Stage II Stage III and IV Diagnosed in 2017 to 2019	Stage 0 and I Regional or remote Mid to low status
Participant describes the expectation that future communication will be more empathetic	Trade or high school Diagnosed in 2016 or before Regional or remote	-

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. The most common theme was that future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

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

No, I don't think so. I think I got everything that was relevant and that was helpful. I think, then, if you start getting a heap of stuff thrown at you, you don't know where you're going. A lot of people need home help and all that because, mentally, they can't cope with

the diagnosis. I suppose if you're strong, then people won't offer you that because they know that you don't need that. Participant 026_2021AUHRP

I think it'd be really helpful to somebody just to talk to you more about diet and exercise. I think especially the exercise stuff just to give you some information, I have certain exercises the can help you with the side effects, I think, or what you can actually do. Or how to modify what exercise you're doing. I think stuff like that could be really important. Participant 052_2021AUHRP

I will take myself out of the equation here because again, I think I was very lucky. I would say that individuals undergoing chemotherapy, I think we really should be focusing on helping them. I think if I had to undergo chemotherapy and I live here alone, I have friends nearby but you don't want to be a burden to your friends. I think I would have struggled had I had to have chemotherapy living here on my own and that even includes getting to the hospital. I cannot tolerate nausea at all. I know there are programs about driving people to take care of and I think you would probably understand. You don't want to be a burden on your friends. I would love to see more programs to really support people who are doing it much worse. Participant 007_2021AUHRP

Participant has no recommendations/is satisfied with care received

I can't think of anything off the top of my head, to be honest, because there may be help and support out there but I didn't reach out for it, so I don't know what's out there and I don't know what's missing as far as that's concerned. Participant 035_2021AUHRP

Yes, I think the model that is used by the martyr the early breast cancer program. Whenever I've mentioned it to anybody, whether they live in Australia or they live in the UK, they have been blown away by what is singularly one of the best things I've ever did. It quells the panic that I had. It quells the overwhelm of information because I have this one point. I've done it via Zoom as a mentor with them. It works via Zoom. I think that should be looked at as a model and should be replicated as a model. Then the other thing is there needs to be something that may be similar or such is really looking at this post-treatment. It's not just relying on Facebook groups because there's a lot of misinformation that comes from people that mean to what is coming from a good place, but it's not helping. Participant 043_2021AUHRP

Nothing I can think of. I've had access to everything I need. Participant 044_2021AUHRP

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'm not big on the charities in as much as I. I think that when this funding I want to see if it's funded like for the breast cancers, I think that all women, regardless of public or private, should have access to regular communication with the breast cancer and that they should be they should be well funded. I think that yeah. Participant 019_2021AUHRP

Just probably more calls just to check up on people. Some kind of liaison service so people just know that someone's thinking of them just, "Oh, how did your treatment go today? How are you feeling today?" It doesn't have to be a lot, but just someone touching base every now and then. Participant 038_2021AUHRP

Yes. As I said, the financial assistance is very tough on people. I wouldn't even know where to start with all of that, but everything was always there apart from-- Everything was always at your fingertips, I think, in the sense of, if you needed help with something, you could still speak to someone. The oncologists are really, really good where if you were struggling with something, they would pass you on to someone. Like I said, I was quite happy.
Participant 008_2021AUHRP

Participant describes the expectation that future care and support will include more long-term condition management (care planning)

I think in lots of ways, breast cancer does better than a lot of other cancers but probably if there's anything resulting around metastatic breast cancer and an increase in awareness and knowledge and communication to the public at large that for a lot of people with breast cancer they're getting to five years isn't the end of it all that it doesn't actually ever end. Participant 023_2021AUHRP

But it seems to me post treatment support because just because you're not you're not checking into the hospital definitely not requires you to contact the social support websites. Participant 002_2021AUHRP

Yeah, look definitely in the area of lymphedema across the whole states, what the country like it's so under resourced, so not known about, you know, there's no support groups, generally, the LOCATON, one fold that it started and it folded because it couldn't continue, because it's all based on volunteer and goodwill, is that, in terms of what's available for through the public system is almost non existent. But me, the intensive treatments only available through the private healthcare system unless you pay for it yourself. So that's the very under known under resourced part of the breast cancer aspect, even though people can have it as primary lymphedema as well. So even though it's there outside of someone from cancer, it's still there's not enough resources in that avenue. And it's chronic, you know, it's ongoing, so. And in terms of that, as well, there's virtually no garment making in Australia as well. So the stress of waiting for garments to come from overseas can be weeks, you know, and then if they get it wrong, you got to send it back. And you could be waiting months. And so trying to get that kind of manufacturing in Australia is really difficult. Participant 013_2021AUHRP

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

Probably more access to the mental health side of things. Yeah.
Participant 033_2021AUHRP

My husband was saying, for him, it was more like there was no one that he could really talk to. You're focused on me, but the breast cancer surgeon, he always asked him, "How are you coping with it all?" He did check up on him, but I think maybe it would've been nice in the chemo, if, I don't know, they did have a partner's group or something, where they could, I don't know, join in for a cup of coffee and a chat.
Participant 040_2021AUHRP

I think that the program that I had at my hospital that helps with distance and management, I think that is a fantastic thing they've done. I just don't think it's funded enough and there's not enough hours there. I think that, potentially, would be something that's perfect that even the best [unintelligible] can get involved on. You have a hotline that you can ring up and use, whether it be your symptoms and stuff, because you can have physical symptoms, but then you can also have things that you're struggling with. It could be mentally troubling you.
Participant 048_2021AUHRP

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)

Perhaps maybe- and they probably use something out there already, but I get a lot of comfort, I guess, from reading other people's stories and listening to other people's stories. Maybe they've been through the next phase that you're just going through or maybe to have that more accessible. It doesn't have to be maybe in person, but just shared stories. As I said, they probably use more things out there that I haven't tapped into. I think it makes you put your mind at rest that when you have children, you go to another group or whatever and other mothers are feeling like you're feeling, and you walk away and think, "Just maybe it feels like that. She's just like that too. That's how I felt." Something like that. Unless you go searching for it, the information is not sent to you. Participant 009_2021AUHRP

The only things that I would have liked, and it's only COVID that's probably stopped it, was to be able to go physically to a support group. Just to actually be face to face with people going through what you're going through. It's not the same talking to strangers online. As I said, most of the breast care support groups are American orientated. The BCNA one in Australia, every time I go into it, nothing much is happening. There's no new conversations. Just to be able to go and physically meet and have a good old heart-to-heart with someone that's going through what you're going through. Participant 010_2021AUHRP

Just someone who's maybe been through it to talk to you. Participant 016_2021AUHRP

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes the expectation that future care and support will include more access to support services	34	65.38	13	68.42	16	76.19	5	41.67	17	58.62	17	73.91	11	57.89	23	69.70
Participant has no recommendations/is satisfied with care received	11	21.15	6	31.58	2	9.52	3	25.00	7	24.14	4	17.39	5	26.32	6	18.18
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)	9	17.31	2	10.53	4	19.05	3	25.00	5	17.24	4	17.39	7	36.84	2	6.06
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	7	13.46	2	10.53	2	9.52	3	25.00	4	13.79	3	13.04	0	0.00	7	21.21
Participant describes the expectation that future care and support will include mental health/emotional support	6	11.54	3	15.79	2	9.52	1	8.33	2	6.90	4	17.39	4	21.05	2	6.06
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	11.54	1	5.26	2	9.52	3	25.00	5	17.24	1	4.35	1	5.26	5	15.15

Expectations of future care and support	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes the expectation that future care and support will include more access to support services	34	65.38	8	80.00	11	68.75	15	57.69	7	63.64	27	65.85	13	72.22	21	61.76
Participant has no recommendations/is satisfied with care received	11	21.15	1	10.00	2	12.50	8	30.77	2	18.18	9	21.95	4	22.22	7	20.59
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)	9	17.31	2	20.00	4	25.00	3	11.54	3	27.27	6	14.63	4	22.22	5	14.71
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	7	13.46	1	10.00	1	6.25	5	19.23	1	9.09	6	14.63	2	11.11	5	14.71
Participant describes the expectation that future care and support will include mental health/emotional support	6	11.54	1	10.00	3	18.75	2	7.69	2	18.18	4	9.76	4	22.22	2	5.88
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	11.54	0	0.00	5	31.25	1	3.85	0	0.00	6	14.63	2	11.11	4	11.76

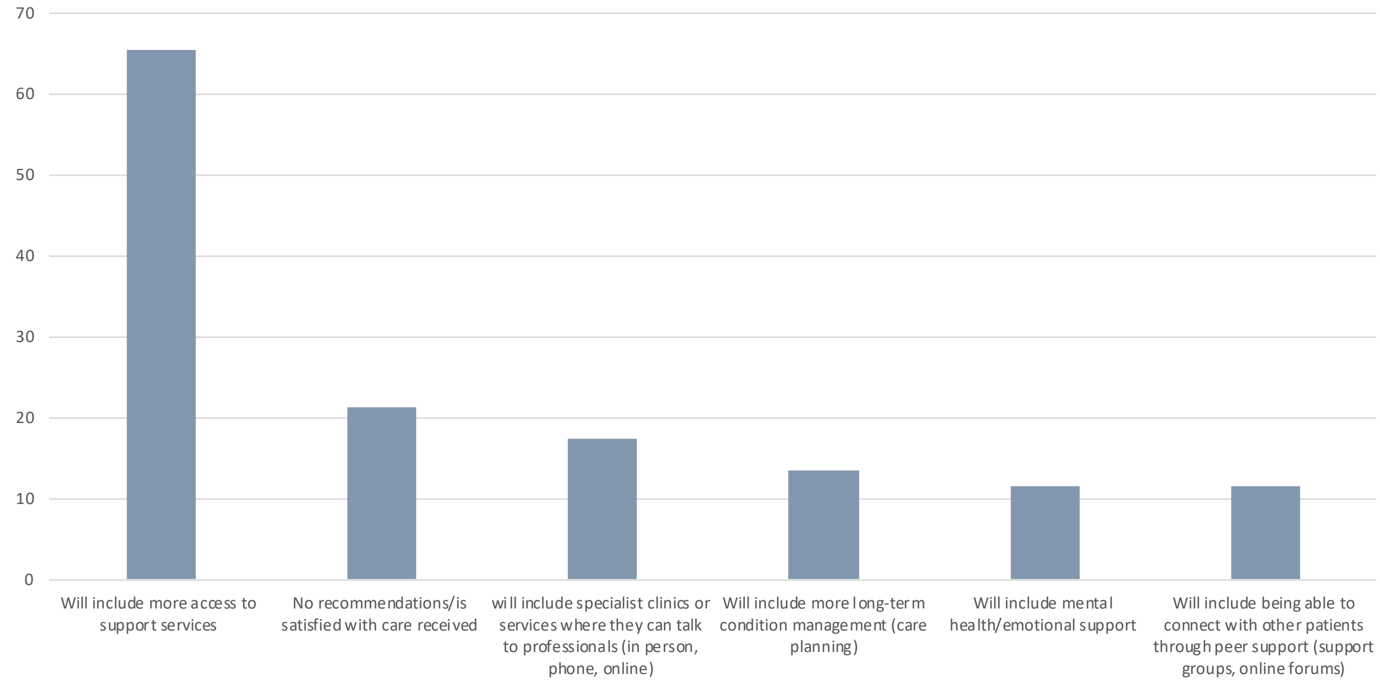

Figure 9.4: Expectations of future care and support

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

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant describes the expectation that future care and support will include more access to support services	Stage III and IV	Stage II Diagnosed in 2016 or before
Participant has no recommendations/is satisfied with care received	Stage II Diagnosed in 2016 or before	Stage 0 and I
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)	University	Trade or high school
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	Trade or high school	Stage III and IV
Participant describes the expectation that future care and support will include mental health/emotional support	-	Mid to low status
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)	Diagnosed in 2016 or before Regional or remote	Stage III and IV Diagnosed in 2017 to 2019

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 were that participants were grateful for the healthcare staff (n=17, 32.77%), and the entire health system (Includes having access to good healthcare and having options) (n=16, 30.77%). Other participants were grateful for access to private healthcare/private insurance (n=15, 28.85%), timely access to treatment (n=13, 25.00%), low cost treatment and medical care through the government (n=12, 23.08%), and timely access to diagnostics (n=6, 11.54%).

Participant is grateful for healthcare staff

The people, particularly the experts, with the specialists. The good treatment that I've had, that I've had access to. The patience that they had with me in terms of-- I think it's not easy being a doctor because a doctor-patient for other doctors because you know stuff. My GP is brilliant in that regard at giving me information at the right level. Treating me like a patient who has some knowledge. I've just been really grateful for the people whose care I've been under. Participant 011_2021AUHRP

Um you know, I saw some of the best specialists, you know, being particularly being in regional Australia, I saw some of the best specialists, you know, outside of a major city. And I was quite lucky in that regard. But, you know, in the same token, living in Australia, they have access to the internet and things like that to be able to go and do my own research. That sort of side things as well. Participant 020_2021AUHRP

But again, I will come back to radiotherapy and the radiation therapist and how caring and holistic in their care they were. They did what they needed to do to get it all right, to make sure that everything was right for you but they also did everything they could to make me as comfortable as they could. Participant 023_2021AUHRP

Participant is grateful for the entire health system

The fact that we're in Australia, that we have a world class system. Despite what people say, we still have a world class system. And we do have a lot of campaigns. And we do have a correct screening program if people take advantage of it. And that Breast screen New South Wales, everything that they do, every appointment, every everything worked like clockwork, I didn't have to chase anybody for anything. And, and so I'm grateful that I'm grateful that I'm educated. And that I can actually do my own research. And then I can also look at alternate therapies. Participant 001_2021AUHRP

All of it really because I went through the system, and the system is amazing for what it covers for no cost. I was very lucky I didn't have to wait for services. I didn't have to pay out of pocket, except for the radiation, but even that could be easily done. I think we are just so lucky to have the health system that we do have. It's a pity that we can't have access to more, so that we can get more patients through because I know the whole system does struggle, but I was lucky. Participant 025_2021AUHRP

All of it. Absolutely all of it. From my GP, getting an appointment for me the next day at the hospital with the surgeon that I need to see to have all this done. All of it, I'm grateful for all of it. I had no idea that our public system was as good as this, but it is a really good system. When you really need it, it does the job. Participant 044_2021AUHRP

Participant is grateful for access to private healthcare/private insurance

I'm grateful for all the treatment really because it was done so fast, but I did have private health insurance. I went through the services privately and I was just delayed for the surgery, for the breast surgery; the reconstruction. If we didn't have private health insurance, we would have to wait a long time to get that. That's the thing that I always thought, that we discussed with my husband and he was like, "Yes, we'll go so that we are able to just pay the things that-- the out-of-pocket expenses." There's other families that don't have that. They have to travel. I saw this little kid, he was only just probably seven or less going through radiation. The dad was on the phone going, "Oh, can I just have it? I've paid this and all these things?" You could see that there's a financial stress in that situation there, that they already have enough going on. They shouldn't be stressing about finances. Participant 040_2021AUHRP

I had private health care. All my treatment has been through private. This is all in relation to that. Thank God it wasn't an American private health care model. The two-tier that we have, I was really fortunate and it worked for me, I guess that. Thank goodness. It was the two-tier private model. We have not the ridiculous American model. Participant 043_2021AUHRP

I think that the fact that I've got private health cover and I didn't have to wait long. The waiting is the worst part, just hanging around and waiting for this test and that test and the other test. I think that could actually probably be worked on. When you actually go to LOCATION REGIONAL, and they actually know that you've got cancer, but they're not allowed to tell you because they do know. They're not there to tell you, "You've got to hang around and wait for another week to be told by the breast surgeon." Did I not get that the waiting is the worst part? The not knowing and having weeks of no sleep because you're imagining all sorts of things. We need to have our minds put at rest by knowing this ASAP. Participant 010_2021AUHRP

Participant is grateful for timely access to treatment

Well, just the timing with everything. I didn't really have to wait to have that operation. I was straight in a week later to have that and then everything lined up after that. Participant 015_2021AUHRP

I will be forever grateful that even though it was during COVID, that because I was classed as a Category 1 urgent, that this happened. I was a public patient, I wasn't a private patient, and it was all done and over in some weeks, as if I was the one and only patient. Participant 026_2021AUHRP

I think having access to all of it has been a blessing and the speed of which I've been able to access has been terrific. I can't fault it. Participant 051_2021AUHRP

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

I'm very happy we have a wonderful surgeon. He works out of the hospital and bulk bills for everything, so you're not out-of-pocket at a private surgery. We're incredibly lucky that way. Very, very lucky that the public system does the radiation, so you're not out-of-pocket that way either. I think we're incredibly lucky in Australia not to have to fork out lots of money. Participant 017_2021AUHRP

PARTICIPANT: Well, the fact that I haven't had to pay for anything has been incredible. I've always said that. I always think that our health system if you're sick, it's there, it's available. There's no reason for people not to go and have mammograms. Well, recently there was because they weren't doing them but generally, you know what I mean?
INTERVIEWER: Yes.
PARTICIPANT: There's always ways if don't have any money there's still ways around it to get stuff done. Participant 038_2021AUHRP

Pretty much grateful for everything because we are lucky where we are. Despite having to wait for things, once you are diagnosed, it is pretty much taken, everything sort of flows, and it is quick to access. The cost is, like I said, I haven't had to pay for anything of my medical treatment at all. Participant 049_2021AUHRP

Participant is grateful for timely access to diagnostics

I think I'm really very grateful to be second ultrasound person that you know, she was told to look at 10 o'clock, and she decided to look at the whole breast. That's where it got picked up. Very grateful for that technician saying I don't do a half job. That was good. Yeah. I guess I'm grateful, it all happened very quickly. Participant 014_2021AUHRP

Yes. I was grateful that I got it diagnosed early. The van came to LOCATION because otherwise, I probably would have put it off. I had to wait. When I was diagnosed, I was contacted by one of the breast care nurses before I could see the specialist. I got in to the specialist within a few days and in the surgery like a week later. Participant 006_2021AUHRP

I think I'm really very grateful to be second ultrasound person that you know, she was told to look at 10 o'clock, and she decided to look at the whole breast. That's where it got picked up. Very grateful for that technician saying I don't do a half job. That was good. Yeah. I guess I'm grateful, it all happened very quickly. Participant 014_2021AUHRP

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

What participants are grateful for in the health system	**All participants**		**Stages 0 and I**		**Stage II**		**Stages III and IV**		**Aged 25 to 54**		**Aged 55 to 74**		**Trade or high school**		**University**	
	n=52	**%**	**n=19**	**%**	**n=21**	**%**	**n=12**	**%**	**n=29**	**%**	**n=23**	**%**	**n=19**	**%**	**n=33**	**%**
Participant is grateful for healthcare staff	17	32.69	6	31.58	8	38.10	3	25.00	10	34.48	7	30.43	5	26.32	12	36.36
Participant is grateful for the entire health system	16	30.77	7	36.84	6	28.57	3	25.00	8	27.59	8	34.78	**3**	**15.79**	13	39.39
Participant is grateful for access to private healthcare/private insurance	15	28.85	6	31.58	**3**	**14.29**	**6**	**50.00**	6	20.69	**9**	**39.13**	6	31.58	9	27.27
Participant is grateful for timely access to treatment	13	25.00	6	31.58	5	23.81	2	16.67	8	27.59	5	21.74	4	21.05	9	27.27
Participant is grateful for low cost/free medical care through the government	12	23.08	4	21.05	5	23.81	3	25.00	6	20.69	6	26.09	**7**	**36.84**	5	15.15
Participant is grateful for timely access to diagnostics	6	11.54	2	10.53	3	14.29	1	8.33	5	17.24	1	4.35	3	15.79	3	9.09

What participants are grateful for in the health system	**All participants**		**Diagnosed in 2016 or before**		**Diagnosed in 2017 to 2019**		**Diagnosed in 2020 or 2021**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=52	**%**	**n=10**	**%**	**n=16**	**%**	**n=26**	**%**	**n=11**	**%**	**n=41**	**%**	**n=18**	**%**	**n=34**	**%**
Participant is grateful for healthcare staff	17	32.69	3	30.00	**3**	**18.75**	11	42.31	3	27.27	14	34.15	7	38.89	10	29.41
Participant is grateful for the entire health system	16	30.77	**1**	**10.00**	4	25.00	**11**	**42.31**	4	36.36	12	29.27	5	27.78	11	32.35
Participant is grateful for access to private healthcare/private insurance	15	28.85	**4**	**40.00**	5	31.25	6	23.08	4	36.36	11	26.83	6	33.33	9	26.47
Participant is grateful for timely access to treatment	13	25.00	**1**	**10.00**	3	18.75	9	34.62	3	27.27	10	24.39	6	33.33	7	20.59
Participant is grateful for low cost/free medical care through the government	12	23.08	**1**	**10.00**	**2**	**12.50**	**9**	**34.62**	3	27.27	9	21.95	5	27.78	7	20.59
Participant is grateful for timely access to diagnostics	6	11.54	**0**	**0.00**	**4**	**25.00**	2	7.69	**0**	**0.00**	6	14.63	1	5.56	5	14.71

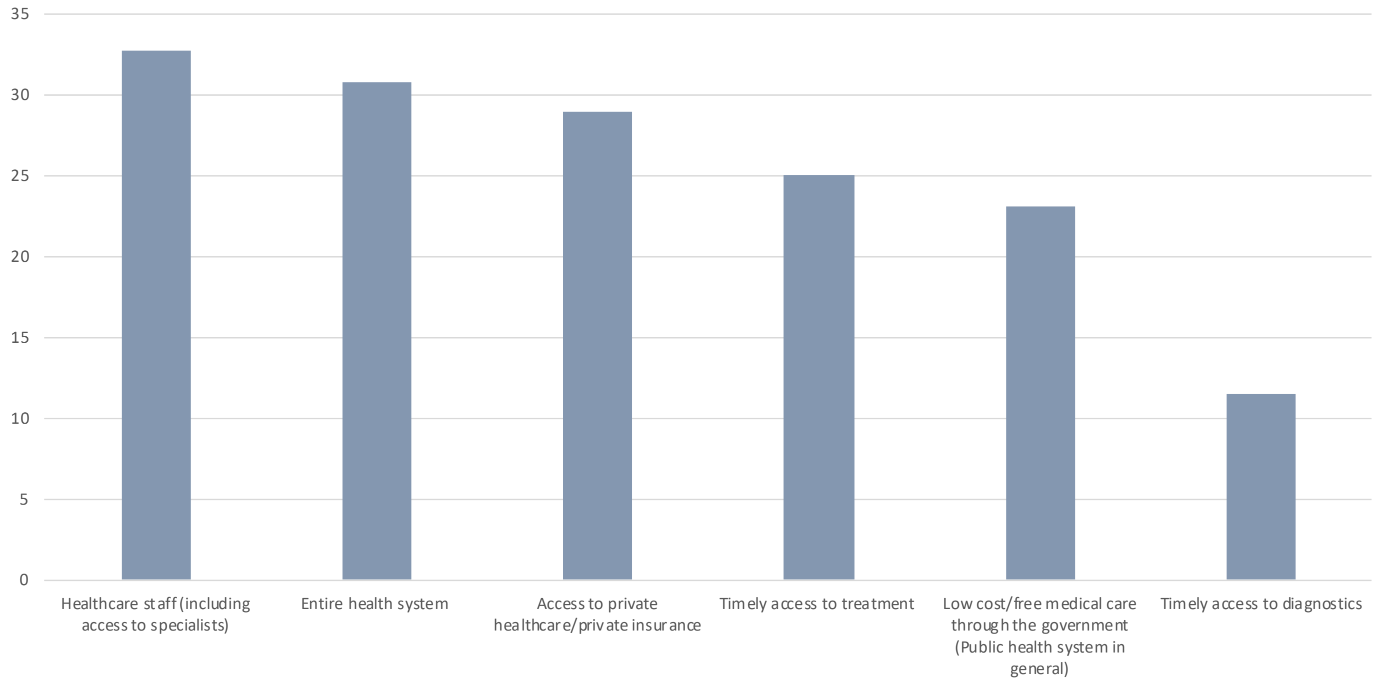

Figure 9.5: What participants are grateful for in the health system

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

What participants are grateful for in the health system	**Reported less frequently**	**Reported more frequently**
Participant is grateful for healthcare staff	Diagnosed in 2017 to 2019	-
Participant is grateful for the entire health system	Trade or high school Diagnosed in 2016 or before	Diagnosed in 2020 or 2021
Participant is grateful for access to private healthcare/private insurance	Stage II	Stage III and IV Aged 55 to 74 Diagnosed in 2016 or before
Participant is grateful for timely access to treatment	Diagnosed in 2016 or before	-
Participant is grateful for low cost/free medical care through the government	Diagnosed in 2016 or before Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2020 or 2021
Participant is grateful for timely access to diagnostics	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019

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 memory loss and cognitive function, fatigue, pain problems with movement and strength, and effects on bones and joints. The least important was fertility.

Table 9.11: Symptoms and aspects of quality of life

Symptom	Weighted average (n=51)
Fatigue Pain	8.12
Lymphoedema	5.43
Fertility	1.78
Menopause and menopausal symptoms	5.37
Anxiety and depression	6.67
Body image	4.41
Sexual difficulties	4.61
Problems with movement and strength	7.33
Heart problems	6.84
Memory loss and cognitive function	8.08
Effects on bones and joints	7.35

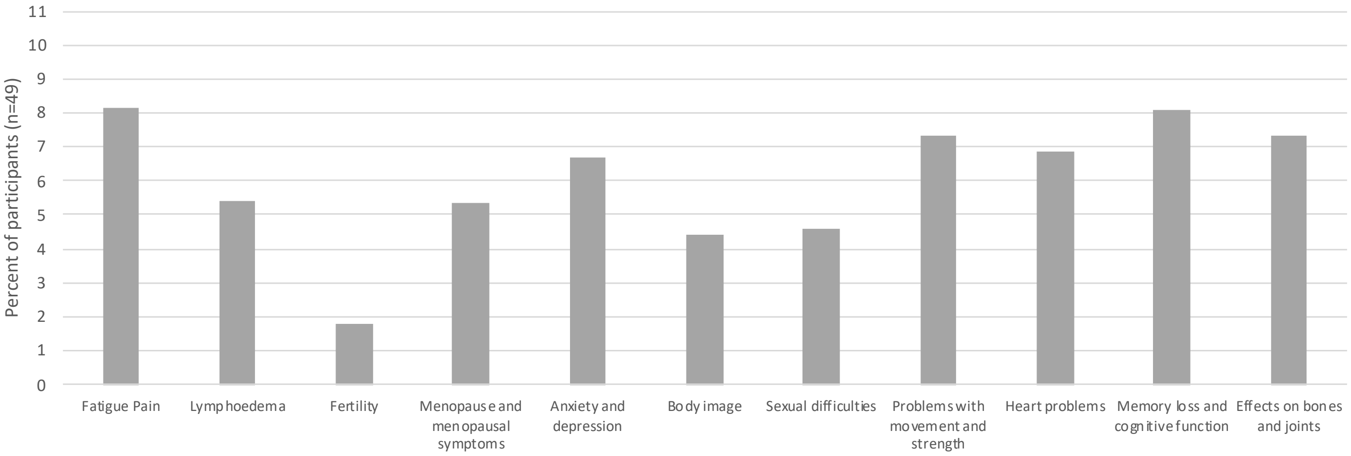

Figure 9.6: Symptoms and aspects of quality of life

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 9.7. 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 9.12: Values for decision makers

Values for decision makers	Weighted average (n=51)
Economic value to government and tax payers	1.22
Economic value to patients and their families	2.55
Quality of life for patients	4.12
Compassion	3.00
All patients being able to access all available treatments and services	4.12

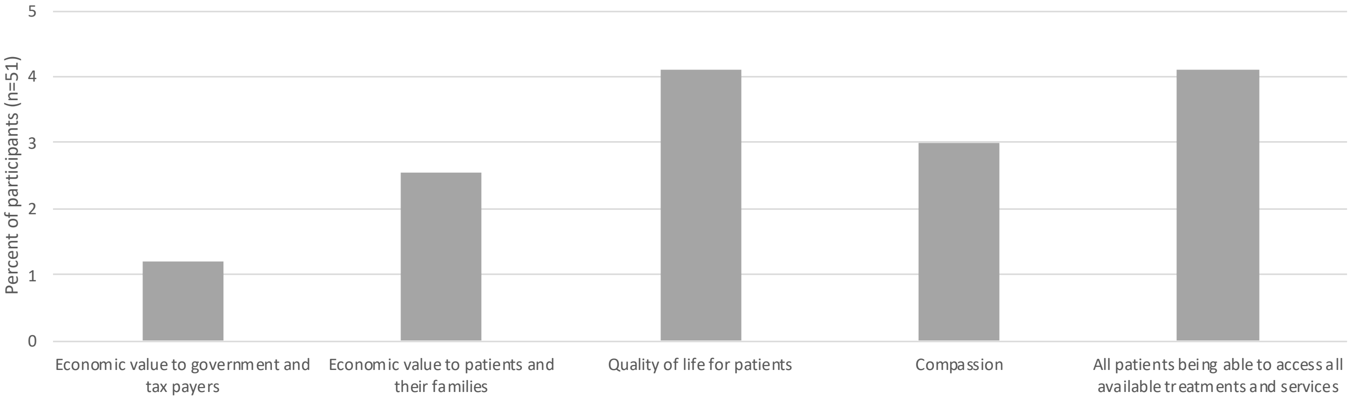

Figure 9.7: Values for decision makers

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 9.8. 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 "The severity of the side effects". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

Table 9.13: Values in making decisions

Values when making decisions	Weighted average (n=51)
How safe the medication is and weighing up the risks and benefits	6.51
The severity of the side effects	5.76
Time impact of the treatment on my quality of life	5.16
How the treatment is administered	3.51
How personalised the treatment is for me	5.35
The ability to include my family in making treatment decisions	2.80
Ability to follow and stick to a treatment regime	3.94
The financial costs to me and my family	2.96

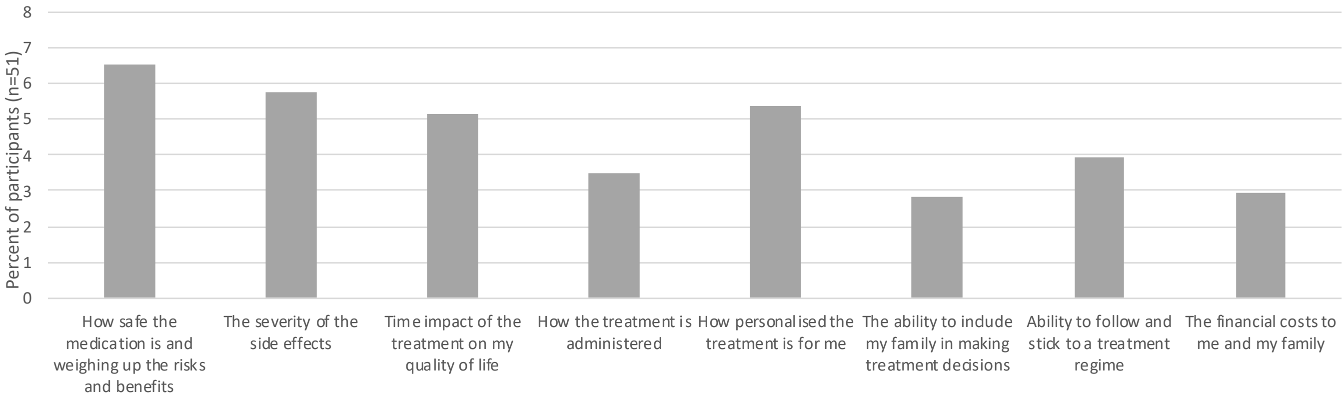

Figure 9.8: Values in making decisions

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.

Almost half of participants (n = 25, 49.02%) 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=51)	Percent
1 to 5 years	24	47.06
5 to 10 years	2	3.92
More than 10 years	25	49.02

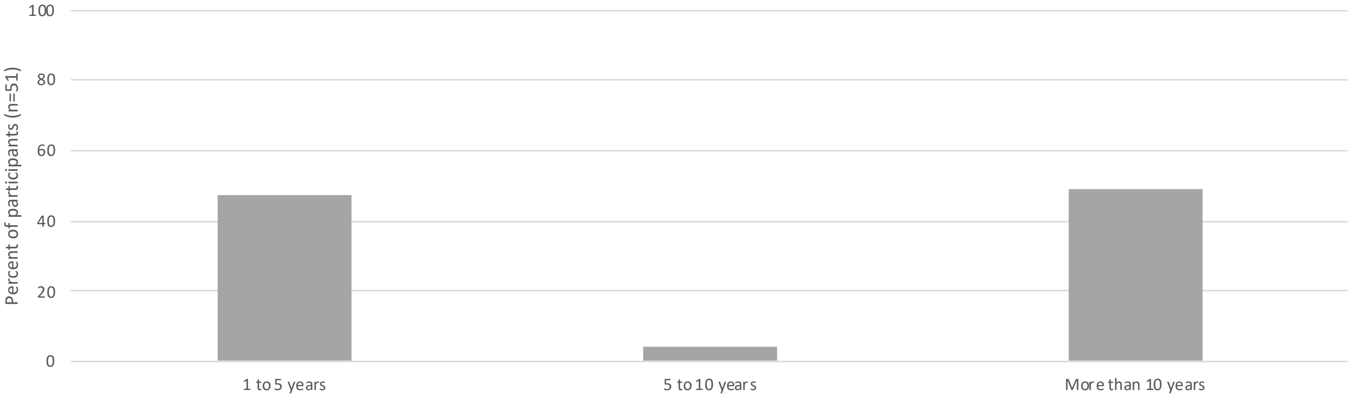

Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

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

Participants most commonly responded that they thought that IV and pill were equally effective (n = 21, 41.18%), followed by not being sure (n = 19, 37.25%) (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Most effective form of medicine	Number (n=51)	Percent
IV form (through a drip in hospital)	5	9.80
In a pill form that can be taken at home	6	11.76
Equally effective	21	41.18
Not sure	19	37.25

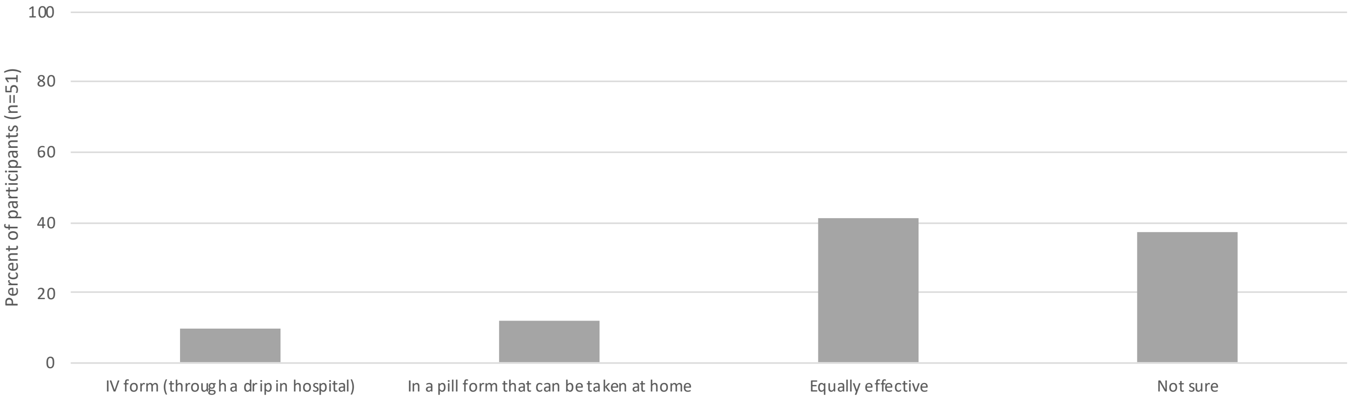

Figure 9.10: Most effective form of medicine

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?” The most common messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

Participant's message is to improve access to support and care

I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want? Participant 025_2021AUHRP

I would say to the health minister, "Make it all free. Make it free. Take away that financial burden for people whilst they're going through breast cancer treatment, and provide additional support that's consistent for everybody." Some people get access to McGrath nurses, some people get access to breast care nurses, other people get access to no support whatsoever. I think make it free and make sure that there is that consistent support for everybody. Participant 037_2021AUHRP

Probably I think people think once you've had treatment and you've had the chemo when your so called cancer free and that's it. I think psychologically afterwards I think women would be good if there was follow up and some sort of psychological or mental health check or Yeah, I think it all happens while you're having treatment and the breast care nurse comes out and all that and then once you're done, that's it, you don't hear from anyone. Except for this study. It's like your treatment's done, but you're better now you're good, off you go. You're on your own, and I still don't have a boob. Participant 041_2021AUHRP

Participant's message is that treatments need to be affordable

I would say that people with breast cancer, there is good access within the system to be had but it is not available to everybody and I'm incredibly privileged in that I'm medical, I have really great health literacy, I don't have problems signing people up to make appointments. Even saying, "No, I need this to happen this week." I'm very privileged in the sense that I don't have to contemplate whether I can afford $500 for an MRI or not. Coming from a place of privilege, where I live in a metropolitan regional place, with access to all those services, and with the skill set to be able to access them, or health services, fantastic. I think it probably isn't that way for everybody.
Participant 005_2021AUHRP

I probably hope that there's no discrimination of age and in regards to the support services, your home health and whether or not you've received care in public or private. It shouldn't matter but when you're dealing with breast cancer, or any cancer for that matter, and it should be all funded through PBS. That's why we pay our taxes. Participant 031_2021AUHRP

Oh, gosh. I don't know. [laughs] It is free if you go through the public system. Maybe pull the private health insurance companies more into line, because they're just getting out of control with their costs. I can't think of anything other than that really. Participant 012_2021AUHRP

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

Breast cancer... I mean, we get great care with breast cancer. I do think that some of the testing should not be out of pocket. They throw millions and billions of dollars at testing that, they would get a lot more if I could understand why we get them, which means genetic testing. I mean, I still may need to find six hundred dollars to get my genetic testing if I don't qualify for the free testing through the NAME HOSPITAL. But I need to know because I have a *daughter who is at the perfect age for getting what I've got. She's thirty one. I have grandchildren. So genetic testing is needed and it maybe through some of the research dollars, not all of them, but just a few of them to maybe look at some of the rarer forms of cancer because everyone's so busy throwing the research dollars and all the research and clinical trials at normal breast cancer. The rest of us are left standing there with no research and no clinical trials. Participant 003_2021AUHRP*

Fund more Stage 4. One in three women potentially will move on to be metastatic. I think it's underfunded. Actually, could I change that? Get more support for stage 4, but particularly research around the recurrence of stage 4. The fact that we don't actually know is outrageous. The fact that they don't actually track and have any statistics about stage 4. More funding and research around stage 4. Participant 043_2021AUHRP

Please keep funding a variety of research into breast cancer. A variety of research. Participant 047_2021AUHRP

Participant's message is that there needs to be more timely access to treatments

I would say to him that through the public health system in the bigger cities and I'm talking from experience because I am supporting a woman who I've never met, but I was put in touch with her through a friend, 71 year old lady. She's got bilateral breast cancer at this stage in both breasts from the time of mammogram and diagnosis and then the period that she had to wait to have a biopsy and then to see a surgeon at LOCATION and then to wait another month or more. Of course, she had surgery. I just think that that that just exacerbates the emotional trauma of the whole experience. So I think that I would say, look, you know, we need more money funding into our hospital waiting lists because it's not you know, it's just not it's it's everything. Participant 019_2021AUHRP

I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want?
Participant 025_2021AUHRP

I think if you're in the public system-- it depends because, I can't talk about doing it through the public system, but for me if people want to get on with it. The sooner they get on with it, the for them. That gives you peace of mind. Keeping people on long waiting lists, it's not mentally healthy for them. I do think too that, psychologists for some people need to be in the mix. Especially if they don't know anybody that's ever been touched by cancer. Participant 032_2021AUHRP

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

The cost costs are terrible. The local public hospital doesn't have testing equipment or an oncology department at all. I guess the public system couldn't provide my healthcare needs and therefore I had to go private as a public patient so it cost a lot. And that's probably it. Participant 014_2021AUHRP

I would say to the health minister, "Make it all free. Make it free. Take away that financial burden for people whilst they're going through breast cancer treatment, and provide additional support that's consistent for everybody." Some people get access to McGrath nurses, some people get access to breast care nurses, other people get access to no support whatsoever. I think make it free and make sure that there is that consistent support for everybody. Participant 037_2021AUHRP

Gee, that's a hard one because I think, for younger women that is possibly really important. I just can't say-- you've caught me-- you realize that not everything can be free. I just think of women with children. There's things like Can Assist where you can get some money. I really don't know how to answer your question there because it's very different for people with children, et cetera, and younger women. Participant 022_2021AUHRP

Participant's message is to be compassionate and empathetic

Being in a big unit of patients whereas I was in a nice small unit, it's just not so daunting. I see people and they would find it daunting because I'd actually done a shift just before my diagnosis in this day unit. I was overwhelmed even as a nurse I was like, "Oh my God, this is huge." Let alone being a patient who's chucked in like sardines. There's no privacy. If they're having a bad day, they can't escape everyone, sort of thing. Does that make sense? Participant 024_2021AUHRP

Again, I'm blowing the trumpet of the stage for people that we need more funding and more concentration of research and fast tracking. I was the novo so that was my first diagnosis and if there's confusion even with early stages. A lot of early stages aren't aware that 30% of them are likely to have recurrent if not progression to Stage 4. I think a lot of people including the health minister would do well to put more into that box of researching and funding. Even though it might be outdated if a two to three year lifespan post diagnosis is what some people have to look at, that's not a lot of time. To say that much a lot of that two to three years may not be in comfort or in emotional well-being, a lot of that might be in immobilized, bedridden, or whatever or just going between appointments rather than actually having a life. I think that's an important thing to throw in there because it's not all sunny days and picnics. Participant 051_2021AUHRP

I think they need to have a look at the whole system and maybe there isn't something to change, but I think from diagnosis to a five-year plan, it needs to be far more transparent and probably a little bit kinder to most of us. The research side of things, if the government spent possibly a little bit more money on the research side, some of the treatments that we have to go through, you wouldn't have to go through. Participant 018_2021AUHRP

Participant's message is that treatments need to be holistic

They need to increase funding for health. I think you need to listen to your nurses. And they tell you that they're actually because that's why mental health isn't well looked after as because nurses and doctors as well, but I'm going to get on the bandwagon of nurses. You know, we can't, you can't give the emotional support. Because you're so busy chasing your tail doing the physical support. He's so busy, like just taking care of patients physically, that you can't, you don't have the time to factor in their emotional. But yeah, it's important that they require like in a clinical setting. You know, we need to we need to be thinking about, you know, okay, if we can't provide this support in a clinical setting, because there's not physically enough nurses to do the job, then we need to step up another way. So either get better patient staff ratio, and provide that full centered holistic nursing care or provide better mental health care that's accessible, so like, either way you can have to spend some money so choose which way you are going to spend it. Participant 033_2021AUHRP

I think my advice would be to look at everything holistically. Don't just look at it as a physical condition because it is such a knock-on effect to all the other aspects of human life. Participant 038_2021AUHRP

It's such a huge thing now, such a big population of people have breast cancer so I think that all hospitals-- I think they are starting to have it now should have specialty areas for that demographic of people. I think that has access through a lot of different services to help people mentally, physically get through this and rehabilitate because it is something that you'll--especially after a double mastectomy or anything. If I had my legs chopped off, I'd be sent to rehab to get a new, and they'll have services available to help me walk again and to do all the things and they'll probably address my mental health and all that stuff more than when you get your breasts cut off. I think that's not recognized. I think that that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Participant's message is to invest in screening/early detection

Well, again, I can only speak from the private system. I have heard from other people who've been through public, it's quite a different experience that given the-- It seems as though breast cancer is, unfortunately, becoming a little bit more common, or a bit more diagnosed in our society, just to make sure that the number of clinics increase, the number of breast care nurses increase, females who choose to have their mammogram to be checked regularly. Participant 004_2021AUHRP

There's many different types of breast cancer for starters. They need to realize that not all breast cancers can be treated the same way, can be found the same way. We need to be more open to offering more available screenings and not at excessive costs like me having to pay $615 because of my breast cancers, the type of breast cancer, there's often found too late because it doesn't show on a mammogram or an ultrasound. Those things that helped to find it earlier, should be made available, and at least at a reasonable cost, if not for free. Participant 010_2021AUHRP

Well, I think they need to screen people earlier with mammogram. What is it now from 50, 50 years old or something? Participant 015_2021AUHRP

Participant's message is that there needs to be better access to care and treatment in rural and remote locations

I would like to see it be a system that supports everybody a little bit more, in particular, people who live a bit further away from all these things. The solution is never going to be have a oncologist in every town, you can't do it, but we need to have better access to get people in and out of the metropolitan areas when they need it. I would also probably have a whinge about the lack of genomic testing being covered by Medicare and MRIs while I was at it, because why not? Participant 005_2021AUHRP

Yes, maybe more to regional areas and more to help people mentally when they're going through it. Participant 016_2021AUHRP

As far as being in a rural area, having to travel two and a half hours and stay in LOCATION for radiation, I suppose all those things. That's what you do, you're living in a rural area, you haven't got much choice, they can't have a radiation machine in every rural town. There's probably not much that can be done about that, but maybe it would be nice to have better accommodation up where the radiation is. [unintelligible 00:54:54] but from all reports, the accommodation at the hospital isn't fantastic. It's like shared kitchen and that sort of thing, that'd be nice, [chuckles] but I can't see it happening. It's going to be a perfect world. Participant 017_2021AUHRP

Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support

I think that there is another problem, if you'd call it a problem, is that so many people are surviving now, so what are you meant to do with the survivors? There's a lot of money spent in treatment but there needs to be what happens after breast cancer treatment? None of that's really discussed. You'd gone through the machine and that's it sort of thing. More in the post-treatment care. I can't comment too much because I didn't have those complications that some people have gone through. Could have been a lot worse. Participant 021_2021AUHRP

I'm afraid, I think possibly because I see a gap, I would be going lymphoedema, lymphoedema, lymphoedema. There are huge gaps in funding, recognition, treatment for lymphoedema. Participant 023_2021AUHRP

I think that's not recognized. I think that that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant's message is to improve access to support and care	26	50.00	8	42.11	11	52.38	7	58.33	12	41.38	**14**	**60.87**	10	52.63	16	48.48
Participant's message is that treatments need to be affordable	13	25.00	**8**	**42.11**	5	23.81	**0**	**0.00**	5	17.24	8	34.78	4	21.05	9	27.27
Participant's message is to invest in research (including to find new treatments)	9	17.31	4	21.05	3	14.29	2	16.67	**1**	**3.45**	**8**	**34.78**	3	15.79	6	18.18
Participant's message is that there needs to be more timely access to treatments	9	17.31	2	10.53	4	19.05	3	25.00	3	10.34	6	26.09	3	15.79	6	18.18
Participant's message is to understand the financial implications (and provide financial support)	8	15.38	3	15.79	2	9.52	3	25.00	7	24.14	**1**	**4.35**	**0**	**0.00**	8	24.24
Participant's message is to be compassionate and empathetic	6	11.54	2	10.53	2	9.52	2	16.67	3	10.34	3	13.04	2	10.53	4	12.12
Participant's message is that treatments need to be holistic	6	11.54	4	21.05	2	9.52	**0**	**0.00**	3	10.34	3	13.04	4	21.05	2	6.06
Participant's message is to invest in screening/early detection	6	11.54	2	10.53	2	9.52	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	6	11.54	3	15.79	1	4.76	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	11.54	2	10.53	3	14.29	1	8.33	2	6.90	4	17.39	3	15.79	3	9.09

Message to decision-makers	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant's message is to improve access to support and care	26	50.00	3	30.00	7	43.75	16	61.54	6	54.55	20	48.78	9	50.00	17	50.00
Participant's message is that treatments need to be affordable	13	25.00	5	50.00	4	25.00	4	15.38	4	36.36	9	21.95	6	33.33	7	20.59
Participant's message is to invest in research (including to find new treatments)	9	17.31	2	20.00	2	12.50	5	19.23	4	36.36	5	12.20	4	22.22	5	14.71
Participant's message is that there needs to be more timely access to treatments	9	17.31	0	0.00	1	6.25	8	30.77	5	45.45	4	9.76	3	16.67	6	17.65
Participant's message is to understand the financial implications (and provide financial support)	8	15.38	3	30.00	2	12.50	3	11.54	0	0.00	8	19.51	2	11.11	6	17.65
Participant's message is to be compassionate and empathetic	6	11.54	1	10.00	0	0.00	5	19.23	2	18.18	4	9.76	1	5.56	5	14.71
Participant's message is that treatments need to be holistic	6	11.54	2	20.00	1	6.25	3	11.54	3	27.27	3	7.32	3	16.67	3	8.82
Participant's message is to invest in screening/early detection	6	11.54	1	10.00	4	25.00	1	3.85	0	0.00	6	14.63	0	0.00	6	17.65
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	6	11.54	0	0.00	2	12.50	4	15.38	0	0.00	6	14.63	1	5.56	5	14.71
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	11.54	1	10.00	2	12.50	3	11.54	1	9.09	5	12.20	2	11.11	4	11.76

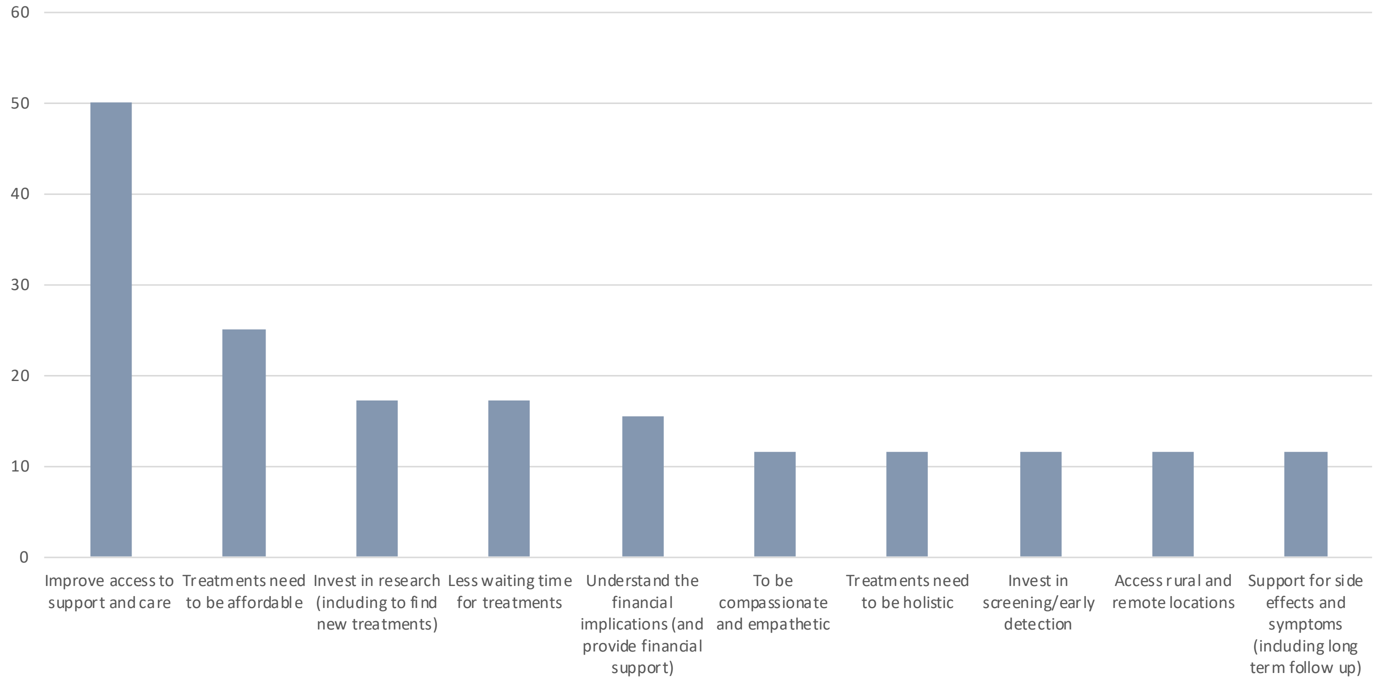

Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Participant's message is to improve access to support and care	Diagnosed in 2016 or before	Aged 55 to 74 Diagnosed in 2020 or 2021
Participant's message is that treatments need to be affordable	Stage III and IV	Stage 0 and I Diagnosed in 2016 or before Regional or remote
Participant's message is to invest in research (including to find new treatments)	Aged 25 to 54	Aged 55 to 74 Regional or remote
Participant's message is that there needs to be more timely access to treatments	Diagnosed in 2016 or before Diagnosed in 2017 to 2019	Diagnosed in 2020 or 2021 Regional or remote
Participant's message is to understand the financial implications (and provide financial support)	Aged 55 to 74 Trade or high school Regional or remote	Diagnosed in 2016 or before
Participant's message is to be compassionate and empathetic	Diagnosed in 2017 to 2019	-
Participant's message is that treatments need to be holistic	Stage III and IV	Regional or remote
Participant's message is to invest in screening/early detection	Regional or remote Mid to low status	Diagnosed in 2017 to 2019
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	Diagnosed in 2016 or before Regional or remote	-