

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Participant describes being presented with multiple options/approaches

My first appointment with the surgeon, he was the first specialist I saw. I suppose he explained triple-negative breast cancer, that it's not related to hormones and all that, and said I had two options. I could either have a lumpectomy and radiotherapy afterwards or I could have a mastectomy and the outcome, he said, for either was very similar. Then he went further, and he described it as a weed in a garden and a mastectomy is ripping up the whole garden bed to get rid of one weed. He explained it that way. Participant_002

So when I went to the surgeon, she went through all the statistics of the different surgical options about whether you have a lumpectomy versus a mastectomy versus a double mastectomy. She talked about because of how aggressive mine was and to do with it being triple negative, that the better option was to do neoadjuvant chemotherapy. And so I was going to be doing IV chemo first. So she explained that generally. And then I went to the oncologist the next week and he went into it further and they talked about the different chemo options, what most women were doing, but versus what they wanted to trial with me as a bit extra to throw the kitchen sink at it because it was so aggressive and it was growing so quickly. So he went through all that there and certainly told you about my prognosis and my statistics and treatment options and which would give me the best outcome. And then it wasn't until halfway through the chemo that I met back up with the surgeon and made the final decision about it because they told me all that back then and to appointments. Participant_010

When I first saw the surgeon and he booked me in pretty much straight away for surgery, and there wasn't really a discussion around other options it was a case of, "You will need surgery, you will need chemo, and you will need radiation for this type of cancer and this is what we do." I was booked in for surgery, and then while doing a little bit of investigating I found a triple-negative trial that was taking place at our local hospital. I followed that up to see if I'd be a participant for the trial. I met with the trial's team and the oncologist because I wanted to see if that was my only option. The trial was for neoadjuvant chemo and immunotherapy. Sadly, I wasn't eligible because the cancer was too far advanced for what they needed. However, those discussions led me to choose to do the chemo first before surgery, but I hadn't known that was an option at the beginning. It was just, "This is what we'll do. It will be surgery, chemo, radiation." Participant_033

Participant describes being presented with one option/approach

Well, I didn't really have an option. It was either treatment or no treatment. That was that discussion. Wasn't really a discussion. It was, this is what we're going to do. If you don't do this, then you've got probably 18 months. That was my discussion. Participant_012

The only one conversation I had was removal. They had to remove both breasts. That's all. They didn't suggest anything else, not a thing. Participant_032

Basically that I had to start chemo as soon as possible. I didn't really have a choice because my cancer was very aggressive and it was very large. It had already travelled to the lymph nodes. They just basically said the smaller they can get it, the safer it would be to have surgery. They really didn't give me an option, in the sense that it was too big and it was growing too fast. They believed that that was the safest and best option for me. Participant_046

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being presented with multiple options/approaches	38	76.00	18	78.26	20	74.07	14	73.68	19	76.00	17	65.38	21	87.50	15	62.50	23	88.46
Participant describes being presented with one options/approach	8	16.00	4	17.39	4	14.81	4	21.05	3	12.00	5	19.23	3	12.50	6	25.00	2	7.69
Participant describes no treatment discussions	1	2.00	0	0.00	1	3.70	0	0.00	1	4.00	1	3.85	0	0.00	1	4.17	0	0.00
Other	2	4.00	1	4.35	1	3.70	1	5.26	1	4.00	1	3.85	1	4.17	1	4.17	1	3.85

Discussions about treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being presented with multiple options/approaches	38	76.00	12	75.00	26	76.47	12	60.00	26	86.67	14	73.68	17	77.27	7	77.78
Participant describes being presented with one options/approach	8	16.00	4	25.00	4	11.76	5	25.00	3	10.00	2	10.53	4	18.18	2	22.22
Participant describes no treatment discussions	1	2.00	0	0.00	2	5.88	1	5.00	1	3.33	1	5.26	1	4.55	0	0.00
Other	2	4.00	0	0.00	1	2.94	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00

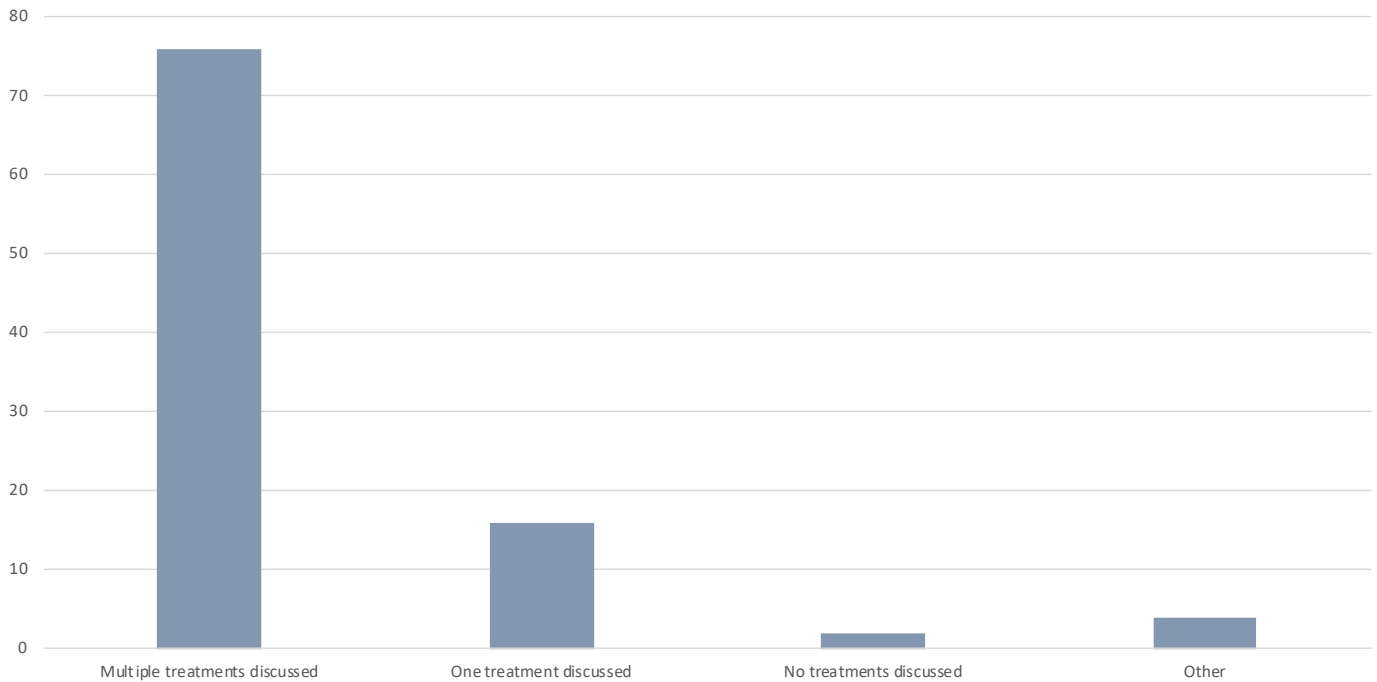


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options/approaches	Diagnosed before 2020 Trade or high school Mid to low status	Diagnosed in 2020 or 2021 University Higher status

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Participant describes feeling that they were told what to do/ little or no discussion

Well, that was actually pretty crap, really, because I went back to the GP to get the results after the biopsy. But I knew because as soon as I felt the lump, you know, I knew what it was. And then when I was having the cold biopsy, just the manner of the guy who was doing it, he sort of quite sympathetic. And I just know this is not good. I know I just knew I had this real gut feeling. That's why I rang the because really horrible after the biopsy. So then I went back to the GP and he pretty much just said, yes, it is breast cancer and you need to make an appointment with the surgeon

because you don't have to get it removed and they'll be able to tell you all the options. So here's the form you need to send this off and try and make an appointment. And it's probably going to take a little while because I do it as soon as you can. That was pretty much it. There really wasn't any discussion. Participant_001

Pretty short, really, because it was triple negative. That basically said and because I was only 37 at the time, as I said, you're young, we want to pump you full of whatever we can to give you the best chance of life, you know, a good life expectancy. But they also, like they said, we will hit you with the chemo and radiotherapy. But that's actually all you can have, the triple negative because it's not a hormonal cancer and that kind of thing. My choices were actually limited. It was that or nothing yet. So it wasn't we didn't need to have a lot of conversation about. Participant_003

Well, I didn't really have an option. It was either treatment or no treatment. That was that discussion. Wasn't really a discussion. It was, this is what we're going to do. If you don't do this, then you've got probably 18 months. That was my discussion. Participant_012

Participant describes feeling that they participated in decision-making/Had informed discussion

I think that discussion probably took place with the breast surgeon. She was talking either lumpectomy or mastectomy, and she just gave me the rundown on both. I said, "Well, why would I have a mastectomy?" There wasn't any really good reason to, so I just went with the lumpectomy. After the surgery, and after the results came back of what type of cancer it was, that led into what I would do next. There was never any discussion about having chemo first. It was always the surgery first and then chemo may or may not happen because of the type of cancer it was and my age. They just went and said, "Yes, you're definitely having chemo and you're actually having radiation as well." That pretty much all took place with the breast surgeon, and then after that, I went over and started with oncology at the hospital. Participant_005

So I had discussions about my options and I was definitely having surgery. It was suggested I have

radiation, but then we discussed, because with the BRAC one, gene, that suggested you have come back because of an underlying bail condition. I opted not to have that with a lot of discussion with my doctor. Participant_006

The very first conversation would have been with my breast surgeon. After that initial consult where all the investigations were ordered and a rough outline was given of what I could expect in the way of treatment. Once I got all of those tests done and the results went back to that breast surgeon, I then went and saw him again, and my treatment plan was then discussed in detail. Because of the type of breast cancer that I had and the size of the lump, it was explained to me that the best course of action was to begin with chemotherapy to reduce the size of the lump. Then from there to have the surgery and following surgery, to go on with radiotherapy. I knew from that second consult what my plan was going to be. Once I then was referred to the medical oncologist I was given an option then of going through treatment with what he explained to me was the routine course of action. I was also given the option of participating in a clinical trial. Once I had that explained to me, I was then given more detail about the clinical trial and I elected to participate in that clinical trial. Participant_013

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes feeling that they were told what to do/little or no discussion	28	56.00	9	39.13	19	70.37	10	52.63	15	60.00	11	42.31	17	70.83	15	62.50	13	50.00
Participant describes feeling that they participated in decision-making/Had informed discussion	19	38.00	13	56.52	6	22.22	8	42.11	8	32.00	12	46.15	7	29.17	7	29.17	12	46.15
Other	3	6.00	1	4.35	2	7.41	1	5.26	2	8.00	1	3.85	2	8.33	2	8.33	1	3.85

Discussions about treatment (Participation in discussions)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes feeling that they were told what to do/little or no discussion			9	56.25	19	55.88	8	40.00	20	66.67	9	47.37	14	63.64	5	55.56
Participant describes feeling that they participated in decision-making/Had informed discussion			12	75.00	0	0.00	2	10.00	1	3.33	8	42.11	7	31.82	4	44.44
Other			0	0.00	3	8.82	2	10.00	1	3.33	2	10.53	1	4.55	0	0.00

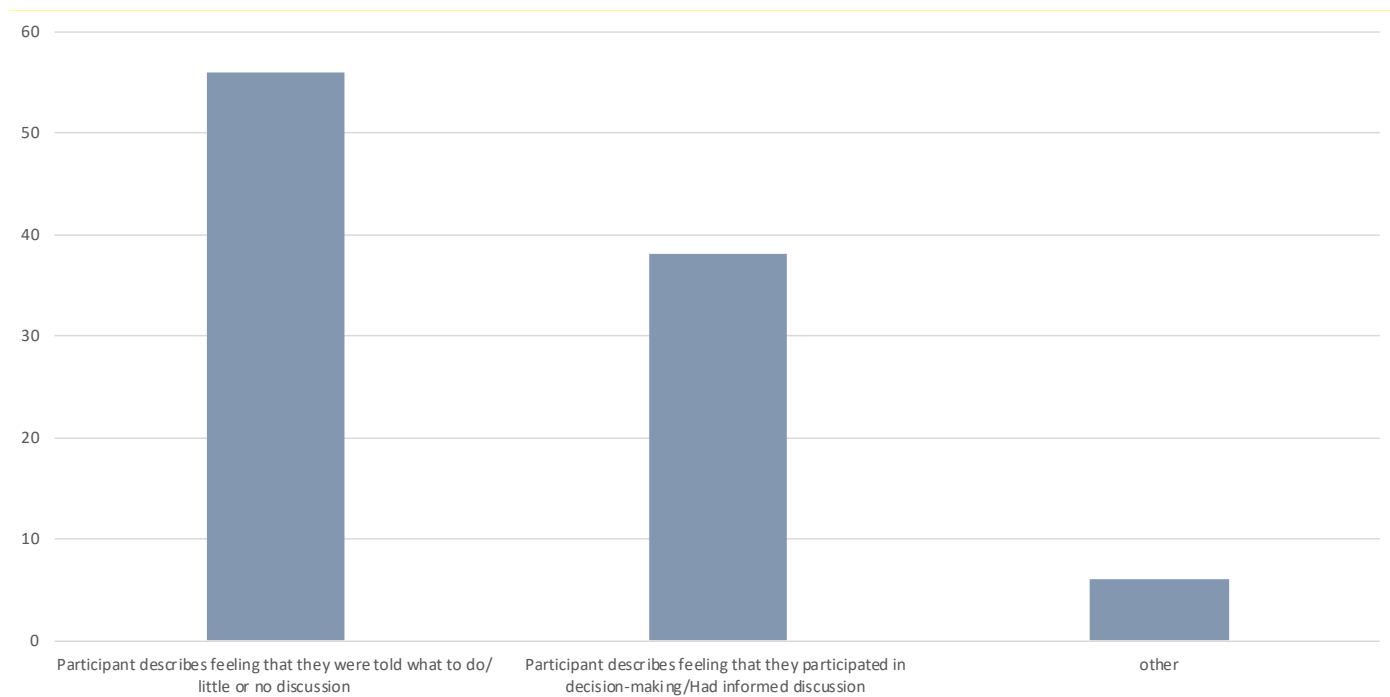


Figure 4.2: Discussions about treatment (Participation in discussions)

Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes feeling that they were told what to do/ little or no discussion	Early breast cancer Diagnosed before 2020 Mid to low status	Advanced breast cancer Diagnosed in 2020 or 2021 Higher status
Participant describes feeling that they participated in decision-making/Had informed discussion	Advanced breast cancer Metropolitan Mid to low status Higher status	Early breast cancer Regional or remote

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)

The biggest thing I take into consideration is obviously the specialist's advice. The other thing was my age, I personally wanted to go as aggressive as possible with this because I'm young and I wanted to give

myself the best chance of surviving this and prevent a reoccurrence, so I think those things. Obviously, also the distance from my house to the hospital. For me, the biggest thing was I had a baby, so I just wanted to have enough provisions, that someone can look after him. Participant_016

To be honest, I didn't know enough information to really make the decisions. I kind of just trusted them and listened to what they said. I was not a very good person. I didn't ask many questions. I kind of just went along with it. Participant_019

I probably was a little stunned at the time. Like I said, my mum has been five years with cancer. I think I just trusted what they were saying to me. I felt like I needed to trust the options they were giving me. I was only ever really given one option and that was to do the chemo first. I don't feel like I really had any options there. I think it was, "This is triple-negative. This is the best course." I think if I'd jumped up and down and said I want to know the other stuff maybe they would have given it to me, but I was quite happy to take under consideration what they were suggesting. Participant_035

Participant describes taking side effects into account when making decisions about treatment (Total)

I guess how it's going to impact my health further. How I'm going to be feeling. I've got to think about my family as well. I've got young children. Can I care for them? Can I go to work? How am I going to earn money? How am I going to support my family? I'm a single parent, and how long it's going to be for, and what the side effects are? Participant_017

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027

The success rate, the side effects, has it been used before for these cases, and, the convenience of it, I guess, like how much it's going to affect my day to day life? Participant_044

Participant describes taking efficacy into account when making decisions about treatment (Total)

I guess efficacy and symptoms and long term side effects and quality of life? Just going through the treatment, I guess it would be a balance, as I say. Participant_001

My biggest consideration is the effectiveness of that treatment. I put that way above any side effects or any long-term effects. If it's effective, then I'm going to want to try it. That's my biggest decision-maker. It's regardless of how terrible I might feel, if it has a good outcome or it's potentially got a good outcome, that would sway me very easily into trying that treatment. That's been my main motivator, I guess. Is what gives me the best chance of getting through this and beating it. The other things are factors, but nothing would sway me away from trying something if it's documented and known to be effective or more likely to be effective. Participant_033

I like to look at some of the research, about the effect, the effectiveness of the treatment, side effects, the cost is an issue with some of the cancer treatments. I will take on board advice from my oncologist, but I'll also check it with getting an alternative opinion or another, not alternative, but another opinion from my naturopathic oncologist. At this stage, my treatment hasn't changed, so I haven't had to re-research things again. I'm still on the same treatment. Yes, side effects, and if there's anything that can help alleviate any of the side effects. Participant_050

Participant describes taking the survival benefit into account when making decisions about treatment (Total)

The biggest thing I take into consideration is obviously the specialist's advice. The other thing was my age, I personally wanted to go as aggressive as possible with this because I'm young and I wanted to give myself the best chance of surviving this and prevent a reoccurrence, so I think those things. Obviously, also the distance from my house to the hospital. For me, the biggest thing was I had a baby, so I just wanted to have enough provisions, that someone can look after him. Participant_016

I guess the first priority is staying alive and making sure that I'm not just saying no to something because I don't want to do it, when I know that really, it's the only option, I've got to do it. The first priority is always being alive and planning on being alive for not just three years, but 70 more years kind of thing. Obviously not 70, but like another 30 plus years. Participant_025

Basically, what the results are. Basically, what the chances are of survival. What's the chances with that form of treatment, and what were the side effects involved. Participant_046

Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)

Well, it was my decision to do neoadjuvant chemo and the reason I chose that or pushed for that was because even though I had the cancer in me, in my body, if it hadn't been cut out, because I had triple-negative, statistically, 3% of women who have triple-negative, chemo doesn't work on that particular type of cancer. Without the tumor, we didn't have a marker to go against. I wouldn't have known whether the chemo was working. Just for me, I wasn't going to go through that horrendous part of the treatment without knowing for certain that it was working. Participant_009

Professional opinion, statistics to a point and I don't know, really. Other than that I probably google. [chuckles] Participant_012

I didn't consider anything. I considered that my oncologist was making all the right decisions for me. It wasn't till the end that I realized I should have taken more charge of my body, and ask more questions, and ask the success statistics. I didn't do any of that. That's what I would do now. If I was to go back in time or I

have to start any treatment again, I'd be asking what are all my alternatives? Why do I have to just have that one? I'd want more options this time, because I was in shock, I just did what they told me to do. Participant_046

Participant describes taking cost into account when making decisions about treatment (Total)

Time frame, cost, although I was lucky it was all pretty much covered. Although, my surgery, I did myself. Side effects, pretty much. Participant_021

Children, finances, physical mobility, probably emotional as well, and that's about it. Participant_024

Cost sometimes comes into it a little bit. I've definitely learned that I just ask now, do I have to pay for this? Can you bulk bill me? Because nobody tells you that

getting cancer is actually expensive so that's definitely something, yes. Participant_043

Participant describes taking quality of life into account when making decisions about treatment (Total)

I guess efficacy and symptoms and long term side effects and quality of life? Just going through the treatment, I guess it would be a balance, as I say. Participant_001

My well-being, my mental health, how it will affect my mental health. How it will affect my life and what the outcome will be. Participant_018

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027

Table 4.5 Considerations when making decisions

Considerations when making decisions	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	18	36.00	9	39.13	9	33.33	6	31.58	8	32.00	8	30.77	10	41.67	8	33.33	10	38.46
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	15	30.00	7	30.43	8	29.63	6	31.58	7	28.00	6	23.08	9	37.50	7	29.17	8	30.77
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	3	6.00	2	8.70	1	3.70	0	0.00	1	4.00	2	7.69	1	4.17	1	4.17	2	7.69
Participant describes taking side effects into account when making decisions about treatment (Total)	11	22.00	4	17.39	7	25.93	6	31.58	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	18.00	4	17.39	5	18.52	5	26.32	4	16.00	6	23.08	3	12.50	3	12.50	6	23.08
Participant describes taking efficacy into account when making decisions about treatment (Total)	7	14.00	3	13.04	4	14.81	3	15.79	3	12.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	0	0.00	0	0.00	0	0.00	1	4.17	1	4.17	0	0.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	4	15.38	2	8.33	0	0.00	6	23.08
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	7	14.00	5	21.74	2	7.41	2	10.53	4	16.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	3	6.00	2	8.70	1	3.70	1	5.26	2	8.00	2	7.69	1	4.17	1	4.17	2	7.69
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	13.04	1	3.70	1	5.26	2	8.00	2	7.69	2	8.33	0	0.00	4	15.38
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	14.00	4	17.39	3	11.11	3	15.79	2	8.00	2	7.69	5	20.83	4	16.67	3	11.54
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	6.00	1	4.35	2	7.41	2	10.53	0	0.00	0	0.00	3	12.50	2	8.33	1	3.85
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	13.04	1	3.70	1	5.26	2	8.00	2	7.69	2	8.33	2	8.33	2	7.69
Participant describes taking cost into account when making decisions about treatment (Total)	6	12.00	2	8.70	4	14.81	3	15.79	3	12.00	6	23.08	0	0.00	3	12.50	3	11.54
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	0	0.00	1	4.00	1	3.85	0	0.00	0	0.00	1	3.85
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	8.70	3	11.11	3	15.79	2	8.00	5	19.23	0	0.00	3	12.50	2	7.69
Participant describes taking quality of life into account when making decisions about treatment (Total)	6	12.00	2	8.70	4	14.81	1	5.26	5	20.00	5	19.23	1	4.17	3	12.50	3	11.54
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	1	5.26	0	0.00	1	3.85	0	0.00	0	0.00	1	3.85
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	8.70	3	11.11	0	0.00	5	20.00	4	15.38	1	4.17	3	12.50	2	7.69

Considerations when making decisions	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	18	36.00	4	25.00	14	41.18	5	25.00	13	43.33	4	21.05	10	45.45	4	44.44
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	15	30.00	2	12.50	13	38.24	4	20.00	11	36.67	3	15.79	9	40.91	3	33.33
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	3	6.00	2	12.50	1	2.94	1	5.00	2	6.67	1	5.26	1	4.55	1	11.11
Participant describes taking side effects into account when making decisions about treatment (Total)	11	22.00	3	18.75	8	23.53	4	20.00	7	23.33	4	21.05	4	18.18	3	33.33
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	4.00	0	0.00	2	5.88	0	0.00	2	6.67	0	0.00	1	4.55	1	11.11
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	18.00	3	18.75	6	17.65	4	20.00	5	16.67	4	21.05	3	13.64	2	22.22
Participant describes taking efficacy into account when making decisions about treatment (Total)	7	14.00	3	18.75	4	11.76	4	20.00	3	10.00	3	15.79	2	9.09	2	22.22
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	2.94	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	2	10.53	2	9.09	2	22.22
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	7	14.00	2	12.50	5	14.71	3	15.00	4	13.33	3	15.79	3	13.64	1	11.11
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	3	6.00	1	6.25	2	5.88	0	0.00	3	10.00	1	5.26	2	9.09	0	0.00
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	1	6.25	3	8.82	3	15.00	1	3.33	2	10.53	1	4.55	1	11.11
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	14.00	5	31.25	2	5.88	6	30.00	1	3.33	1	5.26	5	22.73	1	11.11
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	6.00	2	12.50	1	2.94	3	15.00	0	0.00	0	0.00	3	13.64	0	0.00
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	18.75	1	2.94	3	15.00	1	3.33	1	5.26	2	9.09	1	11.11
Participant describes taking cost into account when making decisions about treatment (Total)	6	12.00	4	25.00	2	5.88	2	10.00	4	13.33	3	15.79	1	4.55	2	22.22
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	1	2.00	1	6.25	0	0.00	0	0.00	1	3.33	1	5.26	0	0.00	0	0.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	3	18.75	2	5.88	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22
Participant describes taking quality of life into account when making decisions about treatment (Total)	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	3	15.79	3	13.64	0	0.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	2.00	1	6.25	0	0.00	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	3	13.64	0	0.00

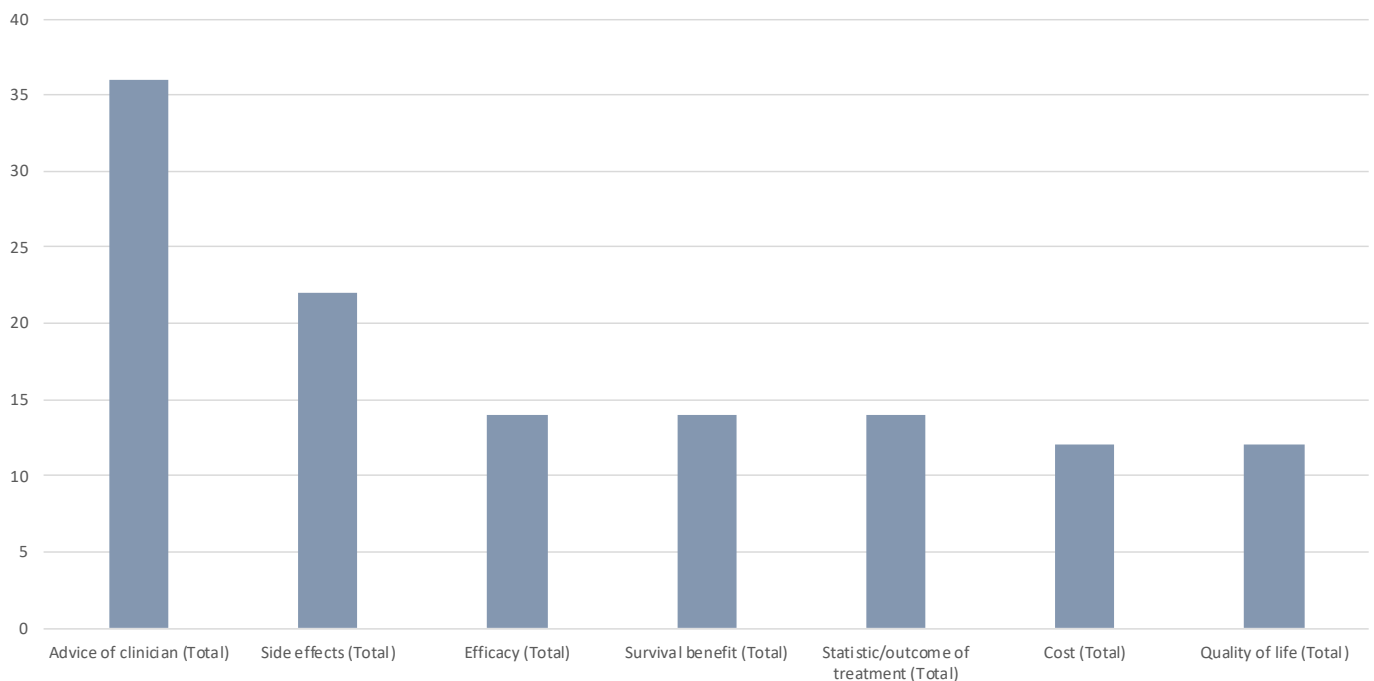


Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Regional or remote Mid to low status Aged 25 to 44	-
Participant describes taking side effects into account when making decisions about treatment (Total)	-	Aged 55 to 74
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	Higher status	Regional or remote Mid to low status
Participant describes taking cost into account when making decisions about treatment (Total)	Diagnosed in 2020 or 2021	Diagnosed before 2020 Regional or remote Aged 55 to 74
Participant describes taking quality of life into account when making decisions about treatment (Total)	Aged 55 to 74	-

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

Participant describes decision-making changing over time as they are more informed and/or more assertive

I've learned to go with my gut instinct and to be my own advocate. If I don't get the answer I want, I'll now keep asking. Whereas before, I would have been like, "Oh, okay. Well, you're the doctor, you know best." Participant_027

PARTICIPANT: I think I evolved as I went along. At first, I couldn't. You're in such deep shock with that diagnosis. I don't care what anybody says, I was so shocked. There's no history of breast cancer or anything in my family, I was not expecting that. In the end, I would take along my list of questions, write down my list of questions, and I would sit there. [chuckles] Like, "I'm going to list the questions I really want them answered." Every time I went somewhere, I had a list of questions so that I could get answers to stuff.

INTERVIEWER: Did it help to write them down?

PARTICIPANT: Yes.

Participant_029

PARTICIPANT: No, I definitely have changed.

INTERVIEWER: Yes? In what way has it changed?

PARTICIPANT: I just look at the big picture and the end result now, not just the immediate-- Initially, I used to just make a decision on, "Okay, what's the right thing

to do right now?" Moving forward now, I ask a lot more questions about why did they say this? Why are they suggesting this for me? Even just my surgery, I was like, "Why am I only having a lumpectomy? Why aren't I having a breast removal? Then she talked to me through that and I was like, "Okay, I'll just have a lumpectomy then." I didn't ask a question. I just went with what she was saying. Participant_045

Participant describes decision-making changing over time as they are more proactive

I think maybe I do more of my own research, maybe rather than I didn't know it was hard. When you're in that situation and it's also you, you just go with what you're told. Yeah, but maybe being a bit more experienced, I think I would try and be a bit quicker in doing my own research and finding out alternative. Participant_001

I think yes, the way I make decisions is probably a little bit more considered than it was before. Prior to diagnosis, I'd be more inclined to be slower with decision-making. Whereas now, with my health, if I find something wrong I'm like ah, I better get on to that just in case. I'm a bit more proactive, I guess is what I'm saying. For example, in the past, I've known I've had high cholesterol, but I hadn't really done much about it. Since diagnosis, I'm like oh, well now I better take these things a bit more seriously. I went through a series of tests to check my cholesterol, and a few different ways of living, and how it was impacted. Now a take a statin to keep that cholesterol under control, because I don't want it to be an issue later on. I know things can happen if you leave things. I'm probably just a bit more proactive. For example, again, I'm having a bone density scan this afternoon which I'm now having every two years because I'm in menopause and blah, blah, blah. I'm just more proactive. Participant_005

It has changed, in the sense, I realized that I thought that the approach I was presented with initially, I felt it was a very tunnel-view, like just, "This is what your treatment should be," kind of thing. Whereas, over the course, I realized I have to be in charge of things a lot more. I think I was quite trusting, and I'm not saying I should doubt the health professionals, but I definitely feel like I have a right to ask questions and it's okay to have a more active role in my treatment rather than passive. Participant_016

Participant describes decision-making changing over time as they are more cautious and considered

No, now I think that I'm more considerate of how my decisions will affect me in my day-to-day life and life going forward. I take time to think about things now, whereas I didn't then. Participant_004

Definitely changed, definitely. I think about the impact of any decision are going to have on my health, whereas before maybe I'd make a decision and not really worry about it, or I'd just go ahead and do it and not even think about the consequences. I do stop and think about it more now. Participant_020

Probably now it's slightly changed in that it was all so quick back then. I probably put a bit more thought to it but I don't think it would change any decision I've made either Participant_021

Participant describes no change in decision-making over time

For me, we pretty much approached the decisions in the same way, but that's because prior to breast cancer, as I mentioned, we had already gone through infertility treatment. For me, breast cancer wasn't the end of my world, I'd already had the bad news. My world had already fallen apart, pretty much, so by the time I got told I had cancer, it was more of a reaction, "Of course it is, why wouldn't it be?" Every decision we've ever made for any medical purpose has always been made with us acknowledging that this is the decision we're making now, based off the information we currently have. We might in 10 months' time, know more information that may have changed the decision we would have made, but right now, this is the reason we're making this decision and that's what we accept. From a medical perspective, it hasn't changed the way that we make decisions. Participant_025

I think for me, I do make decisions in the same way. I rely on the the specialists to be advising me on the best course of action and that I trust my oncologist. Participant_049

I think the same way. I'm a very, fact and research-driven person about anything health-related. Participant_050

Table 4.7: Decision-making over time

Decision-making over time	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes decision-making changing over time	27	54.00	16	69.57	11	40.74	12	63.16	11	44.00	12	46.15	15	62.50	13	54.17	14	53.85
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.00	5	21.74	8	29.63	5	26.32	5	20.00	5	19.23	8	33.33	6	25.00	7	26.92
Participant describes decision-making changing over time as they are more proactive	6	12.00	5	21.74	1	3.70	3	15.79	2	8.00	2	7.69	4	16.67	1	4.17	5	19.23
Participant describes decision-making changing over time as they are more cautious and considered	5	10.00	5	21.74	0	0.00	2	10.53	3	12.00	3	11.54	2	8.33	4	16.67	1	3.85
Participant describes no change in decision-making over time	18	36.00	5	21.74	13	48.15	5	26.32	11	44.00	10	38.46	8	33.33	8	33.33	10	38.46
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.00	2	8.70	5	18.52	3	15.79	4	16.00	4	15.38	3	12.50	5	20.83	2	7.69
Participant describes no change in decision-making over time as they have always been proactive	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	1	3.85	3	12.50	0	0.00	4	15.38
Other	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	2	7.69	4	16.67	4	16.67	2	7.69

Decision-making over time	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes decision-making changing over time	27	54.00	11	68.75	16	47.06	11	55.00	16	53.33	12	63.16	12	54.55	3	33.33
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.00	6	37.50	7	20.59	6	30.00	7	23.33	5	26.32	7	31.82	1	11.11
Participant describes decision-making changing over time as they are more proactive	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	4	18.18	0	0.00
Participant describes decision-making changing over time as they are more cautious and considered	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Participant describes no change in decision-making over time	18	36.00	5	31.25	13	38.24	6	30.00	12	40.00	5	26.32	8	36.36	5	55.56
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	3	15.79	2	9.09	2	22.22
Participant describes no change in decision-making over time as they have always been proactive	4	8.00	2	12.50	2	5.88	2	10.00	2	6.67	0	0.00	3	13.64	1	11.11
Other	6	12.00	0	0.00	6	17.65	3	15.00	3	10.00	2	10.53	3	13.64	1	11.11

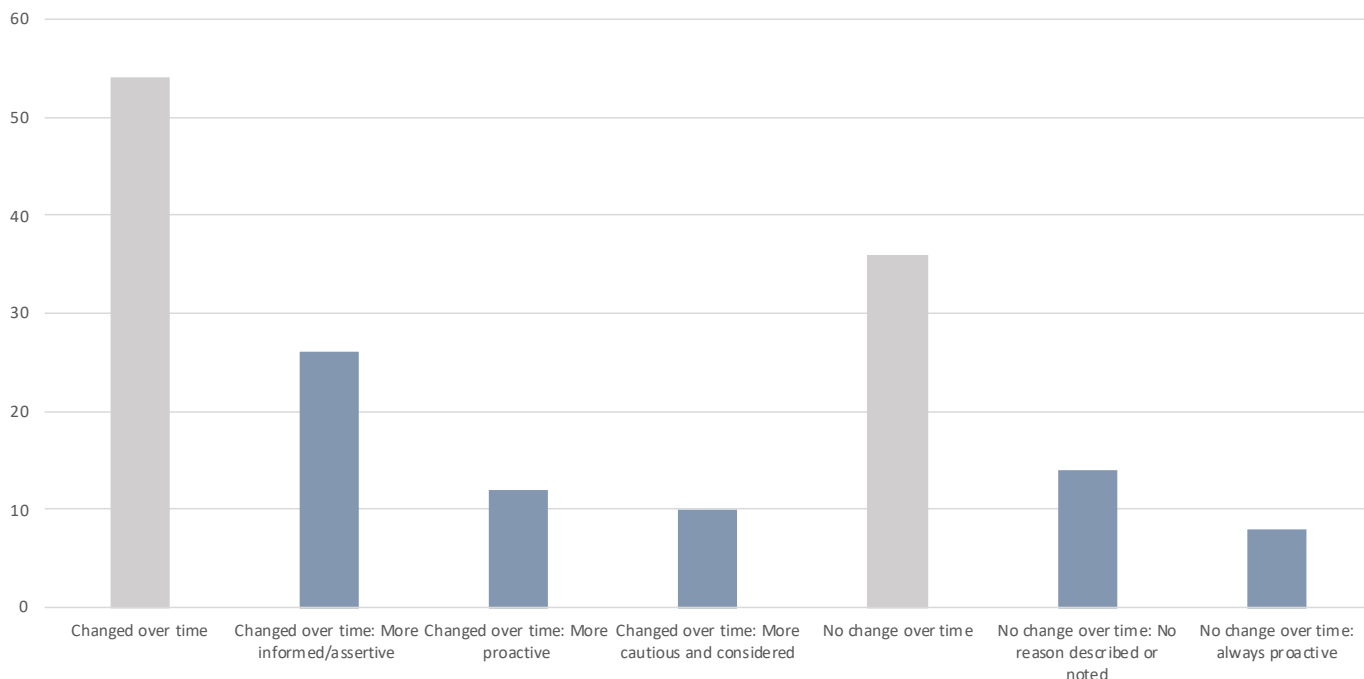


Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes decision-making changing over time	Advanced breast cancer Aged 55 to 74	Early breast cancer Regional or remote
Participant describes no change in decision-making over time	Early breast cancer	Advanced breast cancer Aged 55 to 74

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

Goals of treatment

Participant describes wanting to treat the disease/get better

To be honest, at those first appointments, it was all just about how do we get rid of the cancer? I think all the other stuff kind of just seemed part and parcel that you would have side effects and it would affect your life negatively. But I think my main goals would just how the hell do we get rid of it and the rest will deal with as it comes, if that makes sense. Participant_010

Yes, so my goals were basically just to get the best, praying that the chemo gives me the best outcome. Afterwards, now my goals are from now on just to get back on my feet and basically keep my fitness up. I've modified my diet as well, just to minimize any processed foods and to eliminate anything possibly that could have led to it. Participant_016

Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Participant_025

Participant describes wanting to follow/get through treatment

I think mine were-- I was happy to have whatever was necessary just to get it over and done with. My goals, obviously, it would have been nice to avoid chemo and all those sorts of things, but yes, the goal was really just to get it all done so I could get on with living. I wasn't going to go out and seek alternative therapies or anything like that. I just went through the process, and I think the triple-negative, it funnels you down a

very narrow set of options, from what I could gather. My goal was just to do things efficiently, quickly, and just have it over and done with I suppose. Participant_005

I probably in the initial stages, I think in my mind that I was just really concentrating on treatment and getting through the treatment. I didn't really have a detailed conversation about how that might impact on me once treatment was finished. At the time that I was diagnosed, I was working full time in a fairly-- I had a nurse management position so it was a reasonably stressful job, but I elected, I was lucky enough that I had plenty of leave, so I elected to take leave from work and I actually didn't work for the whole time that I was receiving treatment. I discussed about return to work partway through my treatment and it was indicated to me that once I'd finished chemotherapy and radiation therapy, once I started feeling better then there should be no reason why I couldn't return to work, which I did initially. I returned to work after I completed radiation therapy, but I returned to work full time and I found after six weeks I wasn't coping, so I took more leave. I think I took about three months' leave, and when I returned, I was given the option by my immediate manager to return to work part-time, which I did for six months. I still found that I wasn't coping with the fatigue. I was fortunate enough to be in a position financially that I didn't need to work, so I made the decision to actually retire early. Participant_013

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033

Participant describes wanting to live independently

My goal in treatment really is just to try and continue on with life as normal with as minimal side effects as possible. I think when you're first diagnosed, it's all very overwhelming and you really don't know at that stage whether you've got a year, whether you've got six months or whether you've got 10 years you don't know. I think to have a normal life as possible which is

have as little and minimal side effects as possible was my ultimate gain. Participant_018

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033

I'm not having active treatment anymore because I'm out the other side, I'm having reconstruction and surgeries and stuff like that. My thing is just to try and get back to normal really, I want to feel normal again. Participant_043

Participant described wanting to see mental/emotional health improvements in their condition

I feel I'd like to know more-- and I have been doing stuff by myself but, I think it would be nicer if the establishment told you more about what you can do to minimize your chances of getting a recurrence or metastasis. Also, the whole mental health aspect as well. I feel when you finish treatment, that's not really addressed at all. The fear of recurrence and that sort of thing, I don't feel that there was any support for mental health throughout the whole thing, really, honestly. I had to take it upon myself to go to my GP and ask for a mental health care-plan. Going forward, I'd like to basically know more about what I can do to keep myself healthy and to keep my mental health healthy too. Participant_004

I'm doing a UQ, a trial about exercise helping out with chemotherapy and I'm finding that extremely helpful. That's one of my goals, small goals, like being out of balance and ride on the bike. Physically, I have those goals. Mentally, I've tried to just to be negative if I want to be negative and positive if I want to be positive, and not be too hard on myself. Participant_007

Well, I don't know. I had to actually stop my Taxol treatment early because I got neuropathy and they were worried that if they kept treating me that it'd become permanent. I had to stop that early. Going through chemo has been really, really hard for me. I've had a lot of very bad side effects. I've been very sick. I'm glad I finished chemo. The only thing that I've really done, I haven't even done it yet. I would like to participate in this return to wellness exercise program, et cetera that they're running at LOCATION Health. It's a Paula program. I'm basically waiting to see how I feel. I would like to do that and just like to do more exercise and obviously talk to a psychologist, because this is really bad for mental health as well. I haven't really, really made any plans yet. I just want to get through all this. Participant_028

Participant describes wanting to return to work

I think after radiation, I'm having trouble with my right side. So my goal would be to be able to garden without being in bed and doing my job, my job. I do a lot of reporting and cutting, but I find that if I do a lot of that, then it's all set off just to leave like pain free and be able to do things. Participant_006

All of the above. I've got a lot more physical limitations now and mental as in fatigue and stuff like that. I had quite a senior executive role that I can't do anymore because I've got such bad fatigue and cognitive issues and then body pain as well. I'd love to be able to have some help in terms of that. Participant_008

I don't really know to tell you the truth. I've been through my chemotherapy and I decided to stop work because I had insurance so I didn't work during that period, but I'm just looking at going back to work now and I still got insurance. I'm only going to do that part-time because I know I'm still going to be fatigued and tired and my immune system will be down due to oral chemo. But, physio-wise, while I'm in Perth, I'm seeing a physio when I finish radiation, just to make sure that I've still got movement and make sure I don't have

lymphedema. Other than that, I don't-- I've got my appointments with my oncologist and my surgeon, they will be scheduled but that's about it. Participant_017

Participants describe wanting to see physical improvements in their condition

I'm doing a UQ, a trial about exercise helping out with chemotherapy and I'm finding that extremely helpful. That's one of my goals, small goals, like being out of balance and ride on the bike. Physically, I have those goals. Mentally, I've tried to just to be negative if I want to be negative and positive if I want to be positive, and not be too hard on myself. Participant_007

All of the above. I've got a lot more physical limitations now and mental as in fatigue and stuff like that. I had quite a senior executive role that I can't do anymore because I've got such bad fatigue and cognitive issues and then body pain as well. I'd love to be able to have some help in terms of that. Participant_008

Participant describes wanting to manage the side effects

Look, it's a hard one. I'm extremely fortunate with side effects from the treatments I've had have been minimal and not ongoing as such. Once that treatment's finished, the side effects stopped, I've been really lucky in that sense. I just probably want-- and I will probably do is once the treatments even finished is, I just want more education for people on how to handle the side effects as opposed to just being told what to do and not actually have that support there. Participant_030

I was told I would have chemotherapy, there'd be no question of that. I was just terrified of vomiting, to be honest. I didn't really care about losing my hair or anything like that, it was more just being sick. Participant_040

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes wanting to treat the disease/get better	14	28.00	7	30.43	7	25.93	5	26.32	7	28.00	9	34.62	5	20.83	5	20.83	9	34.62
Participant describes wanting to follow/get through treatment	12	24.00	7	30.43	5	18.52	5	26.32	6	24.00	8	30.77	4	16.67	5	20.83	7	26.92
Participant describes wanting to live independently	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes wanting to see mental/emotional health improvements	6	12.00	3	13.04	3	11.11	2	10.53	3	12.00	2	7.69	4	16.67	4	16.67	2	7.69
Participant describes wanting to returning to work	5	10.00	5	21.74	0	0.00	3	15.79	1	4.00	3	11.54	2	8.33	1	4.17	4	15.38
Participants describe wanting to see physical improvements in their condition	5	10.00	3	13.04	2	7.41	3	15.79	0	0.00	1	3.85	4	16.67	2	8.33	3	11.54
Participant describes wanting to manage the side effects	5	10.00	0	0.00	5	18.52	1	5.26	3	12.00	1	3.85	4	16.67	4	16.67	1	3.85

Personal goals of treatment or care	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes wanting to treat the disease/get better	14	28.00	4	25.00	10	29.41	5	25.00	9	30.00	9	47.37	3	13.64	2	22.22
Participant describes wanting to follow/get through treatment	12	24.00	5	31.25	7	20.59	6	30.00	6	20.00	2	10.53	8	36.36	2	22.22
Participant describes wanting to live independently	7	14.00	4	25.00	3	8.82	2	10.00	5	16.67	6	31.58	1	4.55	0	0.00
Participant describes wanting to see mental/emotional health improvements	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11
Participant describes wanting to returning to work	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	3	15.79	0	0.00	2	22.22
Participants describe wanting to see physical improvements in their condition	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	4	21.05	1	4.55	0	0.00
Participant describes wanting to manage the side effects	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	1	5.26	2	9.09	2	22.22

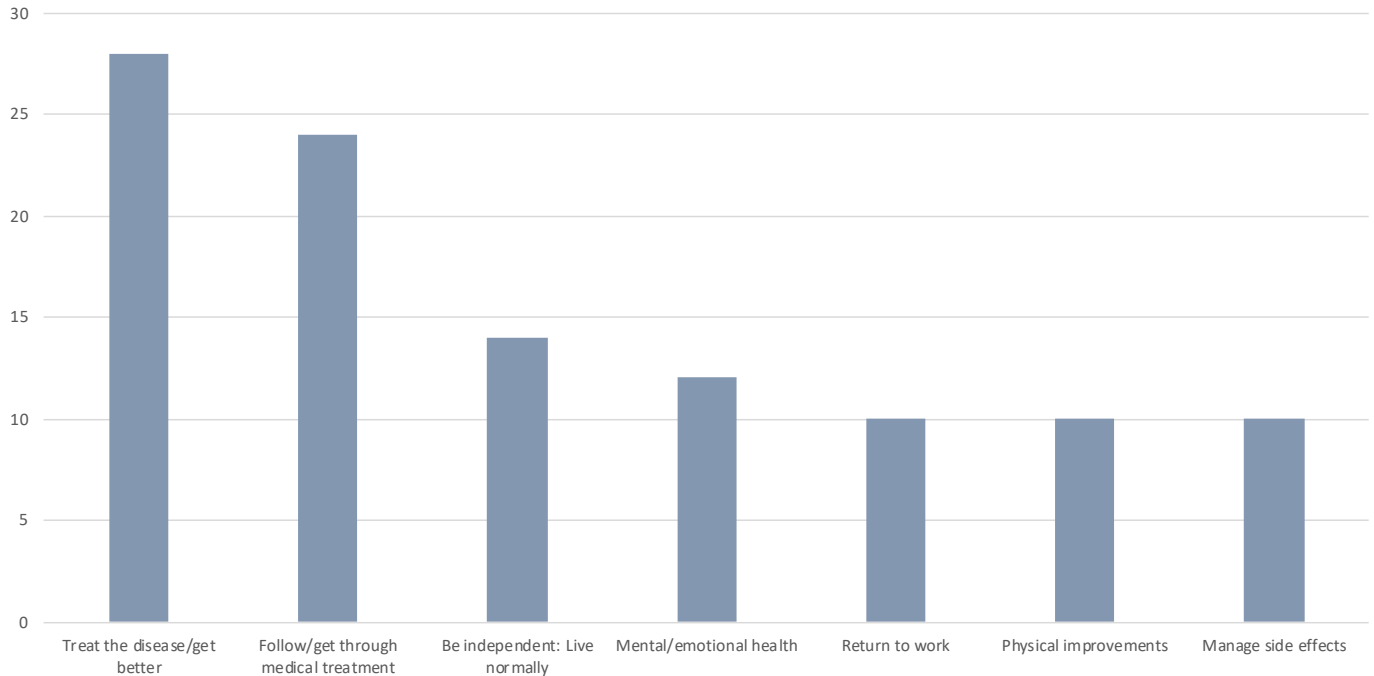


Figure 4.5: Personal goals of treatment or care

Table 4.10: Personal goals of treatment or care – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes wanting to treat the disease/get better	Aged 45 to 54	Aged 25 to 44
Participant describes wanting to follow/get through treatment	Aged 25 to 44	Aged 45 to 54
Participant describes wanting to live independently	Aged 55 to 74	Regional or remote Aged 25 to 44
Participant describes wanting to returning to work	-	Early breast cancer Aged 55 to 74
Participants describe wanting to see physical improvements in their condition	-	Aged 25 to 44
Participant describes wanting to manage the side effects	-	Aged 55 to 74