

## Section 4

### Decision-making

## **Section 4 summary**

### **Discussions about treatment**

The most common description was being presented with multiple treatment options, and this was described by 43 participants (82.69%). This was followed by being presented with one treatment option only (n=8, 15.38%).

### **Discussions about treatment (Participation in discussions)**

In relation to participant in discussions about treatments, there were 23 participants (44.23%) that described that they participated in decision making or had informed discussions, and 21 participants (40.38%) that described that they did not take part in decision making, and nine participants (17.31%) that described feeling that they were told what to do with little or no discussion.

### **Considerations when making decisions**

The most reported theme was taking side effects into consideration and this was described by 24 participants (46.15%). There were 17 participants (32.69%) described taking efficacy of treatment into account, and 15 participants (28.85%) described taking the advice of their clinician. Other considerations included quality of life (n=9, 17.31%), impact on family and dependents (n=8, 15.38%), survival benefit (n=8, 15.38%), ease of administration (n=7, 13.46%), and the ability to work (n=5, 9.62%).

### **Decision-making over time**

Participants were asked if the way they made decisions had changed over time. There were 27 participants (51.92%) that felt the way they made decisions about treatment had not changed over time, and 25 participants (48.08%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have had always been informed and assertive (n=7, 13.46%), or always taken the advice of clinicians (n=6, 11.54%). Where participants had changed the way they make decisions, it was primarily because they had become more informed or more assertive over time (n=17, 32.69%), or because they were more focused on quality of life or the impact of side effects (n=6, 11.54%).

### **Personal goals of treatment or care**

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

## 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 treatment options, and this was described by 43 participants (82.69%). This was followed by being presented with one treatment option only (n=8, 15.38%).

### Participant describes being presented with multiple options/approaches

*The doctor at the breast clinic was very helpful in pushing me, that's the right word ahead to get that test done on that Friday and not have to wait a week or two for it. When I found DOCTOR, I got in to see her on the following Monday. She was absolutely lovely. She spoke to myself and my husband and said that she would be doing a lumpectomy. She would not be doing a mastectomy that she was hoping it would just be the one surgery. Depending on what she found, she wouldn't be removing the whole breast. If that was needed, that would be a second surgery. Yes, she just basically, well, there wasn't all that many options. It was well this is what will happen. You will have had the lumpectomy. They do some pathology while I was under anaesthetic to make sure they got it within the boundaries. She would be taking, well, she didn't know how many lymph nodes but she ended up taking two lymph nodes. As far as I can ascertain, there was no cancer had got out. DOCTOR organized for me to see the oncologist and she also organized for me to see the DOCTOR who was the radiation doctor that was looking after me when I had the radiation. Participant 004\_2021AUHRP*

*INTERVIEWER: Then, what were the types of discussions you had with your clinicians about treatment options, when you first received that diagnosis?*

*PARTICIPANT: Well, surgery, and then radiation, and then we would discuss anything going on further.*

*INTERVIEWER: They said, "Surgery and radiation, that's what you need to do, and then anything from there, we can discuss further"?*

*PARTICIPANT: Yes. Then I was put on medication. Participant 038\_2021AUHRP*

*There's only one specialist in LOCATION, so I just went to him and they more or less said all I really needed was radiation and estrogen blockers and that was it. There was no, really, other discussion. I just went with what they had because they said that the specialists, the oncologists, get together as a team and radiation people and they discuss what is your best treatment. Participant 006\_2021AUHRP*

### Participant describes being presented with one options/approach

*No conversation whatsoever. I was basically told I am getting a mastectomy. I wasn't asked. I was told, we have booked you in for a mastectomy because this is the only thing that's going to save your life. Participant 003\_2021AUHRP*

*Well, in the first instance, it was the medical director who is a GP who was running the breast screening clinic and doing the counselling and the core biopsies and things like that. When she initially called me back and redid the mammogram and ultrasound and then the core biopsy, it was obvious to me, looking at the mammogram, that I obviously had a tumour that was malignant. So at that stage, I was advised that I would be referred to a surgeon. So and then it was left up to me that I wanted to go to the public on a private system. And so at that point, it was just really a case of knowing that I was being directed towards a surgical outcome for my tumours. Participant 019\_2021AUHRP*

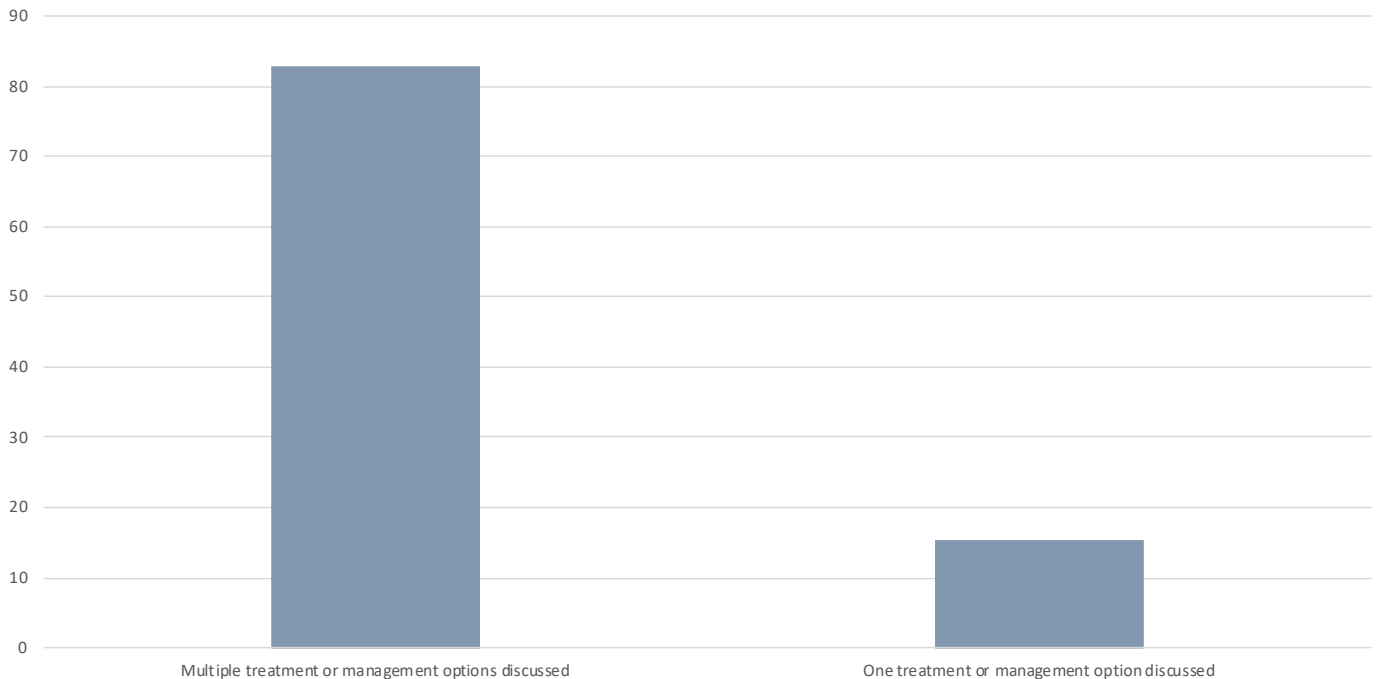
*And she was very open with the survival rate. Is that 100 percent for this type of cancer? So you do have to make some choices about getting rid of it. So she helped me through the originals. So going to go my journey. But the original conversation was about doing a lumpectomy and which is just a wide incision just on the side of the first. I had a quarter with model. From what I can gather, not everyone had a quarter that was probably the most unpleasant of all. I had a quiet and then she went and then I waited three days until my results. Participant 002\_2021AUHRP*

**Table 4.1: Discussions about treatment**

Discussions about 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 being presented with multiple options/approaches	43	82.69	16	84.21	18	85.71	9	75.00	24	82.76	19	82.61	16	84.21	27	81.82
Participant describes being presented with one option/approach	8	15.38	2	10.53	3	14.29	3	25.00	5	17.24	3	13.04	3	15.79	5	15.15

Discussions about 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 being presented with multiple options/approaches	43	82.69	6	60.00	16	100.00	21	80.77	9	81.82	34	82.93	16	88.89	27	79.41
Participant describes being presented with one option/approach	8	15.38	3	30.00	0	0.00	5	19.23	2	18.18	6	14.63	1	5.56	7	20.59



**Figure 4.1: Discussions about treatment (percent of all participants)**

**Table 4.2: Discussions about treatment – subgroup variations**

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options/approaches	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes being presented with one option/approach	Diagnosed in 2017 to 2019	Diagnosed in 2016 or before

**Discussions about treatment (Participation in discussions)**

In relation to participant in discussions about treatments, there were 23 participants (44.23%) that described that they participated in decision making or had informed discussions, and 21 participants (40.38%) that described that they did not take part in decision making, and nine participants (17.31%) that described feeling that they were told what to do with little or no discussion.

**Participant describes taking part in the decision making process**

*I went to the woman first, and she went through the report very carefully from top to toe and then explained to me what she felt needed to be done. She was very clear. I asked her what drugs she was going to use for the chemo. She told me and I thought, "Oh,"*

*because I was a PROFESSION. My immediate reaction was to jump up and say, "I'm not having that." Anyway. Then I realized, "Oh, come to think of it I've got my back to the wall and I'm not in a bargaining position." Anyway, I have to say, she handled my reaction extremely well. Then I asked her what the advantages of it were. I was absolutely shocked when she said there's 7% in chemotherapy. You could have knocked me over with a feather. I thought it mop up 85% or something like that. Anyway, and I said, "Oh do you really think it's worth it?" Well, she reckoned the margins were not good enough. They were less than 0.4 millimetres. She wasn't all that happy about it. She said that if she were me that she would definitely take the chemo. I said, "Okay." I said we were going to LOCATION to see all our children for Christmas. She said, "Oh, that will be fine." Then she*

*worked out a date that I could then fly back a day or two early so I could fit into her schedule and stuff. The guy the next day was terrible. The local guy was so bad I could not believe my ears. Participant 022\_2021AUHRP*

*PARTICIPANT: OK with me? I had a really great first surgeon and she was very thorough. She had the glass notepad that had pictures of everything from ductal to invasive on it. So she would refer to this piece of paper and draw and share exactly with the cancer bone and explain what ductal was. And then she had a little chart below and showed me how it was. Please tell me I'm being very simplistic that someone would try and keep it. Classically said, told me that ductal is like being a prisoner in a cage and sort of said, look, doctor, which is, you know, I think it was considered Zero grade cancer as it was for ductal do I'm not sure whether that might say,*

*INTERVIEWER: yes, it does. Yes, because yes, it does.*

*PARTICIPANT: And she was very open with the survival rate. Is that 100 percent for this type of cancer? So you do have to make some choices about getting rid of it. So she helped me through the originals. So going to go my journey. But the original conversation was about doing a lumpectomy and which is just a wide incision just on the side of the first. I had a quarter with model. From what I can gather, not everyone had a quarter that was probably the most unpleasant of all. I had a quiet and then she went and then I waited three days until my results. Participant 002\_2021AUHRP*

*I feel I had quite a good collection of clinicians, I think they were really excellent. Initially, I had a conversation with a surgeon about whether we were going to look at wide local excision and radiotherapy or a mastectomy. I was fairly reticent on the radiotherapy side of things, mostly because of obviously my experiences in vascular surgery and we see the late complications of radiotherapy. Lymphedema of my upper limb was probably the most concerning thing because that would be career-ending. I was actually leaning towards the mastectomy and probably still am, to be honest [chuckles] but she talked me into a lumpectomy.*

*I had a good conversation with the radiation oncologist, he was lovely, that if you don't have a mastectomy, it's almost a no-brainer that you need to have it. The difficult one was chemo or not. I actually had I believe three or four conversations with my oncologist before excision, and then after we got the grade and everything, and I decided the genomics, whether or not to go ahead with that. That was a long process, a joint decision, and in fact, my consideration*

*was I'd like to go ahead, even though she was like, "Well, you probably don't have to if you don't want to." I actually had quite a good set of people who listen and talk well. Participant 005\_2021AUHRP*

*We had with the surgeon, the specialist, it was quite a long consultation for probably a good hour-and-a-half. My husband and I were in there and had lots of - I had lots of questions written down. He was very patient and agreed to everything. For me, I think my initial-- I went in there. I think like lots of women do, they say, "Just take my breasts, take both the breasts and take them off."*

*He, in the nicest possible way didn't say, "No, we're not doing that," but I think he-- I needed more information from him to make a decision that worked for my type of breast cancer, which he did. I felt like he gave me all the options and was quite clear about it, too. Made me feel that why-- Yes, I don't need to remove this part of my body right now. Participant 009\_2021AUHRP*

#### **Participant describes not taking part in the decision making process**

*I've done the Google search and I've talked to-- some of the doctors will tell you, others won't tell you much at all, to be honest. That's frustrating. You'll talk to one oncologist, he'll just say, "Just do what I ask you to do," type thing. Then you'll talk to a younger one and they'll give you a more honest approach to things. In my experience, the younger the oncologist you talk to, the more information you'll get and the more cutting-edge stuff they'll look at for you. Whereas the older oncologist just go with the standard, "That's just standard. That's just what we do." Participant 018\_2021AUHRP*

*PARTICIPANT: I pretty much just wanted to know what were the steps that we needed to go through to treat this and it was a case of I had the mastectomy first and then recovered from that. Then we would go through chemotherapy and I would have four doses of, I can't remember the name of it, every three weeks, and then I would have weekly doses of paclitaxel, and I got to week six and I was having some pretty bad side effects, so they gave me a week's break, and then I went back and had week seven. Then they said, "No, we've got to stop because the side effects can become permanent if you don't stop early enough." Then I had to go back and have another surgery to have the lymph nodes removed from my armpit and then once I healed from that, it was a case of the radiation treatment to be starting.*

**INTERVIEWER:** Yes. It was sort of, this is the treatment that you need to have done. There wasn't really like too much options given

**PARTICIPANT:** I'll couldn't have a lumpectomy because it was in the ducts and it was too big. Participant 025\_2021AUHRP

I've got referred initially to a breast surgeon and my treatment changed about three or four times initially, I was having a lumpectomy and I was gonna have radiotherapy, then they cancel that. And they said, or no, we're thinking because they weren't sure if I was equivocal HER2 positive as well as the ER PR positive. If they said, Ah, maybe we can just clip the tumour and give you chemo and then we can just remove the tumour once it's gone and it's all good. And they booked me in for that. And then they said, No, we're cancelling that. Can you come in and see me and then he says, I need to have a mastectomy. It's just everywhere. And you just need to cut the whole thing off. And like really? Participant 041\_2021AUHRP

**Participant describes being told what to do without discussion**

We went just bang, bang, bang. This is what we're doing. We didn't even discuss like a full mastectomy

or anything. He just said partial, and I trusted him completely. Participant 027\_2021AUHRP

It was definitely not a conversation, more of a this is what we're, this is what we're doing. You know, there was I wasn't really given any options. As far as treatment options, I was basically just told you will be coming in in two days for mastectomy and the lymph nodes. And then when I saw the oncologist, she was like, and we will be starting chemo on this date. And please don't have any more children was basically the conversation. Yeah. Yeah. Participant 033\_2021AUHRP

It's just a year ago or so. I said I don't want to have a mastectomy and they were like, "You have to have a mastectomy." That was about it. Then they said, "You can have an immediate reconstruction." I went to a plastic surgeon for that and I said-- The one where they use your stomach to do it and they said, "You can't have that, you're too thin, you have to have the one with your back muscle" which I didn't really want. I feel I didn't want them to cut my nipple and stuff off and they just ignored it and did it anyway. I wouldn't really say there was a lot of discussion really. There was a lot of me saying, I don't want that and a lot of everybody else just ignoring me really. Participant 036\_2021AUHRP

**Table 4.3: Discussions about treatment (Participation in discussions)**

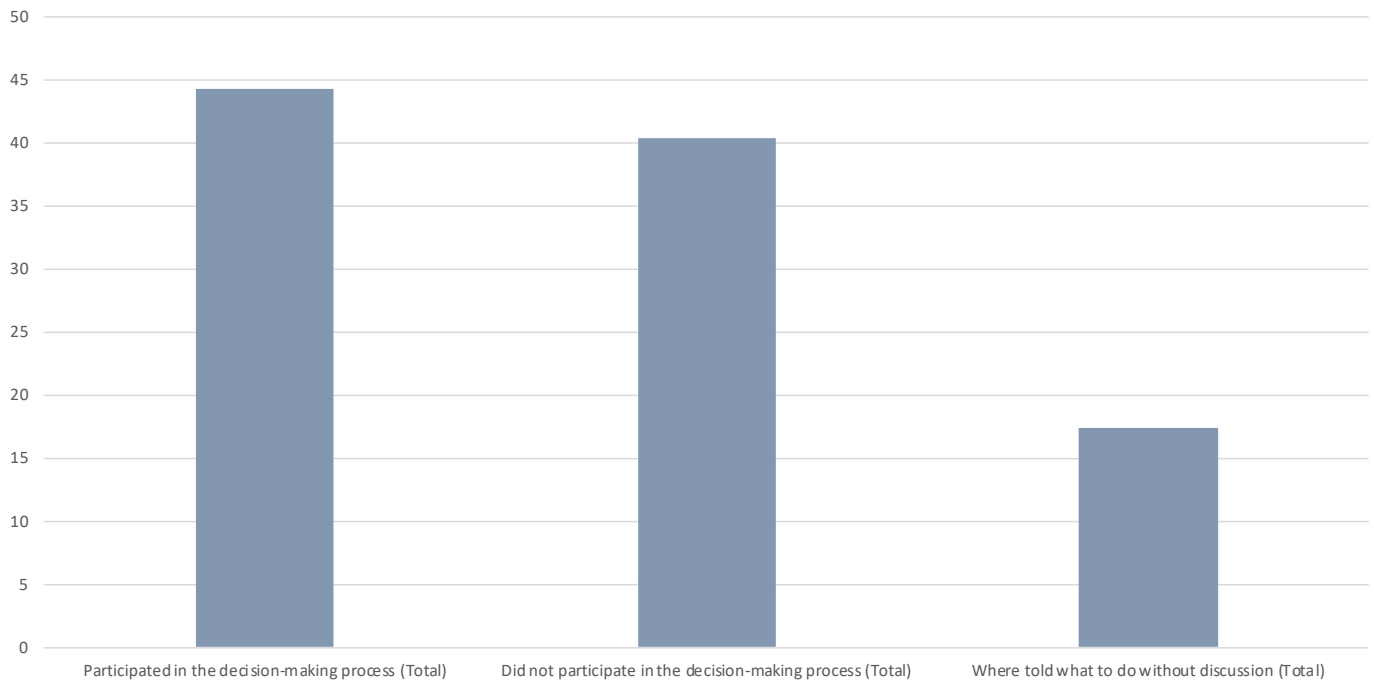
Discussions about treatment (Participation in discussions)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes taking part in the decision making process (Total)	23	44.23	11	57.89	8	38.10	4	33.33	14	48.28	9	39.13	6	31.58	17	51.52
Participant describes taking part in the decision making process (Multiple options/approaches)	21	40.38	10	52.63	7	33.33	4	33.33	12	41.38	9	39.13	6	31.58	15	45.45
Participant describes taking part in the decision making process (One option/approach)	2	3.85	1	5.26	1	4.76	0	0.00	2	6.90	0	0.00	0	0.00	2	6.06
Participant describes not taking part in the decision making process (Total)	21	40.38	5	26.32	10	47.62	6	50.00	11	37.93	10	43.48	9	47.37	12	36.36
Participant describes not taking part in the decision making process (Multiple options/approaches)	17	32.69	4	21.05	9	42.86	4	33.33	9	31.03	8	34.78	8	42.11	9	27.27
Participant describes not taking part in the decision making process (One option/approach)	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09
Participant describes being told what to do without discussion (Total)	9	17.31	3	15.79	3	14.29	3	25.00	5	17.24	4	17.39	3	15.79	6	18.18
Participant describes being told what to do without discussion (Multiple options/approaches)	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	2	10.53	3	9.09
Participant describes being told what to do without discussion (One option/approach)	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09

Discussions about treatment (Participation in discussions)	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 taking part in the decision making process (Total)	23	44.23	5	50.00	8	50.00	10	38.46	4	36.36	19	46.34	7	38.89	16	47.06
Participant describes taking part in the decision making process (Multiple options/approaches)	21	40.38	4	40.00	8	50.00	9	34.62	4	36.36	17	41.46	7	38.89	14	41.18
Participant describes taking part in the decision making process (One option/approach)	2	3.85	1	10.00	0	0.00	1	3.85	0	0.00	2	4.88	0	0.00	2	5.88
Participant describes not taking part in the decision making process (Total)	21	40.38	2	20.00	7	43.75	12	46.15	5	45.45	16	39.02	6	33.33	15	44.12
Participant describes not taking part in the decision making process (Multiple options/approaches)	17	32.69	1	10.00	7	43.75	9	34.62	4	36.36	13	31.71	6	33.33	11	32.35
Participant describes not taking part in the decision making process (One option/approach)	4	7.69	1	10.00	0	0.00	3	11.54	1	9.09	3	7.32	0	0.00	4	11.76
Participant describes being told what to do without discussion (Total)	9	17.31	2	20.00	1	6.25	6	23.08	2	18.18	7	17.07	3	16.67	6	17.65
Participant describes being told what to do without discussion (Multiple options/approaches)	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	3	16.67	2	5.88
Participant describes being told what to do without discussion (One option/approach)	4	7.69	1	10.00	0	0.00	3	11.54	1	9.09	3	7.32	0	0.00	4	11.76



**Figure 4.2: Discussions about treatment (Participation in discussions)**



**Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations (percent of all participants)**

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes taking part in the decision making process (total)	Stage III and IV Trade or high school	Stage 0 and I
Participant describes taking part in the decision making process (Multiple options/approaches)	-	Stage 0 and I
Participant describes not taking part in the decision making process (total)	Stage 0 and I Diagnosed in 2016 or before	-
Participant describes not taking part in the decision making process (Multiple options/approaches)	Stage 0 and I Diagnosed in 2016 or before	Stage II Diagnosed in 2017 to 2019
Participant describes being told what to do without discussion (total)	Diagnosed in 2017 to 2019	-

### 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 side effects into consideration and this was described by 24 participants (46.15%). There were 17 participants (32.69%) described taking efficacy of treatment into account, and 15 participants (28.85%) described taking the advice of their clinician. Other considerations included quality of life (n=9, 17.31%), impact on family and dependents (n=8, 15.38%), survival benefit (n=8, 15.38%), ease of administration (n=7, 13.46%), and the ability to work (n=5, 9.62%).

#### Participant describes taking side effects into account when making decisions about treatment

*I was a bit concerned about what effect radiation would have on your heart and the side effects of that, but I didn't have any. That was okay. That was the only thing I was more or less worried about. Participant 006\_2021AUHRP*

*So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppose. Participant 020\_2021AUHRP*

*Certainly, what are the benefits of the treatment? How much benefit I'm I likely to get from the treatment? Then on the other hand what are the side effects? The side effects and what they might do to my body. Participant 047\_2021AUHRP*

#### Participant describes taking efficacy into account when making decisions about treatment

*Well, I guess, first and foremost, it's a risk-benefit assessment. We look at what is the benefit of the treatment in terms of recurrence, et cetera, and, obviously, removal of tumour, for example. Then, in terms of risk, I guess, we look at the acute risks, things*

like surgery, et cetera, and then long-term, in particular, things that might catch up with you later. That is stuff like your cardiovascular health and bone densities and things. I guess ease of access is important too. Participant 005\_2021AUHRP

I think, first of all, at this point is, is efficacy. I'm very much guided by my oncologist with that, because I know that he's going to, you know, offer me the the option that's likely to be most effective, and obviously, side effects are a consideration. I fortunately, I'm in the position where I don't have to work if I don't need to, because I've got income protection. And although I'm still working at this point, but very much reduced my hours. So you know that the side effects. I think I would tolerate you know, the efficacy, I would put above the side effects that there was the side effects at this point, because I know that I can just spend full time at home if needed. My kids are all teenagers now and fairly independent. So you know, they don't need me as much and my husband's very supportive. So yeah, I guess I guess they're the they're the main ones. Participant 034\_2021AUHRP

Certainly, what are the benefits of the treatment? How much benefit I'm I likely to get from the treatment? Then on the other hand what are the side effects? The side effects and what they might do to my body. Participant 047\_2021AUHRP

**Participant describes taking the advice of their clinician into account when making decisions about treatment**

I very much followed my-- I guess what I did is I followed the lead of my specialists. My specialists would recommend the course of action of treatment and then I'd go off and do some research and I pretty much felt comfortable with my team and what they were recommending. Participant 043\_2021AUHRP

I just went with the experts. They're doing it all the time. If I need an operation, I've got to have an operation. I've had the lumpectomy and I had some lymph nodes taken out and I just accepted it. They told me I would have to have radiation treatment, so I had four weeks of radiation treatment, just to mop up any escaped cells, because when I was initially diagnosed with breast cancer, they told me I had invasive cancer. Participant 032\_2021AUHRP

**PARTICIPANT:** I think probably the main things, to be honest, is the recommendation of the professionals that I'm seeing. [crosstalk]  
**INTERVIEWER:** Oh, sorry. Go ahead.

**PARTICIPANT:** I was just happy that I'd found good people that knew a lot more about this than me, and that I trusted their judgment and would follow their advice pretty much. If I wasn't sure about something, I was happy to ask questions, but at the end of the day, "This is your specialty. I'm going to be guided by what you tell me if you think that." Participant 011\_2021AUHRP

So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppose. Participant 020\_2021AUHRP

**Participant describes taking quality of life into account when making decisions about treatment**

Well, I guess a lot of it is how it's going to make me feel really. I've had a lot of crises in my life, a lot of grief, and a lot of crises, so I'm very-- for want of a better-- I suppose fragile. I've just got to be really careful of my care. I have no compunction of changing doctors, for example, like the one I just told you. You can't go and see a doctor and come out crying every time, it's ridiculous. Participant 038\_2021AUHRP

We talked through them all. And this is supposed to be the one I'm on is supposed to have the least amount of side effects? Yes, I asked the percentage of benefit. Because, you know, I've been told that about chemo, and chemo with 2%. And this medication is less than 4%. Could with considering quality of life with the side effects. But somewhere on the line, he said, and how having had breast cancer have a 50% chance of getting it again, taking this medication only have a 40% chance of getting it again, and I don't know how that works. But I'm just rolling with it. Participant 014\_2021AUHRP

Obviously, quality of life. I think that maybe want you to do certain things in life, how much does that have an impact on you in daily living and is it worth it? Because at the moment, I've just started my hormone suppressing therapy. I'm struggling with-- I've just gone back to work and my bones, joint pain, and all that stuff is really impacting on me. I'm in that mindset of really researching a lot at the moment to determine is this really going to help me or is it going to impede on my life so much that I'm not going to enjoy life anymore? Participant 048\_2021AUHRP



**Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment**

*I think more than the impact on myself, my health, and my family, and what the outcomes are likely to be as well. Participant 037\_2021AUHRP*

*Seems really quite obvious for me. That might help my family when a nine year old daughter. So she is first and foremost, she makes her mom. And my husband and her they do for me now helps them, to be honest with you. I remember first and foremost that to be honest with you want to really know what happened. And I'll just admit that it just took hours and hours of thought. This is not happening to me, that probably I never felt sorry for myself, but I just kind of went and I'll be really honest and I'll have to swear in front of you. Participant 002\_2021AUHRP*

*It'll be probably the impact on my day-to-day life. Reason being was when I was due to start radiation treatment, they only gave me well, an afternoon's notice, and they weren't very cooperative at all. I can distinctly remember because my son had broken his big toe and we had to go to the main hospital service and get him fitted with a moon boot. As we were driving home, they rang and said, "Oh look, we need you in LOCATION tomorrow morning at nine o'clock to start your radiation treatment." At that stage it was one o'clock, two o'clock in the afternoon and I just said, "That is not possible. I'm three hours away, I've got three kids to factor in and organize. To give me an afternoon's notice just was terrible." They spoke to their supervisor and said, "Well, can you be here the next day?" They gave me a day then to get myself organized and get to LOCATION. That part of it I was really disappointed with in the sense that they should have really allotted than half a day ahead that I was going to be required to come to LOCATION. Participant 031\_2021AUHRP*

**Participant describes taking the survival benefit into account when making decisions about treatment**

*Survival. [chuckles] That was pretty much it. Participant 025\_2021AUHRP*

*Just survival rates. I mean I just do whatever is possible to be able to get a good outcome. Participant 046\_2021AUHRP*

*Look, I live alone in Australia, I'm NATIONALITY. I needed something where I, A, felt in control B, that I could still take care of myself. I made decisions with*

*low longevity in mind. I didn't want to alter my physical appearance. I know that sounds vain, but I did not want it to have considered affects me or anything like that. Those were some of my top consideration. Participant 007\_2021AUHRP*

**Participant describes taking the ease of administration into account when making decisions about treatment**

*Side effects that impacts my life on a daily basis, and how invasive the treatment is, for example, I had my ovaries out because I didn't want to have the Zoladex injection. Participant 027\_2021AUHRP*

*Well, I guess, first and foremost, it's a risk-benefit assessment. We look at what is the benefit of the treatment in terms of recurrence, et cetera, and, obviously, removal of tumour, for example. Then, in terms of risk, I guess, we look at the acute risks, things like surgery, et cetera, and then long-term, in particular, things that might catch up with you later. That is stuff like your cardiovascular health and bone densities and things. I guess ease of access is important too. In many ways, it's why I actually preferred three months of chemo done in the center to what is going to be 5 or 10 years of every month accessing the drugs and then taking it to your GP with an appointment to get injected for a long period of time. Participant 005\_2021AUHRP*

*Well cost firstly, how long it will take? Because I work so that can be tricky doing that balance? Where the where that person is located? So do How far do I have to travel to see them? Their background and reputation and often that's word of mouth, talking to other people about who might have seen them or know of then. Then probably off my head the main things I think about. Participant 013\_2021AUHRP*

**Participant describes taking the ability to work into account when making decisions about treatment**

*At the time I was working so time off from work. How to integrate whatever treatment I was having into work as well. That was probably the main thing. Participant 050\_2021AUHRP*

*Well cost firstly, how long it will take? Because I work so that can be tricky doing that balance? Where the where that person is located? So do How far do I have to travel to see them? Their background and reputation and often that's word of mouth, talking to other people about who might have seen them or know of then. Then probably off my head the main things I think about. Participant 013\_2021AUHRP*

*I guess, the long-term impacts and also the short-term inconveniences. For example, I've recently made a decision about surgery and my main reasoning for what I chose, was that it's a better longer-term solution and doesn't require follow-up surgeries as much. Long-term is just to me, a much better option. I also made a decision about not having radiotherapy unless it's absolutely necessary because of the inconvenience and also because of the lack of-- I guess because I don't want to be overtreated so the lack of necessity. The radiation oncologist wasn't certain that I would need it. I said, well, I don't want to have it then unless it's actually necessary. I don't want to have it*

*just in case. I want an actual reasons for going through the effort of attending the hospital five days a week for weeks and missing huge amount of work and dealing with more side effects even after I've gone through chemo and surgery and everything else. In the case of that, the logistical side of things was a factor, but also, the side effects. The risk, versus reward. It didn't seem like it's a necessary thing to do especially considering all the side effects that come from it and the inconvenience of it and the loss of income and everything like that. Those are the main factors. The long-term advantages and the short-term inconveniences. Participant 044\_2021AUHRP*

**Table 4.5 Considerations when making decisions**

Considerations when making decisions	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 taking side effects into account when making decisions about treatment (Total)	24	46.15	13	68.42	9	42.86	2	16.67	13	44.83	11	47.83	8	42.11	16	48.48
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	4	7.69	2	10.53	2	9.52	0	0.00	3	10.34	1	4.35	1	5.26	3	9.09
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	20	38.46	11	57.89	7	33.33	2	16.67	10	34.48	10	43.48	7	36.84	13	39.39
Participant describes taking efficacy into account when making decisions about treatment (Total)	17	32.69	7	36.84	6	28.57	4	33.33	9	31.03	8	34.78	5	26.32	12	36.36
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	4.76	1	8.33	1	3.45	1	4.35	0	0.00	2	6.06
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	28.85	7	36.84	5	23.81	3	25.00	8	27.59	7	30.43	5	26.32	10	30.30
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	15	28.85	5	26.32	6	28.57	4	33.33	7	24.14	8	34.78	7	36.84	8	24.24
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	8	15.38	2	10.53	2	9.52	4	33.33	5	17.24	3	13.04	3	15.79	5	15.15
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	3	15.79	4	19.05	0	0.00	2	6.90	5	21.74	4	21.05	3	9.09
Participant describes taking quality of life into account when making decisions about treatment (Total)	9	17.31	4	21.05	3	14.29	2	16.67	4	13.79	5	21.74	7	36.84	2	6.06
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	1.92	0	0.00	1	4.76	0	0.00	1	3.45	0	0.00	1	5.26	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	15.38	4	21.05	2	9.52	2	16.67	3	10.34	5	21.74	6	31.58	2	6.06
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	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 taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	0	0.00	2	16.67	1	3.45	1	4.35	0	0.00	2	6.06
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	3	15.79	2	9.52	1	8.33	2	6.90	4	17.39	3	15.79	3	9.09
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	8	15.38	2	10.53	4	19.05	2	16.67	7	24.14	1	4.35	2	10.53	6	18.18
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	1	5.26	1	3.03
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	2	10.53	3	14.29	1	8.33	5	17.24	1	4.35	1	5.26	5	15.15
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	2	10.53	5	15.15
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	2	10.53	5	15.15
Participant describes taking the ability to work into account when making decisions about treatment (Total)	5	9.62	3	15.79	2	9.52	0	0.00	2	6.90	3	13.04	1	5.26	4	12.12
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	4	7.69	3	15.79	1	4.76	0	0.00	1	3.45	3	13.04	1	5.26	3	9.09
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	1	1.92	0	0.00	1	4.76	0	0.00	1	3.45	0	0.00	0	0.00	1	3.03

Considerations when making decisions	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 taking side effects into account when making decisions about treatment (Total)	24	46.15	5	50.00	6	37.50	13	50.00	5	45.45	19	46.34	8	44.44	16	47.06
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	1	5.56	3	8.82
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	20	38.46	5	50.00	4	25.00	11	42.31	4	36.36	16	39.02	7	38.89	13	38.24
Participant describes taking efficacy into account when making decisions about treatment (Total)	17	32.69	4	40.00	4	25.00	9	34.62	3	27.27	14	34.15	7	38.89	10	29.41
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	6.25	1	3.85	0	0.00	2	4.88	0	0.00	2	5.88
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	28.85	4	40.00	3	18.75	8	30.77	3	27.27	12	29.27	7	38.89	8	23.53
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	15	28.85	1	10.00	6	37.50	8	30.77	4	36.36	11	26.83	6	33.33	9	26.47
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	8	15.38	0	0.00	5	31.25	3	11.54	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	1	10.00	1	6.25	5	19.23	2	18.18	5	12.20	3	16.67	4	11.76
Participant describes taking quality of life into account when making decisions about treatment (Total)	9	17.31	4	40.00	1	6.25	4	15.38	2	18.18	7	17.07	4	22.22	5	14.71
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	1.92	0	0.00	1	6.25	0	0.00	0	0.00	1	2.44	1	5.56	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	15.38	4	40.00	0	0.00	4	15.38	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	8	15.38	4	40.00	1	6.25	3	11.54	1	9.09	7	17.07	3	16.67	5	14.71
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	0	0.00	2	7.69	0	0.00	2	4.88	0	0.00	2	5.88
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	4	40.00	1	6.25	1	3.85	1	9.09	5	12.20	3	16.67	3	8.82
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	8	15.38	3	30.00	2	12.50	3	11.54	1	9.09	7	17.07	3	16.67	5	14.71
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	2	3.85	1	10.00	0	0.00	1	3.85	1	9.09	1	2.44	1	5.56	1	2.94
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	2	20.00	2	12.50	2	7.69	0	0.00	6	14.63	2	11.11	4	11.76
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	13.46	1	10.00	2	12.50	4	15.38	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	1	10.00	2	12.50	4	15.38	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes taking the ability to work into account when making decisions about treatment (Total)	5	9.62	1	10.00	1	6.25	3	11.54	2	18.18	3	7.32	3	16.67	2	5.88
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	4	7.69	1	10.00	1	6.25	2	7.69	1	9.09	3	7.32	2	11.11	2	5.88
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	1	1.92	0	0.00	0	0.00	1	3.85	1	9.09	0	0.00	1	5.56	0	0.00

Figure 4.3 Considerations when making decisions

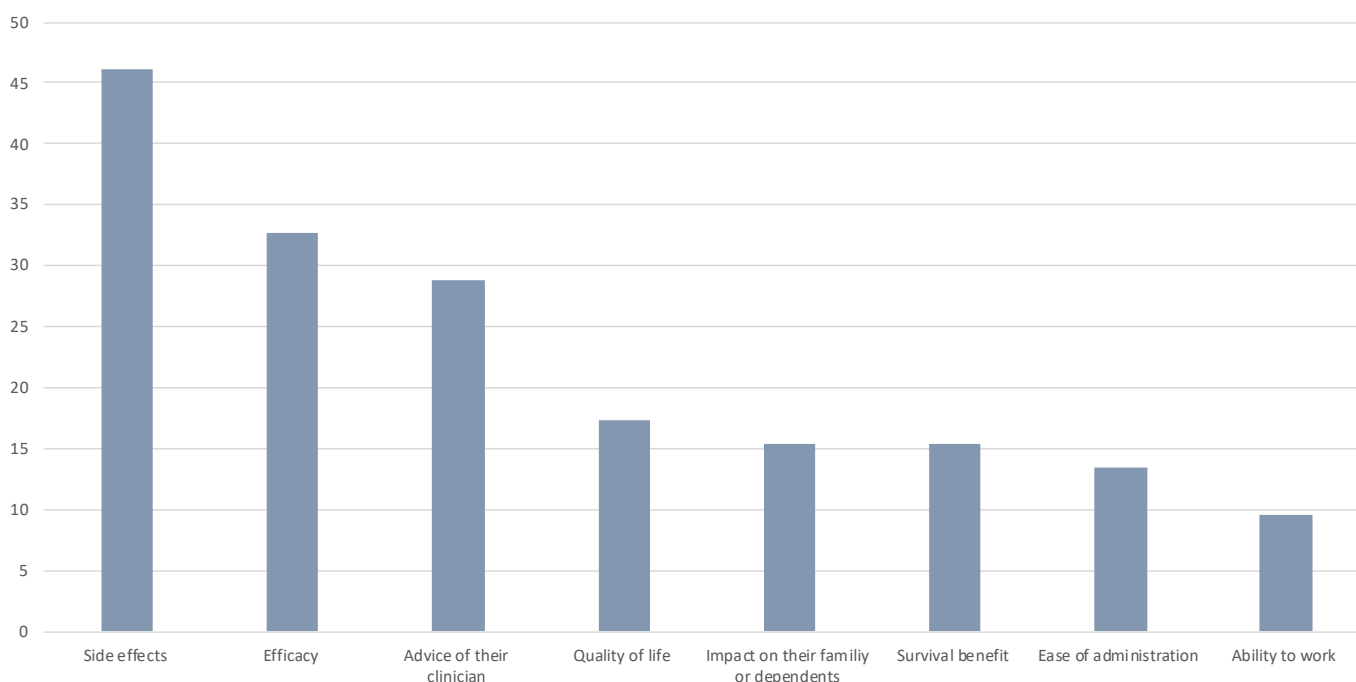


Table 4.6: Considerations when making decisions – subgroup variations (percent of all participants)

Considerations when making decisions	Reported less frequently	Reported more frequently
Participant describes taking side effects into account when making decisions about treatment (Total)	Stage III and IV	Stage 0 and I
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Diagnosed in 2016 or before	-
Participant describes taking quality of life into account when making decisions about treatment (Total)	University Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2016 or before
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	-	Diagnosed in 2016 or before
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	Aged 55 to 74	Diagnosed in 2016 or before

## Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (51.92%) that felt the way they made decisions about treatment had not changed over time, and 25 participants (48.08%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have had always been informed and assertive (n=7, 13.46%), or always taken the advice of clinicians (n=6, 11.54%). Where participants had changed the way they make decisions, it was primarily because they had become more informed or more assertive over time (n=17, 32.69%), or because they were more focused on quality of life or the impact of side effects (n=6, 11.54%).

**Participant describes no change in decision-making over time as they have always been informed/assertive**

*No, I think the same way. I think I'm a pretty common sense sort of person. My husband and I have got a good relationship and we talk about lots of things and we chat about-- Bounce it off each other and see. I think I'm pretty calculated how I make deci-- Yes, I think I'm the same. Participant 009\_2021AUHRP*

*I don't really know at the moment. Sorry. Decision-making's -- I'll put it this way, I generally don't like making very rapid decisions like I had to with this. I'm the sort of the person who likes to go away and think about things for a really long time, so that aspect hasn't changed. Participant 030\_2021AUHRP*

*I think with health-based things, I've always been pretty good with making decisions. I've tried to implement that into my personal and normal life [chuckles] because I'm much more factual and logical about it all. Whereas I've become quite emotional with my personal life so I'm trying to take that really big positive and bring it into [chuckles] the other elements of my life. Participant 042\_2021AUHRP*

*No, it hasn't changed because I am a clinical person myself. It's pretty black and white to me. Participant 027\_2021AUHRP*

**Participant describes no change in decision-making over time as they have always taken advice of clinicians**

*I would approach it the same way. I always like to find who's the best at their job and I'll always listen to their advice. When you've got a cancer diagnosis, time is of the essence. You can't sit around thinking about what you're going to do for too long while the cancer is progressing. I was happy that everything was done in a very timely manner. I was incredibly impressed that they were appointments available for people like myself at the surgeon in less than a week. Participant 004\_2021AUHRP*

*No. I think the specialists in that field, they know exactly what is best for you. Participant 006\_2021AUHRP*

*I think that's probably how it's been. I would be guided by colleagues and professionals with the expertise in the areas of the problem. I don't think that's a new thing for me. Participant 011\_2021AUHRP*

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

*I think I'd acknowledge that I'm braver than I thought I was to change the way I do it now. But I'll probably have more confidence in myself now that I know I can do the hard stuff. Participant 002\_2021AUHRP*

*Maybe more to a -- I'm taking it to the Nth Degree now, I'm very, the more information I have, the more comfortable I feel. So yeah, I go and look for information and read medical studies, medical journals, that sort of thing. That's just the way my brain processes it. But I may have become hypervigilant about it. That's about the only thing. Yes, I've taken it to the Nth degree now Participant 003\_2021AUHRP*

Maybe more to a -- I'm taking it to the Nth Degree now, I'm very, the more information I have, the more comfortable I feel. So yeah, I go and look for information and read medical studies, medical journals, that sort of thing. That's just the way my brain processes it. But I may have become hypervigilant about it. That's about the only thing. Yes, I've taken it to the Nth degree no. Participant 003\_2021AUHRP

I want to know more detail. I ask more questions these days. That would be about the only thing that I've changed. I want to know, what's that? Why is that? Yes, so it's to why, what, where, when type questions, yes. Participant 012\_2021AUHRP

No, I think it's quite different. You know, it's -- when you come from a position of very little knowledge, you make decisions based on the advice that you get from the people who you feel that you can trust with their knowledge-base, experience, etc.. Excuse me, but I think as time goes on and you've experienced your surgery and by that stage you've gleaned a fair amount of information, you've done quite a bit of reading and research and I think that you become more enquiring, selective about the choices that you make, much more so than in the first instance. Participant 019\_2021AUHRP

**PARTICIPANT:** I'll probably ask more questions now, which drives other medical people mad. [laughs]

**INTERVIEWER:** It's good. You're advocating for yourself, which is great. Yes. Participant 039\_2021AUHRP

Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects

That's a little bit hard to say because I haven't been faced with any major health decisions since the diagnosis. For instance, after going through all the treatment, I sort of think, "Shit, for the quality of life, would I do that again?" The answer is, I don't know. My youngest is 16, so it would depend on if the cancer came back, how old I was, how old my kids were, what the long-term prognosis was going to be. If it was going to be terminal regardless, well then, I'd opt for quality of life rather than longevity. I suppose it has changed in that I'd be a little bit more subjective as to the quality of life, I think. Participant 025\_2021AUHRP

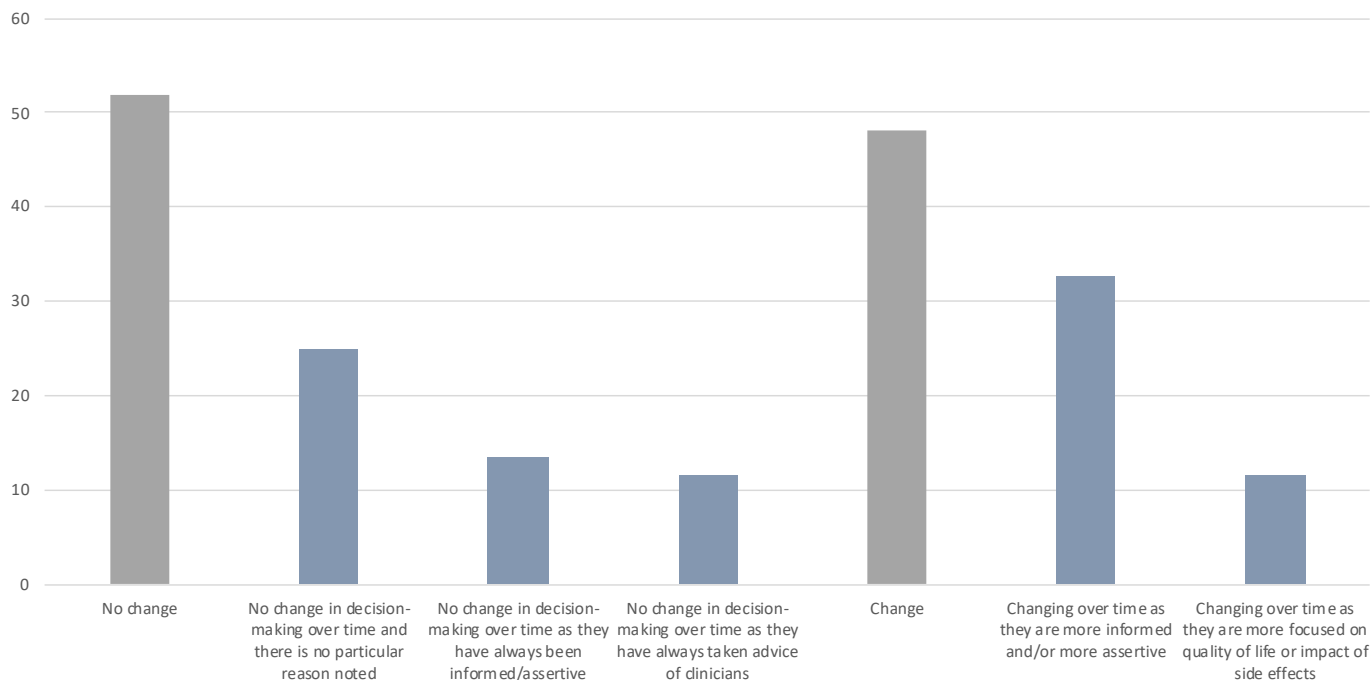
Yes, I think so. Yes, I approach them how they're going to make me feel, on all levels, physically, emotionally, and ethically, and morally, how are things going to make me feel. Participant 038\_2021AUHRP

I think not the way I make them but maybe why I make them. Yeah. I feel I'm still considered and like all the information. But the side effects more than anything that I have focus on knowing what they can be like. Participant 045\_2021AUHRP

**Table 4.7: Decision-making over time**

Decision-making over time	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes no change in decision-making over time	27	51.92	9	47.37	11	52.38	7	58.33	17	58.62	10	43.48	8	42.11	19	57.58
Participant describes no change in decision-making over time and there is no particular reason noted	13	25.00	5	26.32	7	33.33	1	8.33	6	20.69	7	30.43	5	26.32	8	24.24
Participant describes no change in decision-making over time as they have always been informed/assertive	7	13.46	1	5.26	2	9.52	4	33.33	4	13.79	3	13.04	1	5.26	6	18.18
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	11.54	2	10.53	2	9.52	2	16.67	6	20.69	0	0.00	2	10.53	4	12.12
Participant describes decision-making changing over time	25	48.08	10	52.63	10	47.62	5	41.67	12	41.38	13	56.52	11	57.89	14	42.42
Participant describes decision-making changing over time as they are more informed and/or more assertive	17	32.69	9	47.37	6	28.57	2	16.67	7	24.14	10	43.48	6	31.58	11	33.33
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	11.54	3	15.79	2	9.52	1	8.33	3	10.34	3	13.04	2	10.53	4	12.12
Decision-making over time	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes no change in decision-making over time	27	51.92	3	30.00	11	68.75	13	50.00	5	45.45	22	53.66	8	44.44	19	55.88
Participant describes no change in decision-making over time and there is no particular reason noted	13	25.00	2	20.00	3	18.75	8	30.77	4	36.36	9	21.95	3	16.67	10	29.41
Participant describes no change in decision-making over time as they have always been informed/assertive	7	13.46	1	10.00	3	18.75	3	11.54	1	9.09	6	14.63	3	16.67	4	11.76
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	11.54	0	0.00	4	25.00	2	7.69	0	0.00	6	14.63	1	5.56	5	14.71
Participant describes decision-making changing over time	25	48.08	7	70.00	5	31.25	13	50.00	6	54.55	19	46.34	10	55.56	15	44.12
Participant describes decision-making changing over time as they are more informed and/or more assertive	17	32.69	5	50.00	3	18.75	9	34.62	5	45.45	12	29.27	7	38.89	10	29.41
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	11.54	1	10.00	1	6.25	4	15.38	2	18.18	4	9.76	4	22.22	2	5.88





**Figure 4.4: Decision-making over time (percent of all participants)**

**Table 4.8: Decision-making over time – subgroup variations**

Decision-making over time	Reported less frequently	Reported more frequently
No change	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes no change in decision-making over time and there is no particular reason noted	Stage III and IV	Regional or remote
Participant describes no change in decision-making over time as they have always been informed/assertive	-	Stage III and IV
Participant describes no change in decision-making over time as they have always taken advice of clinicians	Aged 55 to 74 Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes decision-making changing over time	Diagnosed in 2017 to 2019	Diagnosed in 2016 or before
Participant describes decision-making changing over time as they are more informed and/or more assertive	Stage III and IV Diagnosed in 2017 to 2019	Stage 0 and I Aged 55 to 74 Diagnosed in 2016 or before Regional or remote
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	-	Mid to low status

### Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

#### Participant describes wanting to be cancer free, avoid recurrence, or increase longevity

*In terms of goals, I guess, minimizing long-term problems related to the hormone therapy, so things like osteoporosis are quite concerning because effectively going into menopause at 36 is not great for cardiovascular health and bone density. They're not limiting me now but they'd be something I'm*

*concerned about future-wise, but obviously, recurrence is also a bad thing [chuckles] because that's what weighs it against it, is not wanting to get a recurrence. Participant 005\_2021AUHRP*

*My own personal goal was not to be diagnosed again. Again, I have recovered 100%. If you and I were going to go run, I'd probably win. I've been very, very fortunate to not have the side effects. I do not have to know which chemo I think would have really been the hardest part for me. Radiation was very simple for me. I had some redness. I had an infection, but it was a very simple process. Participant 007\_2021AUHRP*

*Not really. I suppose the ongoing goals of discussions that I've had with my oncologist is to be healthy and be healthier to reduce the chance that it'll come back. Participant 037\_2021AUHRP*



*My main goal was basically to just still be here. I didn't really go beyond that. I didn't think about, whether there was going to be any limitations or any of that sort of stuff. Just basically survival*  
Participant 050\_2021AUHRP

**Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition**

*My goals are to reduce actually the side effects because I'm still experiencing, which is my lung function, to get my lung function back to normal or as best I can, and the swelling and tenderness in my breast, to reduce that as much as possible. Also, in my left arm to get a full range of movement and strength back in my left arm.* Participant 047\_2021AUHRP

*I guess at the moment because I was diagnosed three and a half years ago and since then I've had three surgeries, which have included ovary removal and hysterectomy reconstruction and stuff like that. I guess at the moment, my goal is to try and find a balance of working in the-- because of the modern aromatase inhibitor, I have pretty much zero estrogens. Just looking to be able to try and find a balance to live with the super surgical menopause that I'm in at the moment.* Participant 043\_2021AUHRP

*My priorities as far as chemo went, I don't want to go through that and have all that poison through my body. I'm natural person, and I don't even like taking Panadol. For me, being told that they'd put all this poison in my body just freaks me out. Chemo was not an option as far as I was concerned. They had really had to talk me into getting radiation because I really didn't want that. They [sound cut] me into it. Sorry, I had the radiation done because I think it's given me more of a chance that I won't get recurring cancer in the same site. From my understanding, that's what the radiation does. It kills all the cancer cells that may be there in the area. Even that, radiation has left me with some legacies that I'm not happy with. It's been a long costly, long process to deal with the side effects of radiation.* Participant 035\_2021AUHRP

**Participant describes no personal goals of treatment or care (no reason given)**

*I didn't have any goals. I was just, "Let's get this done and I'll do what I've got to do to get through it.* Participant 024\_2021AUHRP

*Up until then I'm fit and well, active, go to the gym regularly, working. Probably not the wisest move, but*

*I had the first surgery on Friday and I was back in the gym on Monday morning, which I think there was a bit of denial. [laughs] this is not going to affect me, I'm free to get on with my life. Then I had to go back for the second surgery and then had some fluid accumulating, which did slow me down and was pretty tough probably for a month or so. Then that finally settled. I had radiotherapy and then since then really life is back to normal.* Participant 011\_2021AUHRP

*I'm very much an accepting person, so my goal was to put my faith into the hands of my surgeon and the team. I just did as I was told, basically, because I don't believe you're fighting something, I believe that you've got to accept it and go with it. That's what I did.* Participant 032\_2021AUHRP

**Participant describes wanting to improve quality of life, or return to normality**

*Oh, that's a hard one. It's just to get back on track and to spend more time with the family. It's been difficult anyway, hasn't it? With what's been happening.* Participant 015\_2021AUHRP

*Early on, it just was very to me very clinical straight down the line, not meaning there weren't options, but it was just very matter of fact of the way they came across. They have to be you learn, you know, that that's a bit hard to kind of hear so. But yes, so the surgeon mentioned multiple options, but what he thought would be best given my situation, then definitely the things I wanted out of life or particular procedures that would suit what because I was only 39. So what might suit my lifestyle better as well. So we definitely did have that conversation.* Participant 013\_2021AUHRP

*I just want to be back to normal. I know it sounds silly because that's probably what you get from everybody. I just want to be able to function better. I have terrible memory loss. I'm in constant pain all the time. I get terrible side effects from most of the medications I take. It's just wanting to get back. I'm slowly getting there, but it's just having that normality, the way I look, it's the way I function every day. It's sometimes a hard task. Getting back to even before last year, because as I said to you, I was always incredibly tired and I didn't realize why, and now I obviously know why. Previously, I'd had a lot of energy. I was such a people person, I was very outgoing and now I'm not getting out there as well because I don't like the way that I look, so just having that everyday normal functionality.* Participant 008\_2021AUHRP

*My sexual health is huge. I think that's something I advocate for all the time. It's not about intimate. It's just me feeling like a woman. I didn't want to come out of my surgery being flat-chested. I wanted the reconstruction done through-- some part of it done straight away. I knew there was going to be a lot to lose. My nipples, but then I also understood that they have to go. I think just them hearing my side of it, just to have a little bit of compassion. I'm not just that job for them to do. That I'm a human and that those things are going to change my life dramatically. That was really important to me. That's my body you need to know how I felt about myself and stuff. Participant 048\_2021AUHRP*

**Participant describes wanting to see Improvements in mental or emotional health**

*Now, there's not a lot of information as to what's going to happen when you come off them. Yeah, when you're young, like you just don't, nobody's able to say, you know, will I get my period back or, you know, will the perimenopausal symptoms disappear? Like, you know, Will I lose the weight that apparently tamoxifen doesn't make you put on but you speak to breast cancer victims they will tell you, it does make you put weight on like, yeah, you know, so will all that come off. It's just all that mental health, both body both questions that, you know, 10 years ago, they didn't have answers to I feel like I have more answers now. Participant 033\_2021AUHRP*

*Well, I've only just gone back to work, that was a big thing. I'm pretty limited. I'm a swimming teacher, so in the water it limited me what I could do while I was going to the radiation and to heal from the surgery. That was a big thing to do that. I'm trying to get-- I*

*like to exercise, but I feel a bit limited of what I can and can't do with my-- But I'm starting tomorrow actually doing some Pilates. I'm going to try something like that, which I hadn't done before because I feel like I want to strengthen my body and just for mind. They were some of my goals. I was a bit, with the hormone treatment, wasn't sure what that was going to do to me and how it's going to make me feel but I do feel like I've got myself in a good fight. I feel pretty good. Participant 009\_2021AUHRP*

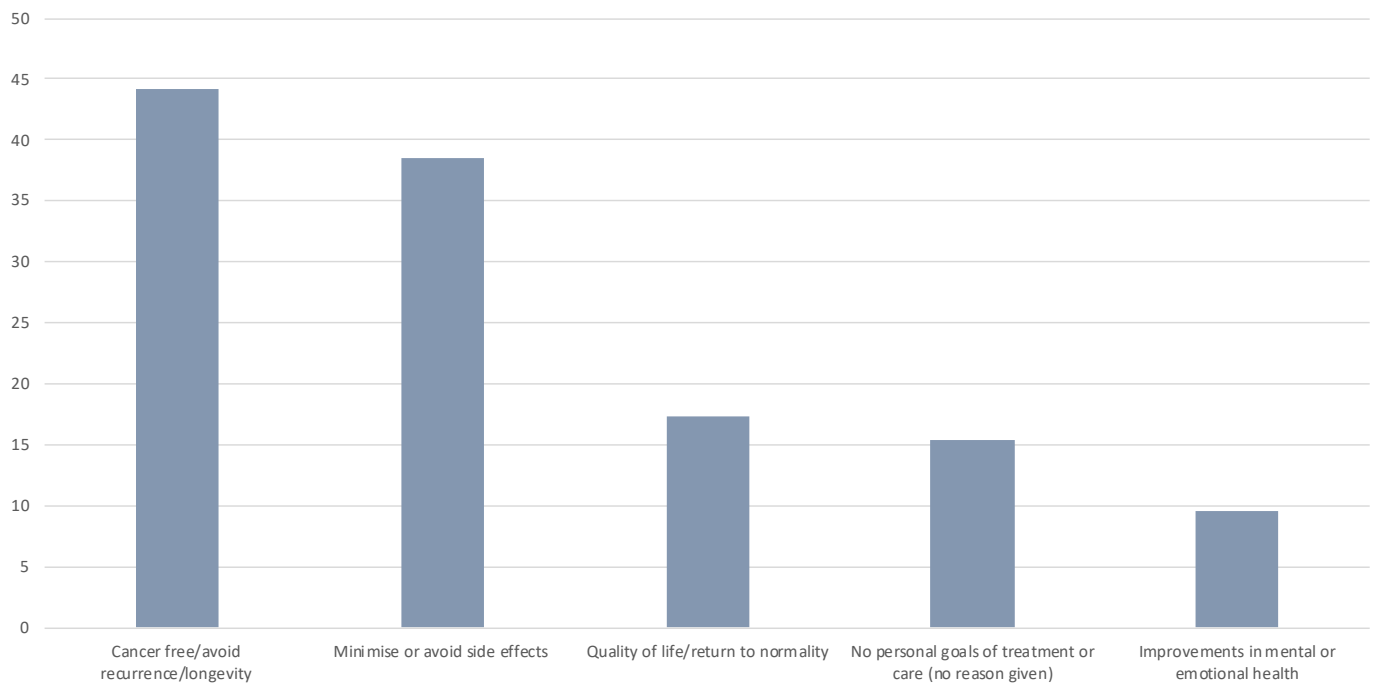
*No, my adoptive mother had reoccurrences of fibroadenoma and I always said to her, look, I'd rather have you flat and alive than with boobs and dead. So it was sort of like, I'd be the biggest hypocrite if I turned around and said -- for me it was never a vanity thing. I didn't want, necessarily, to look the way I'd looked before. I mean, it's sort of a weird thing because I'm sort of, 57. I've got grown up children. So for me, it wasn't a case of I need these to be able to function. It was sort of like they're purely decorative at this stage. I have a very understanding husband who had been through his own cancer journey and he goes, I want you alive. And that's the way I think I was sort of going. Look, I hate wearing bras. So I never have to wear a bra again. I also process things with humour a lot. I basically gave my name, gave him a farewell party. It's just the way I cope with horrible things. So to me, yeah it was more an issue of, look, I've just really got a really good life now. I want to be alive to enjoy it. So for me, it was more just about, yes, getting rid of it. And yes, I have other chronic health issues. So to me, another scar wasn't really a problem. I've already got meters and meters of scars all over my body from the rest that I've got. So that wasn't an issue. It's not like my...You're not that shallow. I was like, let's get rid of it. Participant 003\_2021AUHRP*

**Table 4.9: Personal goals of treatment or care**

Personal goals of treatment or care	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 wanting to be cancer free, avoid recurrence, or increase longevity	23	44.23	6	31.58	11	52.38	6	50.00	12	41.38	11	47.83	8	42.11	15	45.45
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	20	38.46	8	42.11	6	28.57	6	50.00	12	41.38	8	34.78	9	47.37	11	33.33
Participant describes wanting to improve quality of life, or return to normality	9	17.31	3	15.79	5	23.81	1	8.33	5	17.24	4	17.39	3	15.79	6	18.18
Participant describes no personal goals of treatment or care (no reason given)	8	15.38	5	26.32	1	4.76	2	16.67	4	13.79	4	17.39	2	10.53	6	18.18
Participant describes wanting to see Improvements in mental or emotional health	5	9.62	0	0.00	4	19.05	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12

Personal goals of treatment or care	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 wanting to be cancer free, avoid recurrence, or increase longevity	23	44.23	5	50.00	5	31.25	13	50.00	7	63.64	16	39.02	8	44.44	15	44.12
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	20	38.46	5	50.00	4	25.00	11	42.31	5	45.45	15	36.59	6	33.33	14	41.18
Participant describes wanting to improve quality of life, or return to normality	9	17.31	1	10.00	4	25.00	4	15.38	2	18.18	7	17.07	4	22.22	5	14.71
Participant describes no personal goals of treatment or care (no reason given)	8	15.38	0	0.00	3	18.75	5	19.23	1	9.09	7	17.07	2	11.11	6	17.65
Participant describes wanting to see Improvements in mental or emotional health	5	9.62	1	10.00	3	18.75	1	3.85	1	9.09	4	9.76	0	0.00	5	14.71



**Figure 4.5: Personal goals of treatment or care (percent of all participants)**

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

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participant describes wanting to be cancer free, avoid recurrence, or increase longevity	Stage 0 and I Diagnosed in 2017 to 2019	Regional or remote
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2016 or before
Participant describes no personal goals of treatment or care (no reason given)	Stage II Diagnosed in 2016 or before	Stage 0 and I