

## **Section 10**

### **Advice to others in the future: The benefit of hindsight**

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### **Anything participants wish they had known earlier**

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common response was that participants wished they had known what to expect from their condition, particularly symptoms and side effects of treatment (n=22, 42.31%). Other themes included participants wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=10, 19.23%), and they wished that they had sought medical attention or attended screening sooner (n=5, 9.62%). There were eight participants that did not describe anything that they wished they had known (n=10, 19.23%).

### **Aspect of care or treatment they would change**

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).

## Anything participants wish they had known earlier

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### Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

*I guess the thing that dawned on me the slowest of all is how long the journey is. When you're first diagnosed, it's sort of this is the problem that I've got to work out how to tackle it, and then you're like, "Well, okay, you can deal with it and I'll be back to normal in a month," it's like no. Three months? No. Six months? No. Actually, it's 15 years. It will be 15 years from diagnosis when I finally stop treatment. I think the thing that I probably know now that I think it would've been-- I don't know it would've been good to know then, but perhaps the thing that I was really thinking at first was that this is a chronic slow treatment process. It's going to go on a long time. Participant 005\_2021AUHRP*

*Oh no, no, just radiation treatment. The stuff that I found out afterwards that I thought would be temporary that are going to be permanent was nice to know at the start, I wouldn't change my mind. It just would have been nice to know. Participant 014\_2021AUHRP*

*Ooh [laughs]. I don't really. I wish I'd known more about lymphedema and how it would affect me. I don't think things can prepare you though. No matter how much information they give you, nothing can prepare you really for what it is until you go through it sort of thing. [crosstalk] else. Participant 024\_2021AUHRP*

*Just the mental health stuff again, you know, that how vulnerable like how that vulnerability doesn't really go away. I wish somebody had said to me like, this is going to change your brain, your brain works*

*differently now. Just just how it is. So everyone talks about chemo fog, and they talked about, you know, mood swings and bits and pieces. They talked about all that kind of stuff, but they didn't talk about, you know, how that, you know, intrinsically really like it's almost like a PTSD really, isn't it? You know, that acknowledgement that that's actually normal. You know, like, you know, physically, like I knew it was normal, from a professional headspace. Right, you know, you've worked with enough people that have had, like life altering diagnosis as and then you know, working in maternity, you know, life changing thing that changes your brain a bit as well, but just never put two and two together. Yeah. Yeah, yes, it affects me for this period of time, but then I have treatment, and then I'll be fine. Or actually, you know, just you are a different person after I feel. Participant 033\_2021AUHRP*

### Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment

*As I say, about the-- when they tell you you're going to have the sentinel node biopsy, I think that needs explaining more. If there's cancer cells, we're going to have to take more lymph nodes. I just felt that that wasn't explained clearly to me. Participant 012\_2021AUHRP*

*Yeah, it probably will probably, well, if I had known all of it, I would have been a lot less stressful. Yeah, and being and being more comfortable in the early days of the decisions that I make. And I guess in terms of the first surgery and the second surgeries, and it's all hindsight, because I didn't get it a second time, I would have gone back and done things differently. The first diagnosis round, like it would have just had to double mastectomy straight away and just gone up. But that because I was younger, and I was like oh no. And then you know, my surgeon sort of well, meaning that he didn't talk me out of it. We didn't really talk about it. It was an option, but he didn't push it because he said of my scenario and he was genuine about that. And, you know, he was he was well known for being breast conserving. And I'm like yeah, that's good. When about I just, I just look back now and go You can't mess around with that stuff. Participant 013\_2021AUHRP*

*How the system works. This is pretty tricky. I think it would have been nice if they'd maybe been a bit of a flow diagram of, "This is how it could go" and this is, as I said, would be, "and if you need help or if you need from the side effects from anything else, this is who you contact". Participant 047\_2021AUHRP*

**Participant does not describe anything they wish they had known earlier (no reason given)**

*No, no, look, it's one of those things that happens in life. Something...I actually never ever thought it would ever happen to me but it did, so you just have to deal with it. You don't know how strong you are until you're faced with it. I never thought I could deal with it, but you have to. I don't really feel when somebody tells you you've got breast cancer. I really don't know any softer way, there's no soft landing for it. I just got to deal with it. I myself, I like to research. I know another friend of mine who was diagnosed similar, she didn't want to know anything about it, accept it. I think everyone's different, so everyone's journey gotta be their own journey. Participant 004\_2021AUHRP*

*No, well, because as I said to you the first time, if I didn't have treatment well, goodness knows what will happen. Yeah, I can't think of anything you kind of do at the time you think, god I wish I knew that [Unintelligible] I don't know how to answer that one. 045\_2021AUHRP*

**Participant wishes they had sought medical attention sooner, or had population screening sooner**

*I spent a lot of time blaming myself. I wish, in some ways, that some people I could almost feel judgment in their eyes. I blame myself that I should have gone earlier about the lumps that I had and I wish that that the health professionals just, in some ways, say, "It's not your fault" and repeat that, "It's not your fault." Again, "It's not your fault."*

*I was in the false belief that I was a very-- Was, still am, a very healthy person. As I said before, a bit sheltered. "I eat well and I exercise. I am not one of those people. I'm very unlikely. It's for people that are overweight or don't exercise, eat badly." It's given me a new outlook. I've come off my high horse. Participant 021\_2021AUHRP*

*Yes, I wish I'd gone straight away when I got my referral, rather than wait till-- I put it off and put it off and put it off and I'm sure it was growing bigger and bigger and bigger. I wish I'd gone earlier and caught it earlier. I wish I didn't miss my one set up for the year that because it may have been a lot smaller yes, anyway that's one thing I regret. Participant 035\_2021AUHRP*

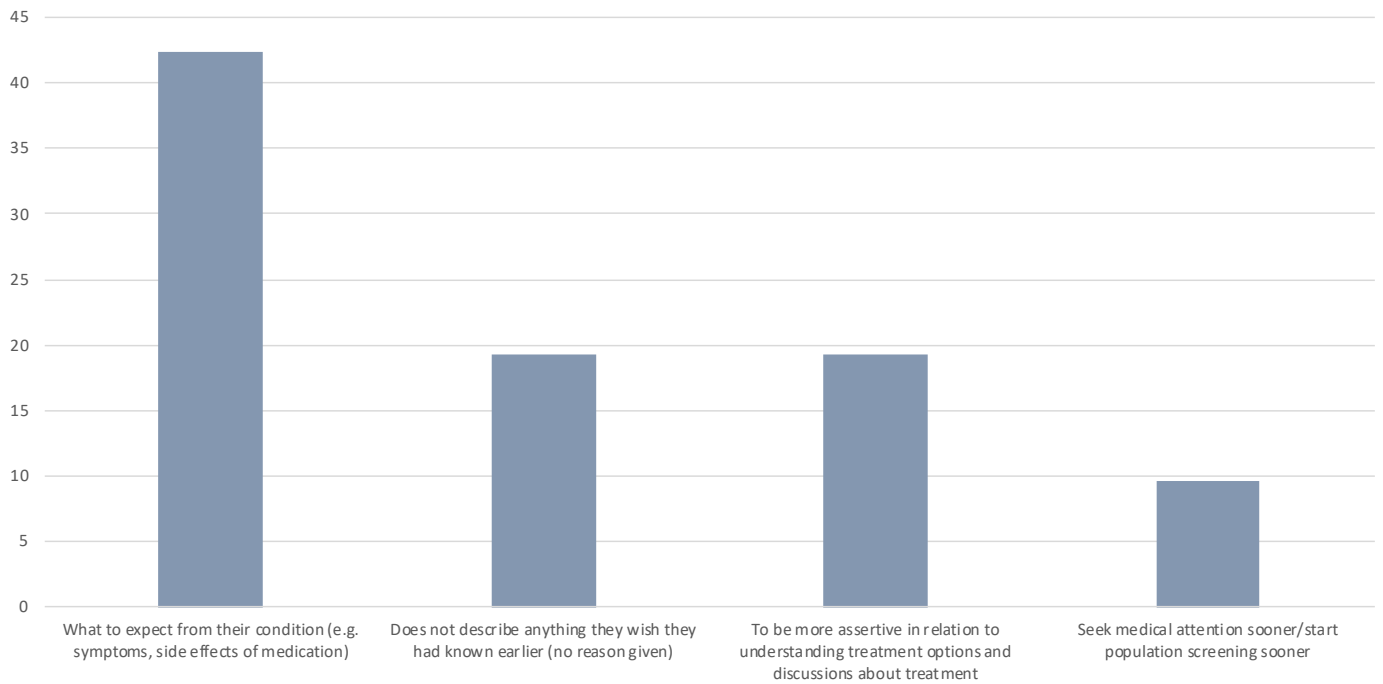
*Well, I think, I probably would've wished-- The first thing I knew about the whole mammogram was getting this letter when-- When you turn 50, you get a whole stack of letters about please go to these things. You can go to a mammogram at 40, which I would've done. That would have been scheduled if that picked up whatever I had when it was a lumpectomy and then I would have avoided all of it. Participant 036\_2021AUHRP*

**Table 10.1: Anything participants wish they had known earlier**

Anything participants wish they had known earlier	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 wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	22	42.31	7	36.84	10	47.62	5	41.67	12	41.38	10	43.48	8	42.11	14	42.42
Participant does not describe anything they wish they had known earlier (no reason given)	10	19.23	5	26.32	3	14.29	2	16.67	6	20.69	4	17.39	4	21.05	6	18.18
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	19.23	2	10.53	6	28.57	2	16.67	5	17.24	5	21.74	3	15.79	7	21.21
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	9.62	1	5.26	1	4.76	3	25.00	4	13.79	1	4.35	2	10.53	3	9.09

Anything participants wish they had known earlier	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 wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	22	42.31	5	50.00	5	31.25	12	46.15	5	45.45	17	41.46	6	33.33	16	47.06
Participant does not describe anything they wish they had known earlier (no reason given)	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	3	16.67	7	20.59
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	19.23	3	30.00	4	25.00	3	11.54	2	18.18	8	19.51	3	16.67	7	20.59
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	9.62	2	20.00	2	12.50	1	3.85	0	0.00	5	12.20	2	11.11	3	8.82



**Figure 10.1: Anything participants wish they had known earlier**

**Table 10.2: Anything participants wish they had known earlier – subgroup variations**

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	Diagnosed in 2017 to 2019	-
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	-	Diagnosed in 2016 or before
Participant wishes they had sought medical attention sooner, or had population screening sooner	-	Stage III and IV Diagnosed in 2016 or before

### Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).

#### Participant would not change any aspect of their care or treatment (no reason given)

*No, because they've got to do what they've got to do really. You can't change anything. Participant 012\_2021AUHRP*

*No, I don't think so. The system is what the system is. I can't change what they offer because that's what they offer. In a perfect world, there would be something better than the chemo train but there's not, is there? Participant 018\_2021AUHRP*

*Not any of the important things, no. Participant 039\_2021AUHRP*

**Participant would not change any aspect of their care or treatment/satisfied with care and treatment received**

*No, I don't think so. It was acted on quickly, from when I got diagnosed on the Friday, I went to the specialist on the Monday, he gave me all the information and had a plan, "I need you to go off and do X, Y, and Z, then come back and see me." It was very quick and less time to worry about it. I felt like it happened quickly. Participant 009\_2021AUHRP*

*No, I don't think so. I think I got through pretty unscathed, and I'm happy with how everything went. Participant 020\_2021AUHRP*

No, I don't think so. I think for a public system where everything that I'm receiving is funded by Medicare, it would be great if I didn't have to wait as long when I turn up to an appointment. Honestly, I wouldn't really change anything about the actual treatment. I understand that I'm being treated in a really good hospital with really good healthcare professionals, and I trust that it's the right thing. I believe it's the right thing for me and it's working. No, there isn't anything to change. It would be lovely if doctors ran on time but that's not a cancer thing. That's a doctor thing. Participant 044\_2021AUHRP

**Participant would have liked to have had a better understanding of their condition**

So it's the fact that we don't know, we don't get polled. It's very much being a mushroom. It's being kept in the dark and fed manure. They don't bring us out into the world, we get told nothing, so we don't know anything unless we go looking for and not everybody does that. I'm very interested in the medical side of things. A lot of women: out of sight, out of mind. I don't want to know about it. And then it's too late and, you know, it's gotten to stage four metastases and that type of thing. That's my issue. To me, this is all very frustrating. Participant 003\_2021AUHRP

No, I don't think so. I'm lucky that I've [unintelligible 01:04:16] early-stage cancer, although, when you get into these groups, you talk about people with early-stage cancer and two years later, they're in stage four. I'd like to know more about why that happens. You get told you've got early stage, and you'll probably live till you're 100. I guess there's such a thing as information overload as well. Maybe you can only take in what you can take in, and maybe sometimes you're better off not to know too much. I don't know. There's many different angles you could look at. I'm one of those people that want to be proactive, I think, and know as much as I can to stop the bloody thing from coming back. Participant 010\_2021AUHRP

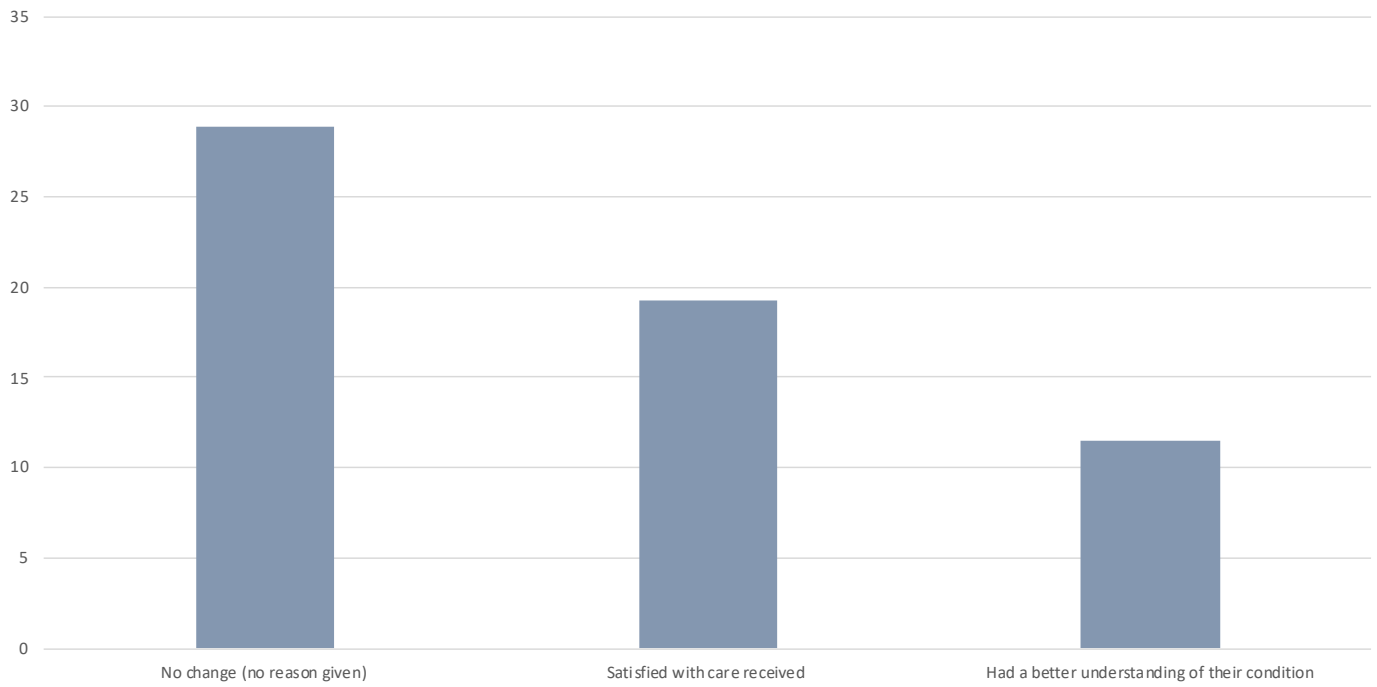
Probably it's the way sometimes they speak as I think I mentioned earlier and sometimes you're not quite a person that can be a bit frustrating angering to get angry but I did find I really had to push to get all the information I wanted. So they kept trying I think to protect me from overwhelming me but when I'm asking for it, yeah. I because I'm ready it's because it's what I want I think again, that's not treating everyone the same. Participant 045\_2021AUHRP

**Table 10.3: Aspect of care or treatment they would change**

Aspect of care or treatment they would change	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 would not change any aspect of their care or treatment (no reason given)	15	28.85	6	31.58	6	28.57	3	25.00	8	27.59	7	30.43	8	42.11	7	21.21
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	19.23	4	21.05	2	9.52	4	33.33	5	17.24	5	21.74	3	15.79	7	21.21
Participant would have liked to have had a better understanding of their condition	6	11.54	4	21.05	1	4.76	1	8.33	1	3.45	5	21.74	1	5.26	5	15.15

Aspect of care or treatment they would change	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 would not change any aspect of their care or treatment (no reason given)	15	28.85	4	40.00	5	31.25	6	23.08	3	27.27	12	29.27	6	33.33	9	26.47
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	19.23	0	0.00	4	25.00	6	23.08	1	9.09	9	21.95	4	22.22	6	17.65
Participant would have liked to have had a better understanding of their condition	6	11.54	3	30.00	1	6.25	2	7.69	2	18.18	4	9.76	3	16.67	3	8.82



**Figure 10.2: Aspect of care or treatment they would change**

**Table 10.4: Anything participants wish they had known earlier – subgroup variations**

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment (no reason given)	-	Trade or high school Diagnosed in 2016 or before
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Diagnosed in 2016 or before Regional or remote	Stage III and IV
Participant would have liked to have had a better understanding of their condition	-	Aged 55 to 74 Diagnosed in 2016 or before