

## **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. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

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

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.

## Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

### Participant wishes they had known more about the pros and cons of treatment options

*I guess the main thing for me would have been to know more about the long-term side effects and that if you need to stop treatment, it's okay to stop treatment. I think more knowledge and discussion about if you're having bad side effects, what your options are, and again what the pros and cons of stopping or continuing would make. For me, yes that would be the biggest one. Participant\_020*

*Not really actually. I think I know most of the things, it's just a few questions and answers, but I don't get a straight answer for that anyway. I wish there was more information on the differences between mastectomy, lumpectomy, and then to choose which. I was put in that situation on making my own decision, what I wanted, and it's a huge decision. I just wish there was a bit more guidance in relation to that. Participant\_016*

*Oh my God, there would be lots of things, but basically, a lot of the things that I have already touched on. I think what happens is so much, that obviously the doctors and staff don't know how it actually feels to be with all the treatment and stuff. I think it would have been nice when they are telling you your treatments things, maybe actually have someone there who's been through it, so you can sit with them, and they can actually tell you what to expect. Participant\_019*

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

*No, it's nothing. Participant\_003*

*Not that I could think of. Participant\_006*

*No. Participant\_007*

### Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology

*I wish I could've seen that I'd come out of it okay but that's impossible. I think maybe talking to people who had-- and I got a certain amount of that through the Facebook group, but talking to people who - someone who's been through the same thing would probably have been useful actually or having access to somebody, not necessarily talking. Participant\_004*

*Yes, just how hard it was going to be. I have stressed what was going to be, not a walk in the park. Participant\_028*

*They don't talk about scans and things at the end. I wish I'd known at diagnosis that they don't scan you at the end of your treatment and things. There's no closure from that point of view. There's no, "I'm getting a PET scan or other scan to make sure it hasn't got anywhere in my body." That seems to be something common that a lot of my friends are all talking about. There's no end-of-treatment scan to say it's all gone. That plays on your mind. I'd like to see that talked about and told that that's the way it's going to be. Also, as I said, the ongoing medical menopause, that side of things afterwards, or how it affects your relationship. I had no idea that at the end of this you wouldn't be-- I knew you'd be not yourself, but I didn't realize that this is still another however many months before you feel well again. All those sort of fud things. Nobody talks about sex either. Nobody tells you that you're not going to have sex the whole time because if you're so sick and then you've got menopause. That's not going to happen either, you need to talk-- I feel as though your partners need to be told that. Your partner is a big part of your life, and that's a big part of most young people's cancer journey. That is just not even discussed, it's a big taboo subject. Participant\_036*

**Participant wishes they had known more about what support was available to them**

*I wish I could've seen that I'd come out of it okay but that's impossible. I think maybe talking to people who had...and I got a certain amount of that through the Facebook group, but talking to people who - someone who's been through the same thing would probably have been useful actually or having access to somebody, not necessarily talking.*

**INTERVIEWER:** How long did it take for you to access the Facebook groups after your diagnosis? Did it take a little while?

**PARTICIPANT:** I think it took at least a couple of weeks. I don't think, I even really realized there were Facebook groups and I'm not sure how I even came across them. Participant\_004

*Definitely the nutrition to start with, the side effects of the chemo, and the neuropathy. If I could have found out there was a way to mitigate that a little bit more. Participant\_029*

*I don't think so. Probably just said access to other services. The broader may be some lists of people that you might consider contacting, and then the track, once you get your head around what's going on for*

*you. In terms of social supports, and physical support at home. Yes. Participant\_050*

**Participant wishes they had known more about side effects of treatments**

*Yes, the effects of radiation. Participant\_012*

*I guess the main thing for me would have been to know more about the long-term side effects and that if you need to stop treatment, it's okay to stop treatment. I think more knowledge and discussion about if you're having bad side effects, what your options are, and again what the pros and cons of stopping or continuing would make. For me, yes that would be the biggest one. Participant\_020*

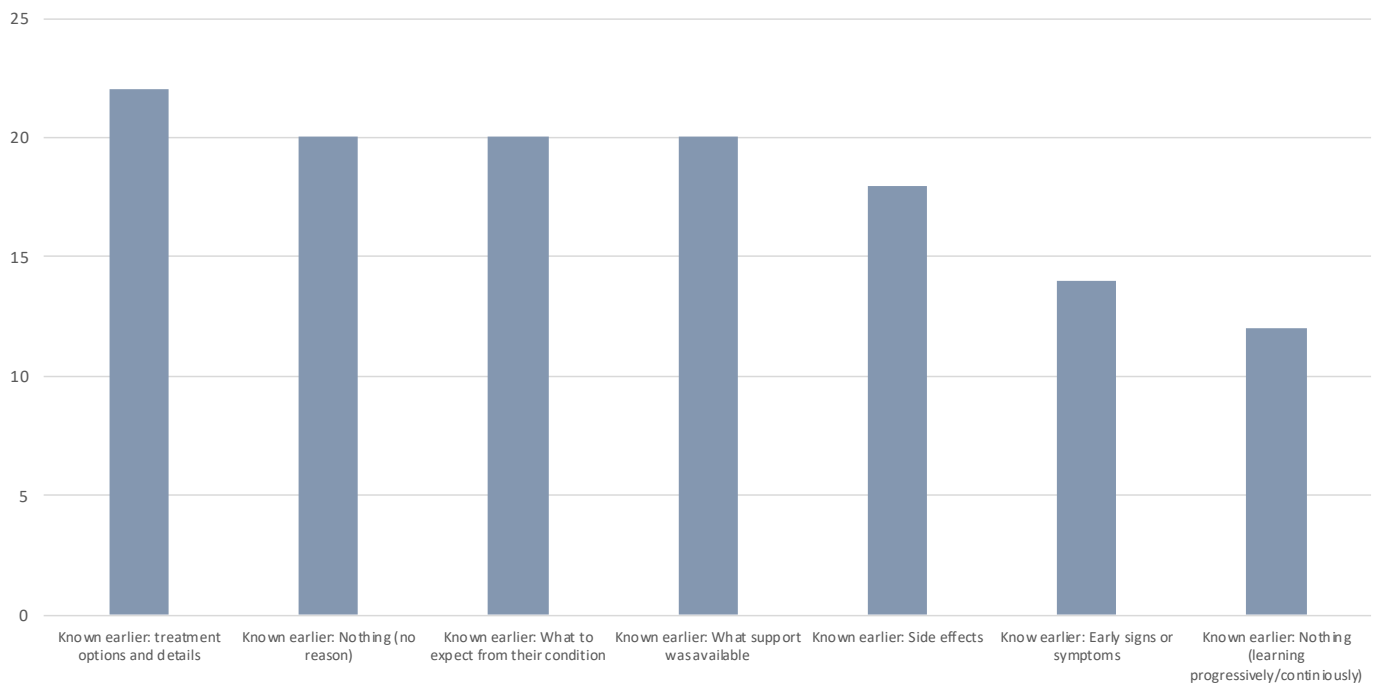
*Yes. Probably wish I had of have known more about the gastrointestinal effect and how that can-- That really does alter your life when you're running to and from a room for months on end. That is the biggest pain in the ass. Knowing more about those sort of things. This is really what you have to look out for. If you're going out for a walk, make sure you got a toilet nearby. Those sort of things. Participant\_034*

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

Anything participants wish they had known earlier	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 wishes they had known more about the pros and cons of treatment options	11	22.00	5	21.74	6	22.22	4	21.05	3	12.00	2	7.69	9	37.50	6	25.00	5	19.23
Participant does not describe anything they wish they had known earlier (no reason given)	10	20.00	6	26.09	4	14.81	4	21.05	6	24.00	4	15.38	6	25.00	4	16.67	6	23.08
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	10	20.00	4	17.39	6	22.22	4	21.05	6	24.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant wishes they had known more about what support was available to them	10	20.00	4	17.39	6	22.22	4	21.05	4	16.00	3	11.54	7	29.17	3	12.50	7	26.92
Participant wishes they had known more about side effects of treatments	9	18.00	5	21.74	4	14.81	4	21.05	3	12.00	4	15.38	5	20.83	4	16.67	5	19.23
Participant wishes they had know the early signs and symptoms of the condition	7	14.00	2	8.70	5	18.52	4	21.05	2	8.00	2	7.69	5	20.83	5	20.83	2	7.69
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	12.00	3	13.04	3	11.11	1	5.26	5	20.00	5	19.23	1	4.17	2	8.33	4	15.38

Anything participants wish they had known earlier	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 wishes they had known more about the pros and cons of treatment options	11	22.00	1	6.25	10	29.41	2	10.00	9	30.00	6	31.58	3	13.64	6	66.67
Participant does not describe anything they wish they had known earlier (no reason given)	10	20.00	3	18.75	7	20.59	7	35.00	3	10.00	1	5.26	8	36.36	1	11.11
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	10	20.00	0	0.00	10	29.41	1	5.00	9	30.00	4	21.05	3	13.64	4	44.44
Participant wishes they had known more about what support was available to them	10	20.00	4	25.00	6	17.65	3	15.00	7	23.33	4	21.05	3	13.64	4	44.44
Participant wishes they had known more about side effects of treatments	9	18.00	3	18.75	6	17.65	4	20.00	5	16.67	3	15.79	4	18.18	3	33.33
Participant wishes they had know the early signs and symptoms of the condition	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	3	15.79	4	18.18	3	33.33
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	12.00	2	12.50	4	11.76	1	5.00	5	16.67	4	21.05	1	4.55	4	44.44



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

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

Theme	Reported less frequently	Reported more frequently
Participant wishes they had known more about the pros and cons of treatment options	Regional or remote Mid to low status	Aged 55 to 74
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology		Aged 55 to 74
Participant wishes they had known more about what support was available to them		Aged 55 to 74
Participant wishes they had known more about side effects of treatments		Aged 55 to 74

### Aspect of care or treatment they would change

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.

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

*No. Tiny little things here and there but no, I was quite happy with how everything went. No, I would keep it all definitely. Participant\_005*

*No, because I'm sitting here cancer free and so I. Any changes that I'd made? Might have changed my outcome now, so I can't live with regret. So what if I think. Participant\_010*

*I don't think so. Like I say, I've been fairly good at taking out what I needed in relation to the exercise, and diet, and looking after myself, if there were issues with my care, asking questions and getting the answers that I needed. Yes, I don't think I would have changed anything. I was fortunate that I was able to access the professionals that I needed to in a timely manner. Treatment started fairly quickly and progressed as I thought. I didn't think of the fact that treatment was going to go over such a significant period of time. Other than, like I said, being aware of the long-term effects of treatment, I don't think there's anything else that I would have changed. Participant\_013*

*I would change-- no. I don't believe so, I have the utmost respect for everybody that has been part of my treatment, and I'm forever grateful, the doctors and nurses that have helped me, so no. Participant\_029*

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

*No, I don't think so. Participant\_021*

*No, not really. Participant\_047*

*No, I don't think so. Participant\_049*

**Participant would change or stop the kind of treatment they received**

*I think if at the time I wasn't so rushed, I understand a lot of ladies now have chemo before surgery and if that has worked, where that's good psychologically is that you know the chemo has started destroying the tumor and it's shrinking or pitted. In my case, it would've made it smaller, so possibly I wouldn't have had to have some of the muscle in the ribs taken out, which is a little bit painful and possibly, it wouldn't have been such a big lump. Even now, and I say to a lot of people, if I had to have my time again, I would have had the double DIEP reconstruction, to take the anxiety out of having still have mammograms or ultrasounds on the other breast. I would always would have done that. I haven't mentioned that I've had a hysterectomy before and I've also had a new*

*neurectomy from anxiety of being worried about my ovary, that I still had left after a hysterectomy 10 years before.*

*INTERVIEWER: Okay. You went ahead with that preventatively?*

*PARTICIPANT: Yes, I did. With the DIEP you can't feel your stomach. When I'd had an ovarian cyst 10 years before, which was a little bit large, I did get flight backache from it and I was worried. Even though the doctors told me it wouldn't happen, I just didn't want to have this ovary sitting in there and never knowing anything about what's going on there. Of course, that's the one cancer that they've got no symptoms. Participant\_040*

*I didn't want to do radiation, and I still don't...I'm not a 100% sure if I did the right thing in having it because obviously, that forced me to have a full surgery rather than have a breast implant put in which is major surgery where he's putting a breast implant and it's not as big a deal. Participant\_043*

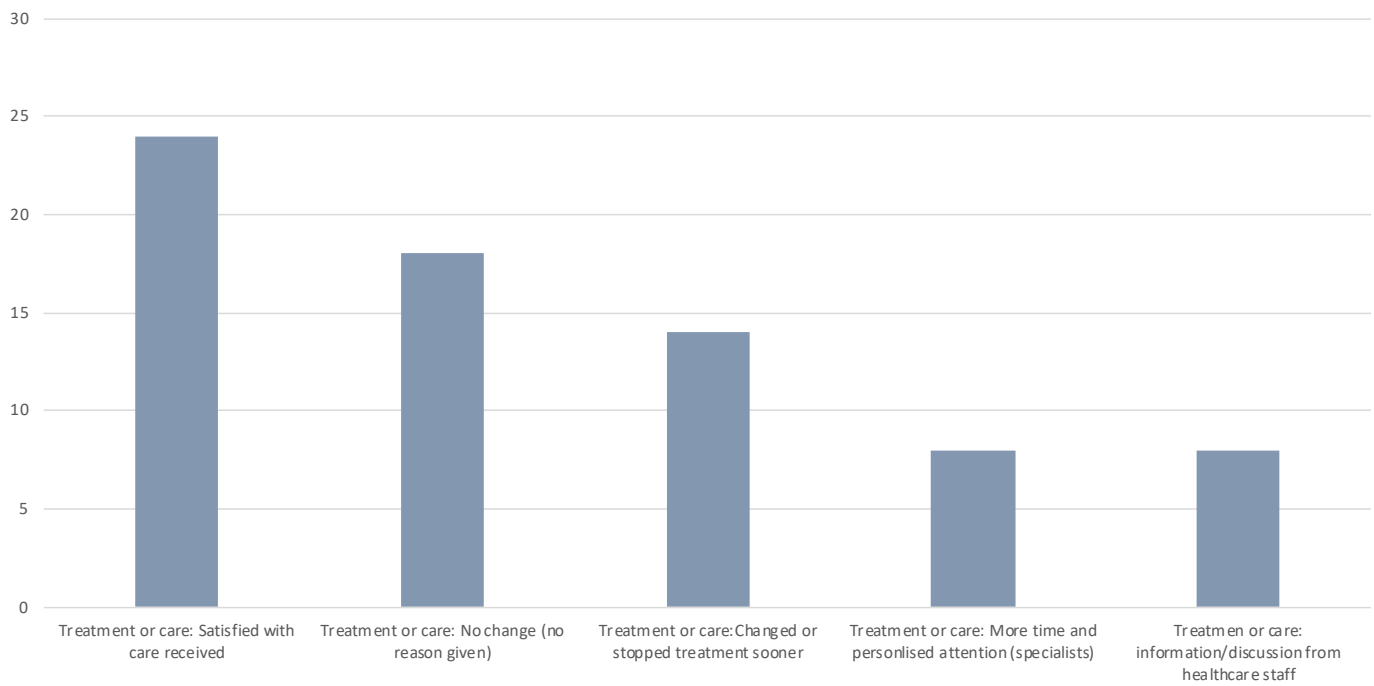
*If I'd known I had the gene, I would've had a double mastectomy, instead of a lumpectomy. Other than that, no. Participant\_037*

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

Aspect of care or treatment they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	12	24.00	9	39.13	3	11.11	4	21.05	7	28.00	6	23.08	6	25.00	3	12.50	9	34.62
Participant would not change any aspect of their care or treatment (no reason given)	9	18.00	3	13.04	6	22.22	5	26.32	4	16.00	6	23.08	3	12.50	5	20.83	4	15.38
Participant would change or stop the kind of treatment they received	7	14.00	2	8.70	5	18.52	2	10.53	3	12.00	5	19.23	2	8.33	4	16.67	3	11.54
Participant would have liked more time and personalised attention with specialists	4	8.00	2	8.70	2	7.41	2	10.53	2	8.00	2	7.69	2	8.33	1	4.17	3	11.54
Participant would have liked more information/discussion from healthcare staff	4	8.00	1	4.35	3	11.11	3	15.79	0	0.00	1	3.85	3	12.50	2	8.33	2	7.69

Aspect of care or treatment they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	12	24.00	5	31.25	7	20.59	6	30.00	6	20.00	4	21.05	5	22.73	4	44.44
Participant would not change any aspect of their care or treatment (no reason given)	9	18.00	6	37.50	3	8.82	5	25.00	4	13.33	3	15.79	4	18.18	3	33.33
Participant would change or stop the kind of treatment they received	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	1	5.26	5	22.73	1	11.11
Participant would have liked more time and personalised attention with specialists	4	8.00	0	0.00	4	11.76	0	0.00	4	13.33	2	10.53	1	4.55	2	22.22
Participant would have liked more information/discussion from healthcare staff	4	8.00	0	0.00	4	11.76	1	5.00	3	10.00	3	15.79	1	4.55	3	33.33



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

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

Theme	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Advanced breast cancer Trade or high school	Early breast cancer University Aged 55 to 74
Participant would not change any aspect of their care or treatment (no reason given)		Regional or remote Aged 55 to 74