

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 things that participants had wished they'd known earlier were understood the trajectory of the disease (27.27%), and to know the early signs and symptoms of their condition (12.12%). Other themes included to be assertive, an advocate, informed, and ask questions (9.09%), and look after their emotional well-being (9.09%).

As a follow up question, participants were asked if this knowledge would have changed their decisions. Most commonly, participants responded that it would not have changed their decision making (75.76%), for others it would have changed their decisions (18.18%).

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 have stopped or changed treatment sooner (30.30%), and would not change any aspect of their care or treatment and were satisfied with care and treatment received (27.27%). Other themes included would not change any aspect of their care or treatment, with no reason given (9.09%), and would have liked to have had access to a specialist in their condition sooner (9.09%).

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Participant wishes they had understood the trajectory of the disease

Probably, probably just those impacts on life a little bit, I suppose again everyone's an individual but hey look you might be able to do this you might be able to do that. This could be the side effects in my circumstance. Yes I did mention graft versus host disease but it can be anything from your skin to your mouth to your lungs. So you got what are the what are the impacts. So probably that and that's probably where the specialists are very, very good. This needs... having suggestion would be like having a branch out sort of support person. That yeah, it can help you look at that choices you have...just somebody Who sits down, you know pre post and all sort of things and just generally have a, you know it could be a two monthly or a quarterly check in with you to make sure that you know both physically and certainly mentally that you're OK

Participant 026_2023AUCRT

No. Probably the long-term effects of the tiredness. They did say to me it takes you two years to get back to somewhat normal, but it's just the little things like the tiredness all the time.

Participant 002_2023AUCRT

No, no, I wish I'd know it was going to turn out as well as it did. I know we're all pretty worried about it. At the beginning there was all this stuff about, you know, three to five years and all this sort of stuff...

Participant 014_2023AUCRT

Participant wishes they had known the early signs and symptoms of their condition

I think yes. I would like the fact that there's not really one blood test for lymphoma because I have four blood tests and keep thinking over different times and they're all normal. And yeah so I think that, yeah, knowing that would have been a good, a good thing. Heads up, most people have a swollen gland and I didn't, which is unfortunate, but yeah, so just, you know, people to act on as a gland, I guess it doesn't go down after a couple weeks, a week or so. But yeah, certainly that there is not one blood test, because I think the other thing I've found is that doctors don't know either. And I've spoken to a couple people when they would have gone down the same line of treatment for my sore knee and like cancer was the last thing that they would think of. And so not that you want cancer be the first thing you think of, but certainly doctors need doctors I think need to know how to read blood tests a bit better as well.

Participant 021_2023AUCRT

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

Yes, but I don't know if it would have been possible for me to know a lot at diagnosis, because as I said, I was very very ill. For me and my sons and daughter-in-laws, none of us knew what was going on really. Nothing was really explained properly or well. As I've found out now, it's up to you to ask the right questions, but you don't know the right questions, so it takes a while to work all that out.

Participant 003_2023AUCRT

Participant wishes they had known to be look after their emotional well-being

Just the emotional side I think, all the other stuff I got pretty good. That was all great, it was really really good.

Participant 004_2023AUCRT

Weirdly, this is going to sound strange. The chemo wards are absolutely if you oh how can I put this? I expected chemo wards to be very depressing and I found the nursing staff somehow magically make it not depressing for most of their patients and I think it was the same in CITY 1 as in CITY 2 and I think I was just overcome by how positive that experience was for me and just how positive the people working in the area are. I also got COVID in the middle of it. So, yeah,

yeah, So. I think that perhaps. I could have asked for help a little earlier when I was having, say, a bad week instead of, you know, being being strong. And yeah,

yeah, so I actually have got better at asking for help. Yeah. So that was the biggest lesson for me. Participant 009_2023AUCRT

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant wishes they had understood the trajectory of the disease	9	27.27	0	0.00	4	40.00	5	31.25	7	26.92	2	28.57	5	33.33	4	22.22
Participant wishes they had known the early signs and symptoms of their condition	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Participant wishes they had known to be look after their emotional well-being	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11

Anything participants wish they had known earlier	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant wishes they had understood the trajectory of the disease	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	5	35.71	4	21.05
Participant wishes they had known the early signs and symptoms of their condition	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	1	7.14	3	15.79
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	0	0.00	3	15.79
Participant wishes they had known to be look after their emotional well-being	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	3	21.43	0	0.00

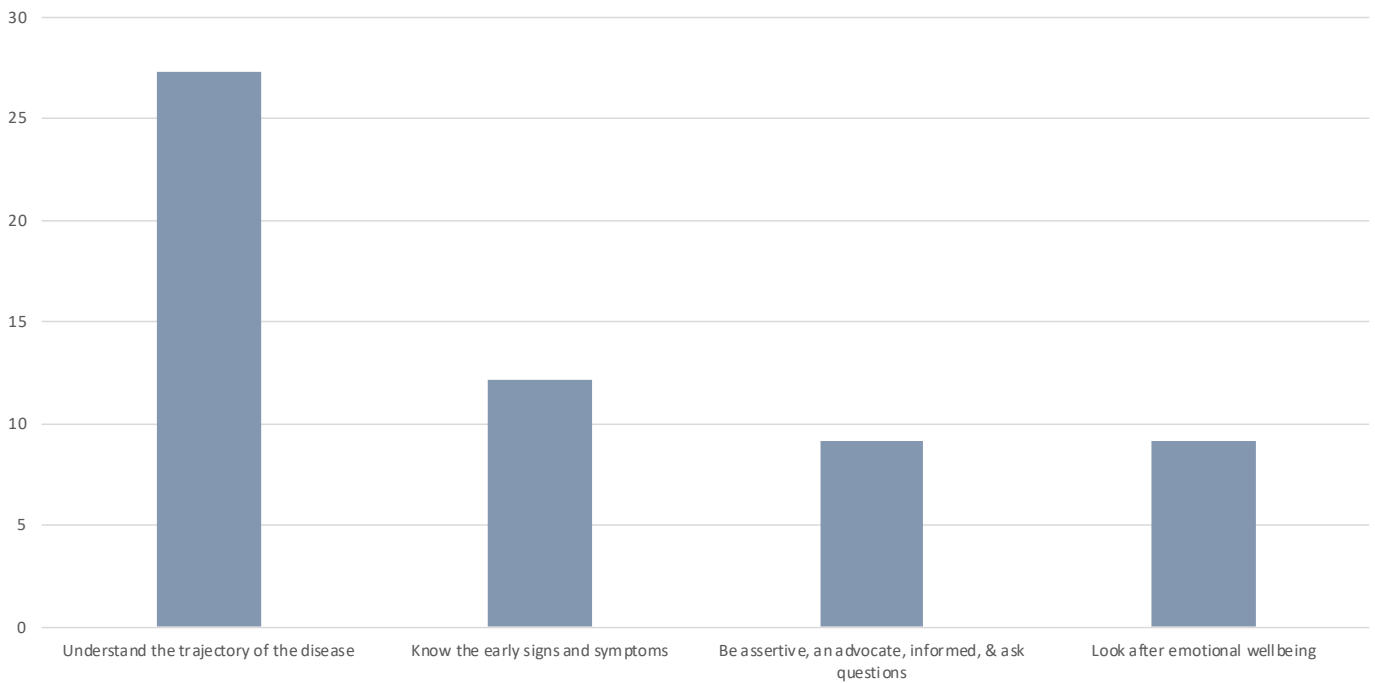
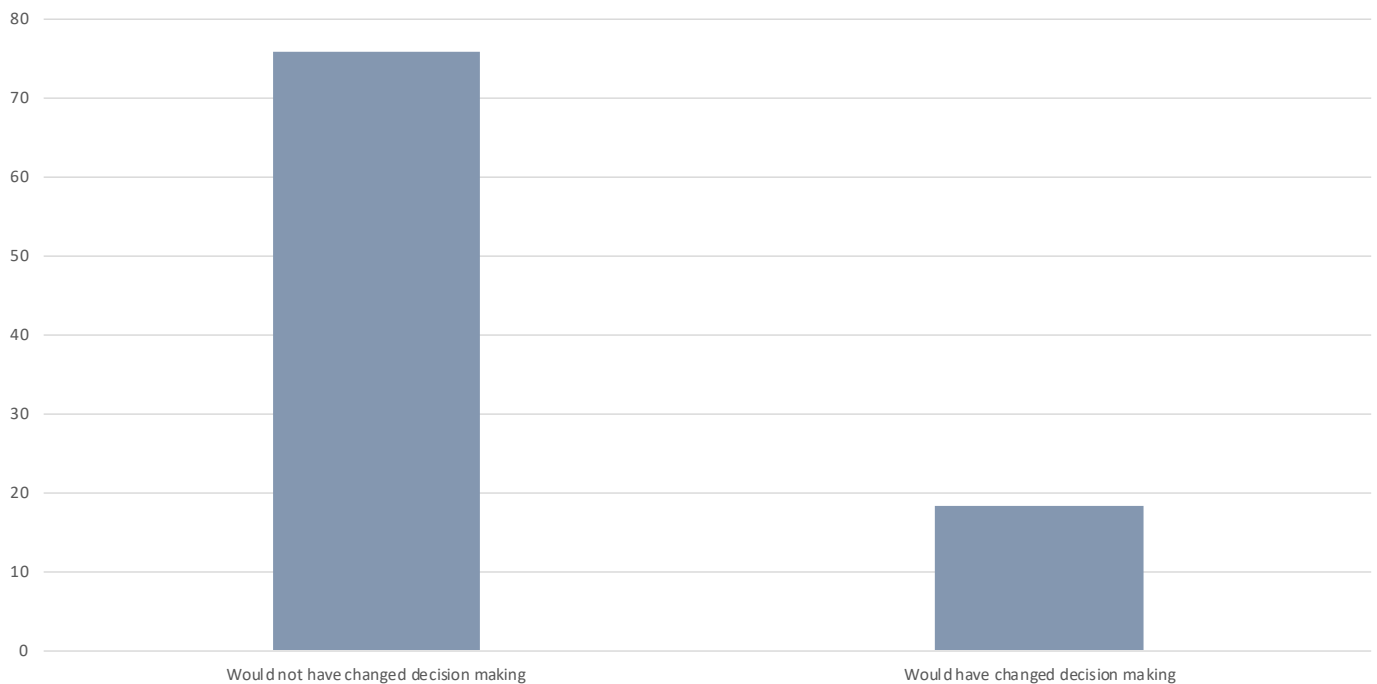


Figure 10.1: Anything participants wish they had known earlier

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 understood the trajectory of the disease	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant wishes they had known the early signs and symptoms of their condition	B-cell acute lymphoblastic leukaemia (ALL)	
Participant wishes they had known to be look after their emotional well-being	-	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status

Figure 10.2: Would that knowledge have changed decision making



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 have stopped or changed treatment sooner (30.30%), and would not change any aspect of their care or treatment and were satisfied with care and treatment received (27.27%). Other themes included would not change any aspect of their care or treatment, with no reason given (9.09%), and would have liked to have had access to a specialist in their condition sooner (9.09%).

Participant would have stopped or changed treatment sooner (incl. starting CAR-T earlier)

Look, the only thing I thought we'll probably could have would have looked into more was maybe when I was sent to the rehabilitation place to see if I could have done the same sort of rehabilitation that had a private facility. Because it was quite horrible there and we had private health cover, so we weren't. I didn't ask enough questions and they didn't really talk to us about okay. Well you need rehab. We can't help you here. So you can either go to the rue or or we can if you've got private health cover you can go to we can make this is a place where you can go to and you can do it that way. So it was sort of like. And I've heard other people say this they don't the two sides don't like the the public don't really offer the options of private. So so that that that that wasn't sort of really suggested to me and that would have that would have been helpful to be able to do that we are.
Participant 006_2023AUCRT

As I said before, not having to go through three failed grounds of chemo before CAR T was available.
009_2023AUCRT

No. I probably with hindsight I would have you know would have asked more questions and would have got the hematologist to refer me to other people. But you know I've kind of just gone with with things and while I haven't been suffering too much I've just gone with it. But as I said, I've been proactive and looked at different other therapies that might help with the pain and found a solution for myself. And you know, anything that I think I can do to help my situation, yeah, I'll do it. You know I can be proactive and find an answer you.
Participant 012_2023AUCRT

Well, I think I would have if I jumped up and down early enough, I wouldn't have been on having diarrhea for 10 years. You know, I think I would have liked to have maybe been taken off it earlier.
Participant 020_2023AUCRT

Yes, I would just like to go into CAR T given now my reading sort of indicates that the chance, you know, it might have worked, but the chances were lower for for the chemo treatment for my particular cancer. So I think it's unfortunate, but it's sort of a, you know, the system as it is now, but as time goes on that I imagine that people would be more readily referred to a CAR T program.
Participant 021_2023AUCRT

Yeah, I would like that that CAR T cell procedure, it's available from the beginning so that we don't have to go through through chemotherapy that would be you know more available another just for those you know critical.

Participant 034_2023AUCRT

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

No, I don't think so, I've really got no complaints. They've pulled me out of the worst thing that could probably happen to anyone. Yes, definitely no complaints there.

Participant 005_2023AUCRT

No, I don't think so. It's keeping me alive.

Participant 013_2023AUCRT

No, there isn't. I'm very happy with it.

Participant 014_2023AUCRT

Participant would have liked to have access to a specialist in their condition, sooner

I would have liked to have been admitted to HOSPITAL earlier, but that was just a process that we had to undergo.

Participant 002_2023AUCRT

I think the, the waiting around in waiting rooms for pathology when people need it urgently and they're sick, that's got to change. Greater equity, an inclusion within the hospital environment, it's very good at hospitals, but it's got a long way to go. So they're the things and the data access across clinicians I think is going to be improved.

Participant 036_2023AUCRT

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant would have stopped or changed treatment sooner	10	30.30	1	14.29	4	40.00	5	31.25	6	23.08	4	57.14	7	46.67	3	16.67
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	9	27.27	2	28.57	1	10.00	6	37.50	9	34.62	0	0.00	2	13.33	7	38.89
Participant would not change any aspect of their care or treatment, with no reason given	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	1	6.67	2	11.11
Participant would have liked to have access to a specialist in their condition, sooner	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	2	13.33	1	5.56

Aspect of care or treatment they would change	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant would have stopped or changed treatment sooner	10	30.30	6	31.58	4	28.57	3	21.43	7	36.84	3	21.43	7	36.84
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Participant would not change any aspect of their care or treatment, with no reason given	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26
Participant would have liked to have access to a specialist in their condition, sooner	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

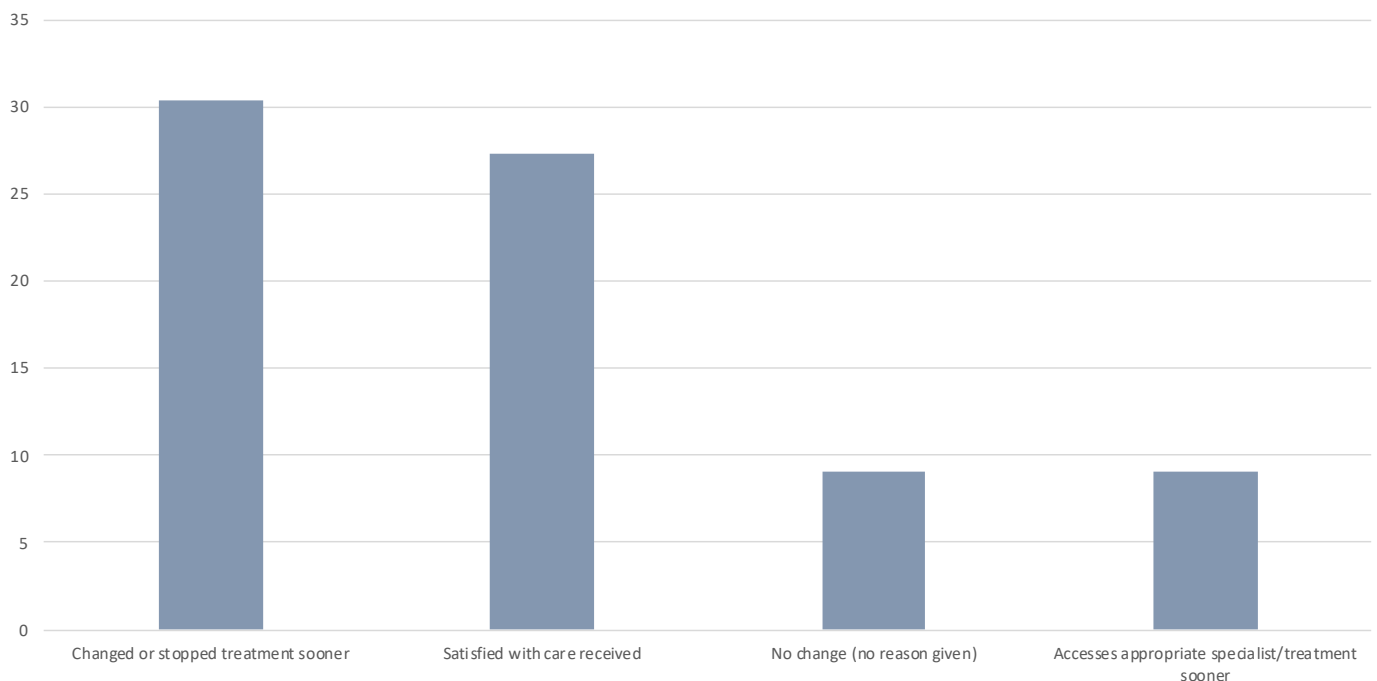


Figure 10.3: Aspect of care or treatment they would change

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 have stopped or changed treatment sooner	B-cell acute lymphoblastic leukaemia (ALL) Male	CAR T-Cell therapy Female
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Participant would not change any aspect of their care or treatment, with no reason given	-	Diffuse Large B-Cell Lymphoma
Participant would have liked to have access to a specialist in their condition, sooner	-	Diffuse Large B-Cell Lymphoma