

## Section 4

### Decision-making

## Section 4 summary

### Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants described being presented with one treatment option (63.64%), multiple options (24.24%), and no discussions about treatment (6.06 %).

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

For those with a single treatment option, most commonly they had a medical emergency/urgent treatment required (27.27%), were comfortable deferring to doctor/accept recommended approach (21.21%), or gave no reason (12.12 %). Other themes included and was well informed by doctor (12.12%), and having some but very little discussion (6.06%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (15.15%), were comfortable deferring to doctor or accept the recommended approach (6.06%).

Participants that had no treatment options offered at diagnosis described not needing treatments initially(6.06 %).

### Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24 %). Other themes included ability to follow treatments (12.12%), and quality of life (9.09%). There were 4 participants (12.12%) described that they had not been given options, and that considerations not taken into account (12.12%).

### Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (57.58%), and had changed the way they make decisions (33.33%).

Where participants had not changed the way they make decisions, the most common themes were that they had changed but did not mention any reason (18.18%), they have always been informed/assertive (9.09%), and have always taken advice of clinicians (9.09 %).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (15.15%), and were more informed and/or more assertive (12.12%).

### Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to be cancer free, avoid recurrence, increase longevity (45.45%), have quality of life/return to normality (27.27%), and have physical improvements in their condition (21.21 %). Other themes included to minimise or avoid side effects (15.15%), maintain their condition or prevent worsening of their condition (12.12%), and not having treatment goals as they are satisfied or their condition has little impact on life (9.09%).

## Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants described being presented with one treatment option (63.64%), multiple options (24.24%), and no discussions about treatment (6.06 %).

### Participant describes one option being presented

*I think it was pretty much a one way conversation. I was told what the treatment would be and I accepted that. I don't think I was given...I didn't know anyway about various treatment options, mostly I think from me looking it up on the Internet, but I was pretty much presented with a treatment plan and accepted it and this was that I would take a drug in combination with the prednisolone. So that's how I started.*

*Participant 014\_2023AUCRT*

*Well, it was just a matter of initially the first line of treatment was there was only one option really was the chemo. There was no other, there was no other trials or there was no options for CAR T Cell or various other trials that people have been on since.*

*Participant 032\_2023AUCRT*

*OK, so the main conversation was the day I was diagnosed when there was the haematologist, the resident and the neurologist there and I said to them or they explained to me that it was not curable and they said there's essentially one line of treatment that can help but won't cure you. And they said this is the only treatments we have. And I said what if we don't do that? And they said, well, you know, you've got six months really.*

*Participant 022\_2023AUCRT*

### Participant describes multiple options being presented

*I was offered chemo. To be honest, there wasn't a lot of discussion except for me saying that I didn't want to, actually, I didn't want to do it. That was my only option. It was either that or palliative care at the time. My friends convinced me that I should have chemo. There wasn't a lot of discussion.*

*Participant 003\_2023AUCRT*

*OK, so my GP deferred back to my hematologist, so they drew a line in my treatment between them. Basically the hematologist left pain management etc with my GP and the hematologist dealt with the cancer and it's byproducts of the cancer. So yeah, so there basically there was how can we say there was no contrast with the drugs and so forth being used. But basically that's where the line was drawn.*

*Participant 027\_2023AUCRT*

### Participant describes no treatments being discussed

*Well, I saw an oncologist who went through what was involved and how he continued to monitor me. But he he said within the next 5-10 years you probably need some form of treatment. I went for checkups and as my markers gradually went up very slowly, but they went up each time I went to the point where it reached Stage 1 multiple myeloma. And that's when he well said I'd start chemotherapy.*

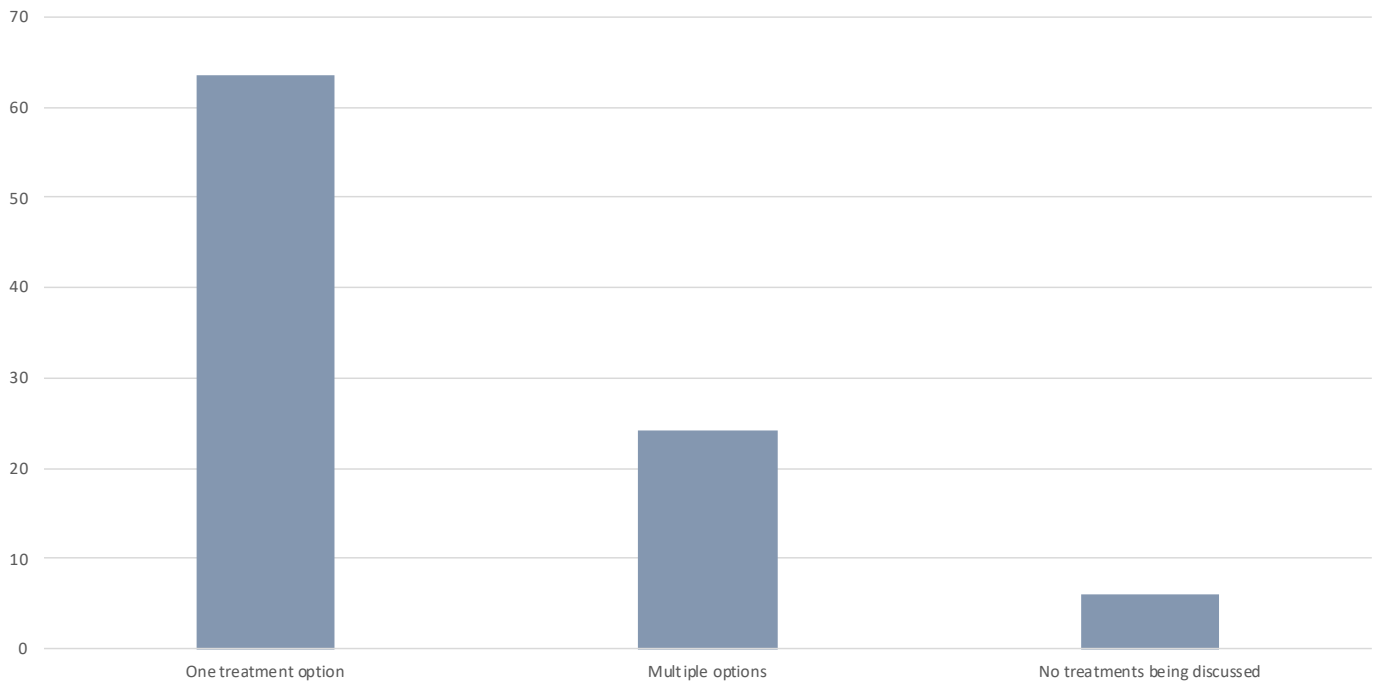
*Participant 015\_2023AUCRT*

**Table 4.1: Discussions about treatment**

Discussions about treatment	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 describes one option being presented	21	63.64	6	85.71	7	70.00	8	50.00	18	69.23	3	42.86	11	73.33	10	55.56
Participant describes multiple options being presented	8	24.24	1	14.29	2	20.00	5	31.25	6	23.08	2	28.57	3	20.00	5	27.78
Participant describes no treatments being discussed	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	1	6.67	1	5.56
No particular comment	2	6.06	0	0.00	0	0.00	2	12.50	1	3.85	1	14.29	0	0.00	2	11.11

Discussions about treatment	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 describes one option being presented	21	63.64	14	73.68	7	50.00	7	50.00	14	73.68	7	50.00	14	73.68
Participant describes multiple options being presented	8	24.24	3	15.79	5	35.71	6	42.86	2	10.53	6	42.86	2	10.53
Participant describes no treatments being discussed	2	6.06	2	10.53	0	0.00	1	7.14	1	5.26	1	7.14	1	5.26
No particular comment	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53



**Figure 4.1: Discussions about treatment**

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

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes one option being presented	Multiple Myeloma CAR T-Cell therapy Aged 65 or older Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Metropolitan Higher status
Participant describes multiple options being presented	Metropolitan Higher status	Aged 65 or older Regional or remote Mid to low status

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

For those with a single treatment option, most commonly they had a medical emergency/urgent treatment required (27.27%), were comfortable deferring to doctor/accept recommended approach (21.21%), or gave no reason (12.12 %). Other themes included and was well informed by doctor (12.12%), and having some but very little discussion (6.06%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (15.15%), were comfortable deferring to doctor or accept the recommended approach (6.06%).

Participants that had no treatment options offered at diagnosis described not needing treatments initially(6.06 %).

**Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required**

*Well, when I was first diagnosed, I was already preparing for the treatment. That was maybe about 11:00 or midnight that night. They knew at that stage that if it was or wasn't, or more likely it was going to be what I had, that my body was going to need to be prepared. The next morning, Doctor came in and chatted to me and listed what's going to go on otherwise. He was very...just going to be brutal and said 'If you don't have the treatment, you've two to three weeks to live'*  
Participant 001\_2023AUCRT

*When I was first diagnosed, he told me I'd have to start chemo ASAP. It was a whirlwind because he organized for me to have, I think, a lung capacity test and some other test on my heart. Then on the Tuesday, I went into hospital to have the PICC line put in and then chemo pretty much started on the Wednesday.*  
Participant 002\_2023AUCRT

**Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach**

*Well, it was pretty well, they said, well, we've got to start chemotherapy straight away. There wasn't really any other options that that was basically that that was it. That was what they said. They've got to start it right away and they and they did tell me because of my age they said I'm I'm actually young for for this type of leukemia so that makes it better. And I was in other than the leukemia I was quite healthy and that sort of thing so but they they didn't really say. Instead of chemotherapy, you can do this or you can do that. And I mean, I just, when they said you need to have chemotherapy, I just said okay, What? I didn't have any thoughts of, Oh no, I'd rather try something else. I just talked to that they were the experts in the field and that what they would be saying was right. Participant 0\_2023AUCRT*

*I don't really know about conversations. They just told me that I needed to do this chemotherapy and you know, I remember some of the words and I just thought, I'll just let it. I just left it up to them because they knew what they were doing and I didn't. What what was I going to say? I didn't, you know, I didn't like, you know, I was inquisitive and I read what they gave me a bit of literature and that to read, but it didn't, you know, I couldn't get my head around a lot of it, you know, like in the words, you know. The drug names and things like that, I can still recall some of them, but not all of them. Like when I filled out that, you know, that questionnaire you sent me that. Participant 010\_2023AUCRT*

**Participant describes being presented with one option/approach, and was well informed by doctor**

*He explained to me what I'll be going on, what protocol and talked, talked me through what what sort of things were were happening and I sort of did a little bit of research. There's a medical library next to the hospital and there's a medical library nearby. So I went in there and and I got the regime up myself. He suggested that I keep a diary just because you're just a number in hospital and sometimes mistakes happen. So I kept the diary and just studied the drugs and their purposes and sort of got an idea of what was gonna be happening to me. Participant 024\_2023AUCRT*

*Basically explained to me that because of the way my health, because once I filled in the forms and they sat with them, explained to them a whole lot of things and they asked me about what other issues I've had*

*and I have it really no other medical issues whatsoever, a slight bit of hypertension and that's it. And nothing else has ever occurred. I've actually been extremely healthy. They said I'd be a very good candidate for a stem cell transplant and they said that particular time period of time that was one of the best options for getting on getting on top of it. So I went along with it. They explained to me everything that was involved with it. I wasn't going to say no anything for me. I never say no. I was convinced they would give me the right right information at that particular time. Participant 018\_2023AUCRT*

**Participant describes being presented with one option/approach, and had some but very little discussion**

*Basically, I wasn't presented with options. I was basically told that it was so advanced is not quite the right word, but so far along that they had had to hit me with pretty extreme chemo early and and that happened very quickly. I have a little bit of information about what to expect from chemo, but but nothing that you told actually prepares you for how awful that can be, the first course of chemo. Participant 009\_2023AUCRT*

**Participant describes being presented with multiple options and participated in the decision-making process**

*Well that was that was obviously a question which I asked the the hematologist and the those that it was advised that I would be suitable. They felt that I would be suitable for a stem cell transplant and and you know the diagnosis, the diagnosis was about August 2020 and so things that have happened fairly quickly. So the treatment, the treatment options that were given to me were that I've commenced almost straight away on the course of chemotherapy and have you know different sort of blood tests done and all that stuff have and then have stem cells recovered at the hospital and then have the then have the then have the various tests done and then have then have the transplant. So that was that was that was the treatment plan was to start with chemotherapy stem cell transplant at that stage also it was discussed. I was referred to a doctor at the hospital and she at that stage, even prior to the transplant, she said after the transplant I signed up for for a trial drug there, but she did discuss after the transplant in terms of maintenance that there's a trial drug available. Participant 023\_2023AUCRT*

Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach

*OK, so my GP deferred back to my hematologist, so they drew a line in my treatment between them. Basically the hematologist left pain management etc with my GP and the hematologist dealt with the cancer and it's byproducts of the cancer. So yeah, so there basically there was how can we say there was cross match between the two. So make sure there was no contrast with the drugs and so forth being used. But basically that's where the line was drawn.  
Participant 027\_2023AUCRT*

Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed

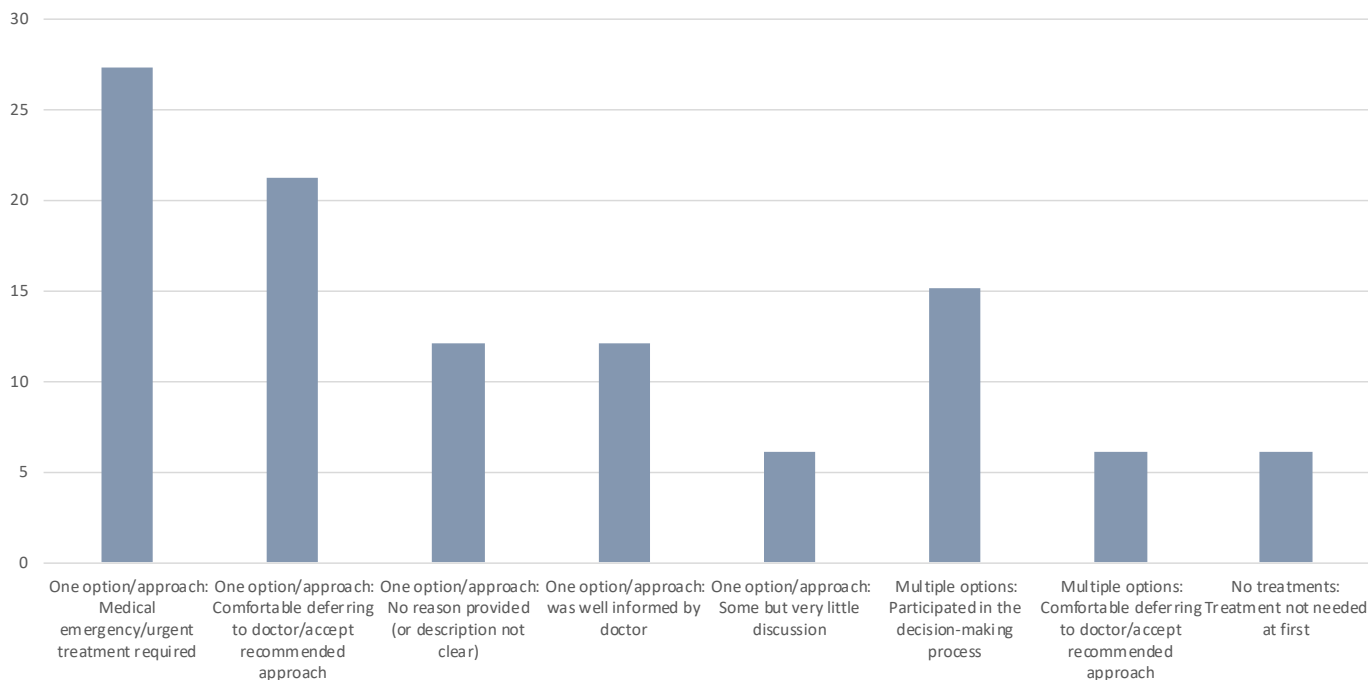
*Well, I saw an oncologist who went through what was involved and how he continued to monitor me. But he he said within the next 5-10 years you probably need some form of treatment. I went for checkups and as my markers gradually went up very slowly, but they went up each time I went to the point where it reached Stage 1 multiple myeloma. And that's when he well said I'd start chemotherapy.  
Participant 015\_2023AUCRT*

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

Discussions about treatment (Participation in discussions)	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 describes being presented with one option/approach because it was a medical emergency/urgent treatment required	9	27.27	5	71.43	3	30.00	1	6.25	8	30.77	1	14.29	7	46.67	2	11.11
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach	7	21.21	1	14.29	4	40.00	2	12.50	6	23.08	1	14.29	2	13.33	5	27.78
Participant describes being presented with one option/approach, but did not give a description or reason for this	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes being presented with one option/approach, and was well informed by doctor	4	12.12	0	0.00	2	20.00	2	12.50	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes being presented with one option/approach, and had some but very little discussion	2	6.06	0	0.00	2	20.00	0	0.00	0	0.00	2	28.57	1	6.67	1	5.56
Participant describes being presented with multiple options and participated in the decision-making process	5	15.15	0	0.00	2	20.00	3	18.75	4	15.38	1	14.29	3	20.00	2	11.11
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	2	6.06	1	14.29	0	0.00	1	6.25	2	7.69	0	0.00	0	0.00	2	11.11
Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	0	0.00	2	11.11

Discussions about treatment (Participation in discussions)	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 describes being presented with one option/approach because it was a medical emergency/urgent treatment required	9	27.27	9	47.37	0	0.00	3	21.43	6	31.58	3	21.43	6	31.58
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes being presented with one option/approach, but did not give a description or reason for this	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes being presented with one option/approach, and was well informed by doctor	4	12.12	1	5.26	3	21.43	4	28.57	0	0.00	4	28.57	0	0.00
Participant describes being presented with one option/approach, and had some but very little discussion	2	6.06	1	5.26	1	7.14	2	14.29	0	0.00	1	7.14	1	5.26
Participant describes being presented with multiple options and participated in the decision-making process	5	15.15	1	5.26	4	28.57	3	21.43	2	10.53	4	28.57	1	5.26
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	2	6.06	2	10.53	0	0.00	2	14.29	0	0.00	2	14.29	0	0.00
Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53



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

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

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach		Diffuse Large B-Cell Lymphoma
Participant describes being presented with one option/approach, but did not give a description or reason for this	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	
Participant describes being presented with one option/approach, and was well informed by doctor	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status	Regional or remote Mid to low status
Participant describes being presented with one option/approach, and had some but very little discussion		Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes being presented with multiple options and participated in the decision-making process	B-cell acute lymphoblastic leukaemia (ALL)	Aged 65 or older Mid to low status

### Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24%). Other themes included ability to follow treatments (12.12%), and quality of life (9.09%). There were 4 participants (12.12%) described that they had not been given options, and that considerations not taken into account (12.12%).

#### Participant describes taking the advice of their clinician into account when making decisions about treatments

*Basically, we've always looked at the confidence of the doctors. If the doctors have recommended this is what we should do, that's what we've done.*  
Participant 002\_2023AUCRT

*Do what the specialist tells me to do. Simple as that. And I mean my my current treatment and it's been similar for the last year or so as I said is is very simple a check in with the with the hematologist and the daily pill and the three monthly infusion.*  
Participant 013\_2023AUCRT

*I suppose the short term and long term effects and what they could be, if that's short term, you're gonna feel pretty ordinary and you might have this, this, this and this or but the long term results are that. So that's probably what they generally look for. But yeah, certainly guided by the health professionals around all of those decisions.*  
Participant 026\_2023AUCRT

*Look, I think for me, with this, I mean this is the first time I've ever been unwell, so I didn't have any experience to reference it to, which is so important in*

decision making. You know, what have you done before? I did it work, blah blah. I had nothing at all to reference this to and I was so unwell. I think that I was a very passive decision maker in that process and I really did relinquish my absolute research in that decision making space. I think I really did relinquish my decision making to the professionals around me, but in terms of it retrospectively, if I say it, if somebody said to me now I had to do something, it would be the impact of the treatment on my kids and my partner.  
Participant 016\_2023AUCRT

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

Well, the risks of, you know, the side effects, but you sort of almost grab it in a sense because you haven't got many options. I mean, that's a fatal illness. So you know, I accepted that that stage just under a different hematologist and she was very good and went through it all.  
Participant 035\_2023AUCRT

Well, side effects? Outcomes impact on you, me and others. Cost is something I'm fortunate. I've had well paid jobs with financial and I have good medical insurance. So yeah, those things what's available is it current. I like to know that I'm having something that's up to date and and I I like to talk to the specialists about the impact of the treatment, how long it takes, all those things that's where I come to the revaccination program. It's rarely mentioned early in the piece that and the but the the thing that is mentioned in CAR T is the lack of immunoglobulins might be ongoing. And so my T cell stopped working after about six months in terms of defending my body from lymphoma tumors. And it's they've just been hanging in there and they haven't died and they could be reactivated. And I've had this conversation with my specialist, but they're they weren't actively running around in my body doing the job and my numbers equalized quite quickly comparatively to what's expected. So, you know, you'd like to know, worst case scenario, what might happen. What happens if?  
Participant 036\_2023AUCRT

Yeah, probably just the main thing is having all the facts to knowing. I mean, I ask a lot of questions and I take notes. So it's always knowing all the side effects and what to do, just being informed, I think that's the most important thing as I go into making decisions to know, yeah, to know what the pros and cons, I guess, to know what the side effects might be. I've never considered not taking the treatments because I don't know any better. I don't think I've had. I'm not against

all this other holistic approaches, but just don't know enough. Yeah.

Participant 021\_2023AUCRT

#### **Participant describes taking efficacy into account when making decisions about treatments**

Was, I guess, what the outcome and prognosis with life.

Participant 001\_2023AUCRT

Well, just saving my life. So yeah, there there probably wasn't really decisions that such it was like, well, you have to if you want to live and and if you don't have a stem cell transplant you probably won't live as well. So it was just like, OK, well that's what I need to do. That's what I need need to do. So it was there wasn't really any treatment decisions where they where there was sort of two options where they could say we can do this and this will happen and we'll do that and that'll happen. So, So yeah, the most important thing was always what was best for my health and what was going to have the best outcome.

Participant 006\_2023AUCRT

Well, probably mainly the side effects and how effective it might be.

Participant 012\_2023AUCRT

#### **Participant describes taking their ability to follow treatments into account when making decisions about treatments**

I just got to allow the time you know to allow you to diarize everything and just provide me with the with the schedule and I just write and make sure nothing clashes with my treatment. So otherwise you know when it's prescribed...but the other I mean I have a regular I, as I said before, the hydrotherapy and the exercise physiology, the regular thing, which we, you know, we pencil in and make sure nothing's gonna clash with that. So that consistency is the important thing.

Participant 032\_2023AUCRT

Mostly it's it's about how I'm going to manage the logistics of it. I live alone and I don't drive. So all of those things like access, extra care. If it's needed that, I really worry about logistics, I'm much more concerned about that than the treatment really because fundamentally I'm, I just go with whatever the doctors are recommending to me basically.

Participant 009\_2023AUCRT



**Participant describes that they were not given any treatment options**

*Well, I haven't had to make a decision really. Yeah, obviously it hasn't come. I'm in remission, so I haven't had to make a decision, but I'd like to know what I should be, you know, what I should be doing in regard to exercise, food and drink and stuff like that.*

*Participant 010\_2023AUCRT*

*They just gave me chemo. I didn't really make a decision whether I had chemo or not. That was it.*

*Participant 003\_2023AUCRT*

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

*How it's going to affect my life day-to-day*

*Participant 025\_2023AUCRT*

*Well, improving life, improving, you know, just your day-to-day well-being, you know, and I sort of, I mean I had a really good friend of mine that had multiple myeloma and after a year of hospitalization and really bad times that he had was self assisted and he passed away and his choice was if he went into a coma he said 'don't wake me up'. He said I've had enough of this and look, those thoughts have crossed my mind. You know I think you know what is there in life, you know, but if you can improve your quality of life.*

*Participant 031\_2023AUCRT*

**Table 4.5 Considerations when making decisions**

Considerations when making decisions about treatment	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 describes taking the advice of their clinician into account when making decisions about treatments (Total)	15	45.45	3	42.86	7	70.00	5	31.25	11	42.31	4	57.14	8	53.33	7	38.89
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	30.30	2	28.57	5	50.00	3	18.75	7	26.92	3	42.86	6	40.00	4	22.22
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	2	13.33	3	16.67
Participant describes taking side effects into account when making decisions about treatments (Total)	13	39.39	3	42.86	3	30.00	7	43.75	10	38.46	3	42.86	5	33.33	8	44.44
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	33.33	2	28.57	3	30.00	6	37.50	9	34.62	2	28.57	5	33.33	6	33.33
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	6.06	1	14.29	0	0.00	1	6.25	1	3.85	1	14.29	0	0.00	2	11.11
Participant describes taking efficacy into account when making decisions about treatments (Total)	8	24.24	2	28.57	3	30.00	3	18.75	5	19.23	3	42.86	5	33.33	3	16.67
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	15.15	0	0.00	3	30.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	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 describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	0	0.00	1	5.56
Participant describes that they were not given any treatment options (Total)	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes that they were not given options, but described considerations that are important to them when making treatment decisions	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 that they were not given options, and did not describe any considerations when making treatment decisions	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes taking quality of life into account when making decisions about treatments (Total)	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	2	13.33	1	5.56
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	1	6.67	0	0.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	1	6.67	1	5.56

Considerations when making decisions about treatment	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 describes taking the advice of their clinician into account when making decisions about treatments (Total)	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	5	35.71	10	52.63
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	30.30	8	42.11	2	14.29	5	35.71	5	26.32	4	28.57	6	31.58
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes taking side effects into account when making decisions about treatments (Total)	13	39.39	9	47.37	4	28.57	6	42.86	7	36.84	7	50.00	6	31.58
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	33.33	8	42.11	3	21.43	5	35.71	6	31.58	6	42.86	5	26.32
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26
Participant describes taking efficacy into account when making decisions about treatments (Total)	8	24.24	5	26.32	3	21.43	2	14.29	6	31.58	4	28.57	4	21.05
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	3	21.43	2	10.53
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	1	7.14	3	15.79
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	1	7.14	2	10.53
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
Participant describes that they were not given any treatment options (Total)	4	12.12	2	10.53	2	14.29	4	28.57	0	0.00	4	28.57	0	0.00
Participant describes that they were not given options, but described considerations that are important to them when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options, and did not describe any considerations when making treatment decisions	4	12.12	2	10.53	2	14.29	4	28.57	0	0.00	4	28.57	0	0.00
Participant describes taking quality of life into account when making decisions about treatments (Total)	3	9.09	0	0.00	3	21.43	0	0.00	3	15.79	0	0.00	3	15.79
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53

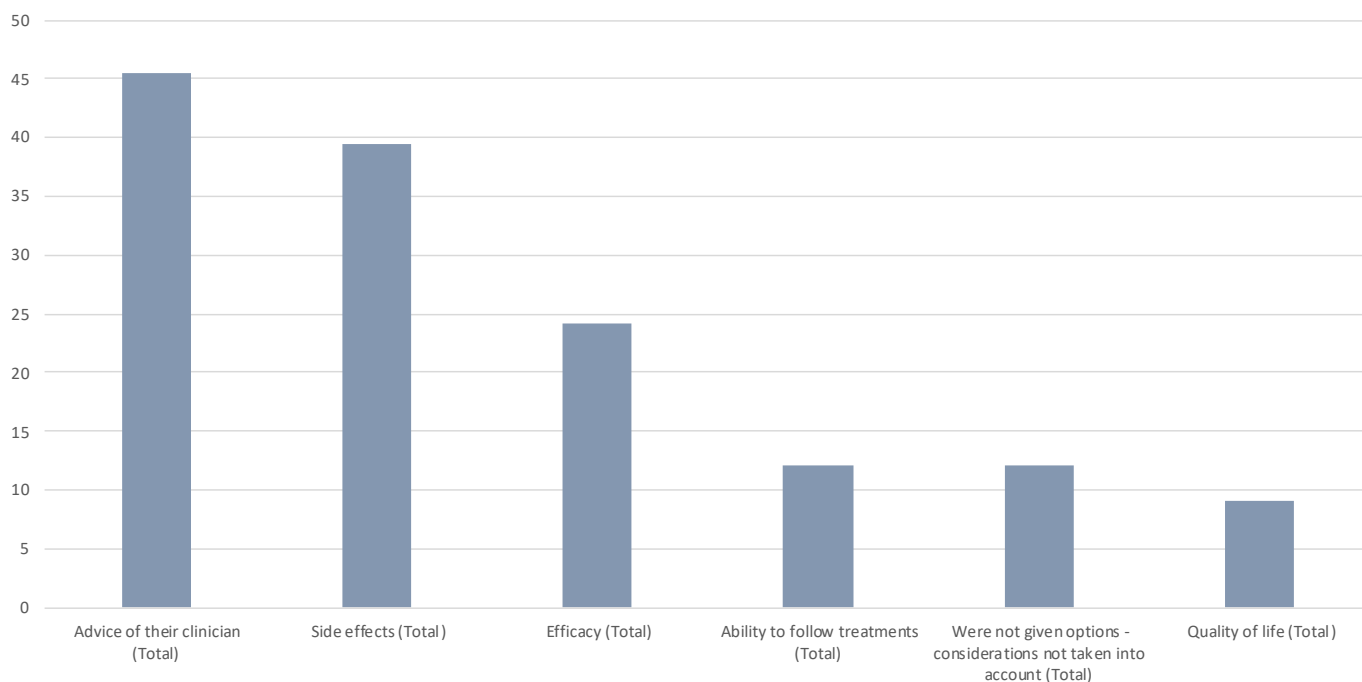


Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	Multiple Myeloma Aged 65 or older	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64
Participant describes taking side effects into account when making decisions about treatments (Total)	Aged 65 or older	Mid to low status
Participant describes taking efficacy into account when making decisions about treatments (Total)		CAR T-Cell therapy
Participant describes that they were not given any treatment options (Total)	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status
Participant describes taking quality of life into account when making decisions about treatments (Total)		Aged 65 or older

## Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (57.58%), and had changed the way they make decisions (33.33%).

Where participants had not changed the way they make decisions, the most common themes were that they had changed but did not mention any reason (18.18%), they have always been informed/assertive (9.09%), and have always taken advice of clinicians (9.09 %).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (15.15%), and were more informed and/or more assertive (12.12%).

### No change in decision-making over time as they have always been informed/assertive

*PARTICIPANT: Yes. I've always been quite analytical. I like to research. I like to know what's going on. I've always worked that way. It's what I do. It does work for me. It might not work for everyone. A lot of people don't want to know but I need to know. I need to know and work it all out. As I said, I knew that I have no option so, "Right, I'm going to do this and I'm going to get through it and I'm going to be fine."*

*Participant 004\_2023AUCRT*

### No change in decision-making over time as they have always taken advice of clinicians

*No, I mean, they're the experts that are advising me. So the only way is to express my faith in them and do what they tell me to do.*

*Participant 013\_2023AUCRT*

*I think pretty much the same. I'm very clinical. I'm a I've been an academic for a long time. I'm a researcher. I want information. I'm very happy to be advised by physicians that I trust and nursing staff. You know, I've had amazing nursing care and but not always, you know, there's one or two occasions when I've I walked away from one guy, the cardiologist at the hospital and went back to my own cardiologist because he would not explain what he wanted and why he wanted it to do things. And he just got really*

*pissed with me at the end and and that's fine. I didn't ever want to go back to him. I went along with what he asked for for a while. But I didn't know why and I found in the end I found the treatment that all the tests that he was running a bit distressing because I didn't understand why I was doing them and he couldn't tell me. So I said right. So I went back to my specialist, whom I trusted, and things are good.*

*Participant 036\_2023AUCRT*

### Changing over time as they are more aware of their health, responsibilities and/or limitations

*I am more aware of what is happening to me and what has I'm I'm learning my lessons by looking at what has happened to me so far and what might be on the way ahead. And I'm studying more. I'm coming across more people who have had those treatments or who are going to have them and just talking to people about the things like that, studying a little bit more and adjusting my expectations and all of these things are, yeah, probably affecting the way that I'm thinking about it.*

*Participant 017\_2023AUCRT*

### Changing over time as they are more informed and/or more assertive

*It's probably pretty much the same way, although I probably a few years ago, when I was in four, three or four years ago, I suppose I probably would have just said yes to whatever they told me. Now I probably would just question the why if if they were to say we're going to change the treatment, I'd go, well, why? What's the reasoning behind that? If, if and then if. It's just come down to the effectiveness, I'd say, well, how's this going to be different? Blah blah and that sort of thing. So I suppose I'd probably be a little bit more nuanced to a little bit more knowledgeable.*

*Participant 019\_2023AUCRT*

*I think I asked more and more questions. So I guess as time goes, I know, yeah, I asked. I think we always ask the doctor, what would they do if you know someone they knew that's always a good indication. And yeah, just a bit more direct with is if the other side effects with the risk, yeah. It is a treatment worth of side effects etcetera etcetera.*

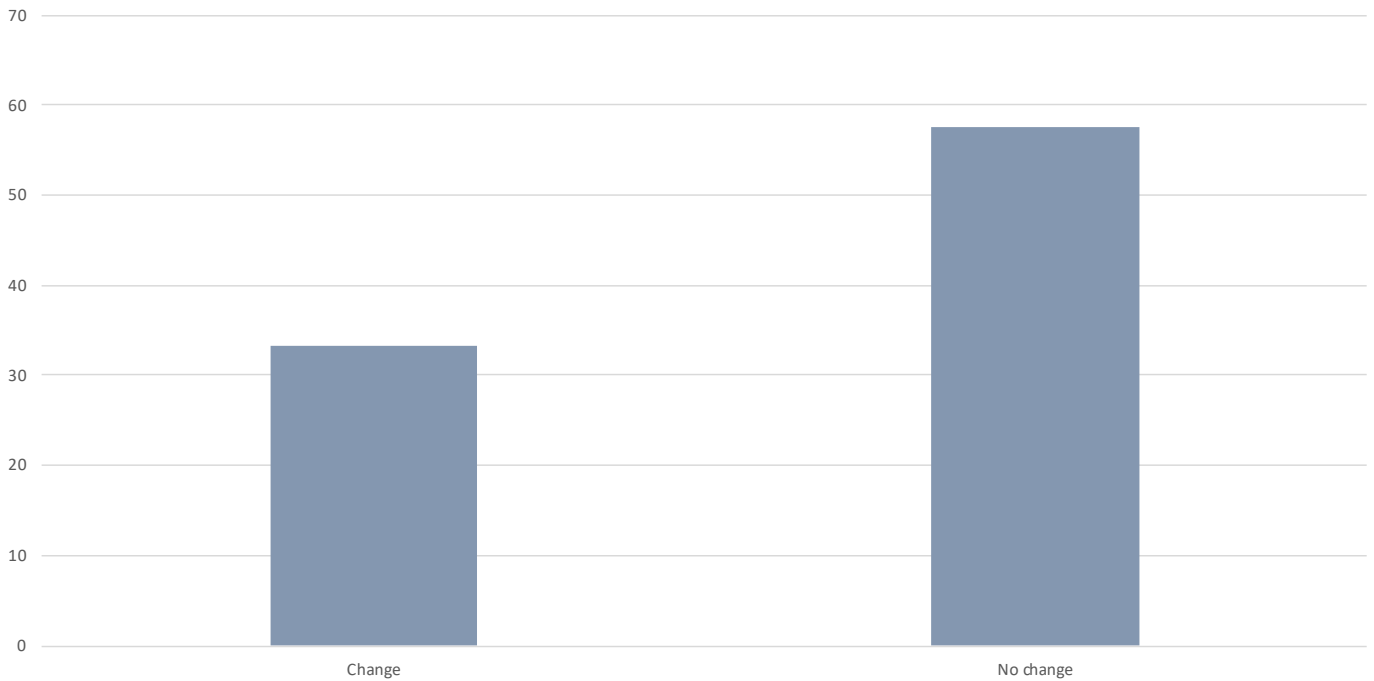
*Participant 021\_2023AUCRT*

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

Decision-making over time	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	%
Change in decision-making over time as they have always been informed/assertive	11	33.33	2	28.57	1	10.00	8	50.00	9	34.62	2	28.57	4	26.67	7	38.89
No change in decision-making over time as they have always taken advice of clinicians	19	57.58	5	71.43	8	80.00	6	37.50	15	57.69	4	57.14	9	60.00	10	55.56
Other/no response	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56

Decision-making over time	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	%
Change in decision-making over time as they have always been informed/assertive	11	33.33	6	31.58	5	35.71	4	28.57	7	36.84	5	35.71	6	31.58
No change in decision-making over time as they have always taken advice of clinicians	19	57.58	13	68.42	6	42.86	9	64.29	10	52.63	8	57.14	11	57.89
Other/no response	3	9.09	0	0.00	3	21.43	1	7.14	2	10.53	1	7.14	2	10.53



**Figure 4.4: Decision-making over time**

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

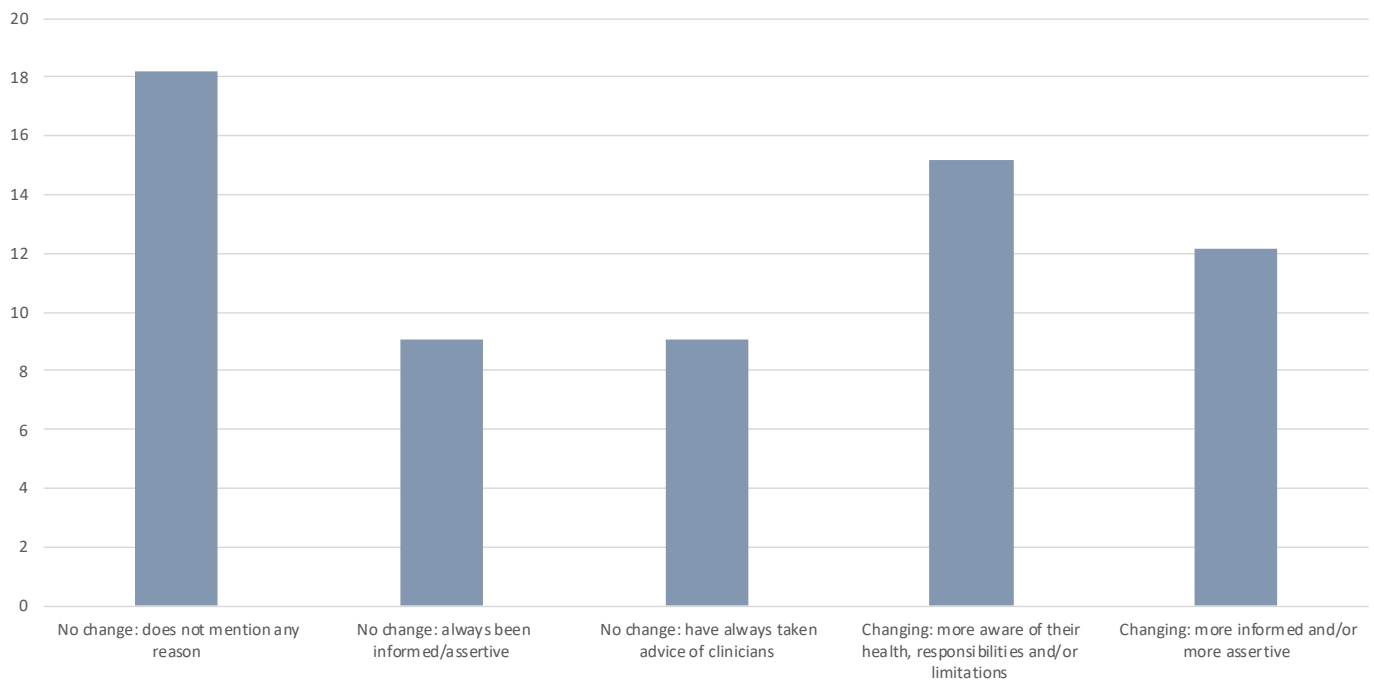
Decision-making over time	Reported less frequently	Reported more frequently
Change in decision-making over time as they have always been informed/assertive	Diffuse Large B-Cell Lymphoma	Multiple Myeloma
No change in decision-making over time as they have always taken advice of clinicians	Multiple Myeloma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Aged 25 to 64

**Table 4.9: Decision-making over time (descriptions)**

Decision-making over time (reasons)	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	%
No change in decision-making over time and there is no particular reason noted	6	18.18	3	42.86	0	0.00	3	18.75	5	19.23	1	14.29	2	13.33	4	22.22
No change in decision-making over time as they have always been informed/assertive	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	2	13.33	1	5.56
No change in decision-making over time as they have always taken advice of clinicians	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	1	6.67	2	11.11
Changing over time as they are more aware of their health, responsibilities and/or limitations	5	15.15	0	0.00	0	0.00	5	31.25	5	19.23	0	0.00	0	0.00	5	27.78
Changing over time as they are more informed and/or more assertive	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11

Decision-making over time (reasons)	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	%
No change in decision-making over time and there is no particular reason noted	6	18.18	5	26.32	1	7.14	3	21.43	3	15.79	2	14.29	4	21.05
No change in decision-making over time as they have always been informed/assertive	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
No change in decision-making over time as they have always taken advice of clinicians	3	9.09	0	0.00	3	21.43	0	0.00	3	15.79	0	0.00	3	15.79
Changing over time as they are more aware of their health, responsibilities and/or limitations	5	15.15	2	10.53	3	21.43	3	21.43	2	10.53	3	21.43	2	10.53
Changing over time as they are more informed and/or more assertive	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	2	14.29	2	10.53



**Figure 4.5: Decision-making over time (descriptions)**

**Table 4.10: Decision-making over time (descriptions)**

Decision-making over time (reasons)	Reported less frequently	Reported more frequently
No change in decision-making over time and there is no particular reason noted	Diffuse Large B-Cell Lymphoma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)
No change in decision-making over time as they have always been informed/assertive	-	Diffuse Large B-Cell Lymphoma
No change in decision-making over time as they have always taken advice of clinicians	-	Aged 65 or older
Changing over time as they are more aware of their health, responsibilities and/or limitations	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Changing over time as they are more informed and/or more assertive	Aged 65 or older	-

## Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to be cancer free, avoid recurrence, increase longevity (45.45%), have quality of life/return to normality (27.27%), and have physical improvements in their condition (21.21 %). Other themes included to minimise or avoid side effects (15.15%), maintain their condition or prevent worsening of their condition (12.12%), and not having treatment goals as they are satisfied or their condition has little impact on life (9.09%).

### Participants describe wanting to be cancer free, avoid recurrence or increase longevity

*I hope it doesn't come back so I don't have to have that chemotherapy again.*

*Participant 011\_2023AUCRT*

*My goals in treatment is to hopefully I can stay healthy enough that should they have another breakthrough in a drug or one of those things that is*

*little in my view at that particular period of time wasn't available wasn't the PBS, it was available not on the PBS and so. As time goes by, there'll be better products coming out on the market that will hopefully look after my condition. There is a Car T cell, which is extremely expensive.*

*Participant 018\_2023AUCRT*

*Yeah, I have nothing else in my mind, but just to be cancer free and to to prolong my lifespan. I mean, it's just nothing more, nothing less than that.*

*034\_2023AUCRT*

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

*I'm quite independent, just like to get back to more strength, like to be able to do participate more range of activities which I was doing before...I must admit, because that's surprisingly apart from when I was undergoing treatment, I would have times when I was unwell and would have a fever, but I haven't actually caught anything in between other than that and I've managed to go. So this is a bit of a shock. Yeah, really, really annoying. And so sort of just when I was feeling like I was doing more exercise, but I'm starting to get stage where I was walking. You know, we walk every day and at least do 5 to 10 KS. And yeah, and I was just starting to do more stretching and thinking about getting back into light weights or doing some more, we've done a little bit of bike riding things. My next step was really just to go, having recovered from being very weak...going to the next being more stronger overall, I guess.*

*Participant 021\_2023AUCRT*

**Participants describe wanting to see physical improvements in their condition**

*I think for me personally, obviously, I want to try to retain optimum health. I've still got my strength because I still get a little bit tired from time to time. Obviously, reducing medications that I'm on.*

*Participant 002\_2023AUCRT*

*Now you say, yeah, yeah, look, there's definitely a limitation with what I'm at. Yeah, it's probably reduced probably by about 60% only probably the last last three to four years, up until four years ago. The the transplant, yeah, it was, you know, wasn't too bad. Fairly head stocked first and mind you, yeah and yeah, but the last four years has certainly been challenging and you just want to improve.*

*Participant 026\_2023AUCRT*

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

*The difficulty also is what what are effects from cancer... So it's a bit hard to sort things like energy levels, fatigue levels. Even some of the sort of nerve painy stuff. So it it's a very complex thing and I'm not sure I can never be certain about what it is. Yeah. So I think the the complication of that makes my*

*experience of daily living. A little bit more hard to deal with, I suppose.*

*Participant 009\_2023AUCRT*

**Participant describes wanting to maintain their condition/prevent worsening of their condition**

*Yeah, he gave me the statistics, which weren't good because I had, as you know... So he just suggested to, oh, because I was pretty fit. It was probably the fittest I've ever been, which was in my favor. And he just suggested keeping away from people and restaurants and, you know, don't go out to places where there's sort of with no immunity just to keep yourself healthy and away from other implications that could affect my health, basically. That's about it.*

*Participant 024\_2023AUCRT*

*Well, I don't really have, I mean I've got side effects like brain brain fog and some neuropathy, but that's manageable. So I I don't, I choose not to pursue anything else for treatment and they are you know the treatment will. As far as I can see, we'll just keep going and then the longer I maintain almost remission sort of level of cancer, I think by the time I need something else, there'll be something equally less invasive around the the third line of treatment.*

*Participant 032\_2023AUCRT*

**Participant describes no treatment goals as they are satisfied or their condition has little impact on life**

*In terms of the in terms of the cancer, it oh okay, one of my bloods, the various components, some of them are not that good. And so I always blame them that I can't walk uphill as fast or without puffing as I used to do but a lot of that could be because of advancing years. But look, that's the really the only effect I noticed. I live a full and contented life...so in that sense, the cancer doesn't affects me very, very little.*

*Participant 013\_2023AUCRT*

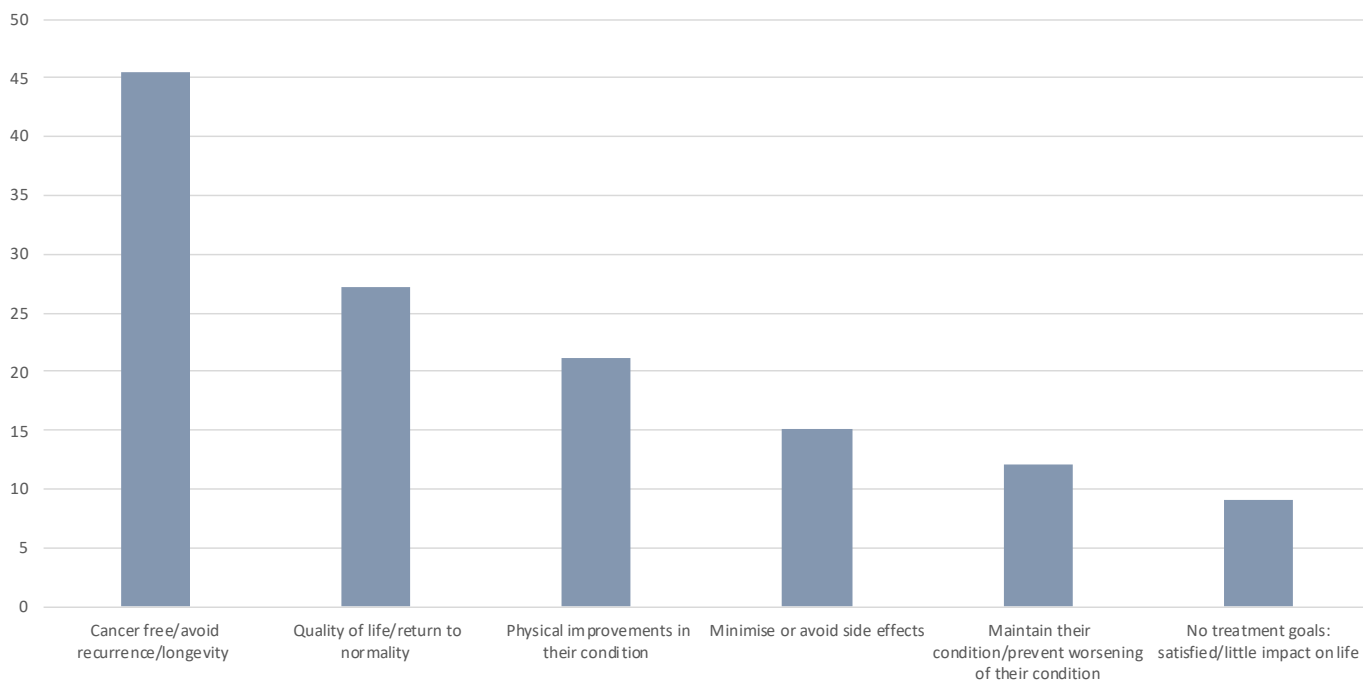
*Well, I don't really. As I said before, I think it's there and it's it's just in the background, it's quiet, it's not doing anything to me when we're monitoring it now every three months. Originally it was every month and I don't really think about it, so I don't. I don't have any goals. I don't see it as a now as something that's really relevant in my in my life.*

*Participant 014\_2023AUCRT*

**Table 4.11: Personal goals of treatment or care**

Personal goals of treatment or care	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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	15	45.45	3	42.86	5	50.00	7	43.75	12	46.15	3	42.86	8	53.33	7	38.89
Participant describes wanting to improve their quality of life or return to normality	9	27.27	1	14.29	3	30.00	5	31.25	6	23.08	3	42.86	5	33.33	4	22.22
Participants describe wanting to see physical improvements in their condition	7	21.21	3	42.86	2	20.00	2	12.50	4	15.38	3	42.86	5	33.33	2	11.11
Participant describes wanting to minimise or avoid side effects of treatment for their condition	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	4	26.67	1	5.56
Participant describes wanting to maintain their condition/prevent worsening of their condition	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	0	0.00	3	16.67

Personal goals of treatment or care	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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	5	35.71	10	52.63
Participant describes wanting to improve their quality of life or return to normality	9	27.27	7	36.84	2	14.29	5	35.71	4	21.05	5	35.71	4	21.05
Participants describe wanting to see physical improvements in their condition	7	21.21	5	26.32	2	14.29	2	14.29	5	26.32	3	21.43	4	21.05
Participant describes wanting to minimise or avoid side effects of treatment for their condition	5	15.15	4	21.05	1	7.14	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes wanting to maintain their condition/prevent worsening of their condition	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	3	9.09	0	0.00	3	21.43	1	7.14	2	10.53	1	7.14	2	10.53



**Figure 4.6: Personal goals of treatment or care**

**Table 4.12: Personal goals of treatment or care – subgroup variations**

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	Aged 65 or older	Aged 25 to 64
Participant describes wanting to improve their quality of life or return to normality	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy
Participants describe wanting to see physical improvements in their condition	Male	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy
Participant describes wanting to minimise or avoid side effects of treatment for their condition	-	Female
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	-	Aged 65 or older