

## **Section 9**

### **Expectations and messages to decision-makers**

## **Section 9: Expectations of future treatment, care and support, information and communication**

### **Expectations of future treatment**

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (30.30%), have fewer or less intense side effects/more discussion about side effects (27.27%), and involve more clinical trials (including to access new technologies and treatments and funding) (24.24 %). Other themes included future treatment should be easier to administer or able to administer at home or less invasive (18.18%), will include having choice, including availability, accessibility and discussions in relation to treatment options (18.18%), and be more effective or targeted (9.09%).

There were

4 participants (12.12%) that were satisfied with the treatment they received.

### **Expectations of future information**

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will provide more details about disease trajectory and what to expect (24.24%), include the ability to talk to/access to a health professional (12.12 %), provide more details about new treatments or trials (12.12%) and provide more details on subgroups and specific classifications of their condition (12.12%). Other themes included be in a variety of formats (9.09%), and be more accessible/easy to find (9.09%). There were 6 participants (18.18%) that were satisfied with the information they received.

### **Expectations of future healthcare professional communication**

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common response was that they were satisfied with the communication they had with healthcare professionals (45.45%). The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (21.21%), and will include a multidisciplinary and coordinated approach (15.15%). Other themes included that communication will be more empathetic (12.12%), will allow people more time to meet with their clinician (9.09%), and will be more understandable (9.09%).

### **Expectations of future care and support**

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common response was that they were satisfied with the care and support they received (27.27%). The most common expectations for future care and support were that it will include a multidisciplinary and coordinated approach (18.18%), will include more access to support services (15.15 %) and will be more holistic (including emotional health) (15.15%). Other themes included that care and support will include being able to connect with other patients through peer support (support groups, online forums) (12.12%), practical support (home care, transport, financial) (12.12%), and community awareness (9.09%).

### **What participants are grateful for in the health system**

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (36.36%), and low cost or free medical care through the government (33.33%). Other themes included the entire health system (30.30%), and timely access to treatment (9.09%).

### **Symptoms and aspects of quality of life**

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were "The severity of the side effects", and "How safe the medication is and

weighing up the risks and benefits". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

### **Values for decision makers**

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

### **Time taking medication to improve quality of life**

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. Most commonly participants would use a treatment for more than 5 to 10 years for a good quality of life even if it didn't offer a cure (n=12, 38.71%), or for more than 10 years (n=11, 35.48%).

### **Most effective form of medicine**

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants most commonly responded that they did not know (n=17, 36.96%), followed by equally effective (n=15, 32.61%).

There were 9 participants (29.03%) that thought that medicine delivered by all forms were equally effective, 4 participants (12.90%) thought that q cell or immunotherapy that uses the body's own immune defense was most effective, and 3 participants (9.678%) that thought as a stem cell/bone marrow transplant was most effective. There were 11 participants (35.48%) that were not sure.

### **Messages to decision-makers**

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27%). Other themes included that treatments need to be affordable (21.21%), to invest in health professionals to service the patient population (18.18%), to help raise community awareness (12.12%), to improve rural services (12.12%), to have a holistic approach to the condition (including emotional support) (9.09%), and to increase investment (general) (9.09%).

## Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (30.30%), have fewer or less intense side effects/more discussion about side effects (27.27%), and involve more clinical trials (including to access new technologies and treatments and funding) (24.24 %). Other themes included future treatment should be easier to administer or able to administer at home or less invasive (18.18%), will include having choice, including availability, accessibility and discussions in relation to treatment options (18.18%), and be more effective or targeted (9.09%). There were 4 participants (12.12%) that were satisfied with the treatment they received.

### Future treatment will be more affordable

*I think they should look at the cost of things. An example is, I think I was on one medication. I had a prescription and my son went over to the chemist to fill it for me and it had come off the PBS list and it was...the cost was \$4,000, and I'm just wondering how people could afford that cost. I think treatment is what it is, and then every day, it's evolving and they're finding new treatment and things that work better on some people, but it's mainly, I think, people need to afford the cost of things. Participant 002\_2023AUCRT*

*Well, I guess for people who you know for who the cost is a burden, I would like that to be a consideration so everyone would have access to the best treatments that are available.*

*Participant 012\_2023AUCRT*

*Well, I think that anyone who has a a thing like this like like leukemia or diabetes or not those sorts of things. I don't think that you should have to wait till you get to the safety net. I think that you should have that immediately rather than having having to wait. I I don't think that it's fair that some people get their medications for free for \$6 all year round, whereas we have to pay that high amount of money until we get to that that point. So yeah, at the moment, because it's the start of the year between because my husband's got a few things as well, even though a lot of it died down, we're probably still spending 3 or \$400.00 a month on medication. So I think that that's not right. That should be better subsidised. No, that's not. There's not too many other things that that that I would would would probably criticise or change, yeah, no, I think that the treatment that that I've that I've*

*had been good and the support that I've had and that sort of thing so.*

*Participant 006\_2023AUCRT*

*Yeah, making the cost affordable. But lots of new treatments are not apparently, in the Medicare system. My friend had to pay out of pocket for the immunotherapy because they believe that this is not a treatment that works for that sort of cancer that my friend's wife has got. Not recommended by Medicare or during one of these webinars I was listening to a lady who had to pay like 1500 a month for her treatment....So understanding these things and well, when your life is online and you you would sell your house, I don't know, you would forget everything and then try to stick to life of course. But yeah, I think this is something that Medicare needs to find out and understand that people like me and need probably it would be expensive people to keep alive, but that is life. So that's why we have paid and tax for many years. And so it's not, it's not good enough to say that this is this treatment is too expensive or we cannot afford it by the government. It should be brought in if it is a treatment.*

*Participant 017\_2023AUCRT*

### Future treatments will have fewer or less intense side effects/more discussion about side effects

*For example, the way that they're administered or reduction in side effects...yeah, I suppose one of the things I did, I used to try and travel myself to CITY, but it got too much. As in fatigue and concentration. Yes, the cost is the fatigue.*

*Participant 015\_2023AUCRT*

*All of that, like if they come up with a miracle drug that wasn't chemo and it didn't have the side effects and it was cheap, would be great.*

*Participant 011\_2023AUCRT*

### Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

*I think that probably. CAR-T should be offered before your half dead from chemo. I had to fail three courses of chemo to qualify for CAR-T and by the time I got to CAR-T. I was running very low on reserves.*

*Participant 009\_2023AUCRT*

*I'd like to see CAR-T go on the PBS and I'd like to see it more readily available earlier. And I would also like to*

see the, and I'm trying to think of the name of them, the group that recommend and approve new drugs to go on the PBS. Yeah, my my sense is that there's large lobby groups around breast cancer and prostate cancer and all the biggies. But if you cop a rare one, you know there's not a lot of money to be made from a really rare drug that's only gonna be used by a few people. So there isn't that push and that promotion to get stuff on the list.

Participant 022\_2023AUCRT

**Future treatment will be easier to administer and/or able to administer at home and/or less invasive**

*I think the hardest thing to wrap my head around was the length of the treatment protocol. Because it went from February through till November, it was almost a full year. Once you've finished each round of treatment you know that you're getting a bit closer but then you know that you've got to go through it again and feel sick again and everything, so that was a bit of a hard slog. Everything else was incredible, I couldn't have asked for a better outcome. After I finished treatment and obviously I was still in remission, they offered me if I wanted to freeze some of my stem cells, do a stem cell collection, just like a rainy day harvest, I guess. [chuckles]*

*That was incredible. I ummed and aahed, just the thought of laying down for another four or five hours after I'd spent a whole year laying down with needles in my arm, I balked at it a little bit, then I thought, "When else am I going to have this opportunity? It's a good insurance policy, I guess, having healthy stem cells frozen, just in case I ever need them." Yes, that was really wonderful to be able to do that.*

Participant 005\_2023AUCRT

*Yeah, I don't think I would have changed really much in from my situation because I found it was all kind of working quite well. I mean, if you have to have an infusion for a chemotherapy, I don't think there's another way you can actually possibly have it unless I have change where it might be a tablet form or some other form of self medicating perhaps, but I don't. I think the drugs are that sort of, you know, when someone walks in and they're wearing the suit and the*

*mask and things like that and you're not, you're thinking, well, this can't be a good drug.*

Participant 024\_2023AUCRT

*I'd love to be able to do everything at at home. Like I said earlier it'd be lovely to be able to just take a pill each day and and that's it. Not not have to go in for my infusions but I still have to get my blood test. So I don't think there's a way around that unless a nurse turned up and did it here at our place. I don't think I deserve that. So I no, I I'm, I'm sort of losing the plot here. But I I would say no. The way things are are good. If if they can continue with the way things are, I'm very happy with it. It's working well, yeah.*

Participant 018\_2023AUCRT

**Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)**

*I really don't. I can't think of anything. I think it's just information. I really think information is power. Knowledge is power and if there's a new treatment then how do you get knowledge of it and yeah, how do you access it and and more equitable. I'd like to see a much more equitable and inclusive approach to medical treatment that's proactive in those ways rather than accidental. You get it because you asked or you happen to be in the city. I mean, I'm a white privileged woman. Seriously. I'm not representative of the Australian community and I know the privilege I have because of my education, age, experience, all those things.*

Participant 036\_2023AUCRT

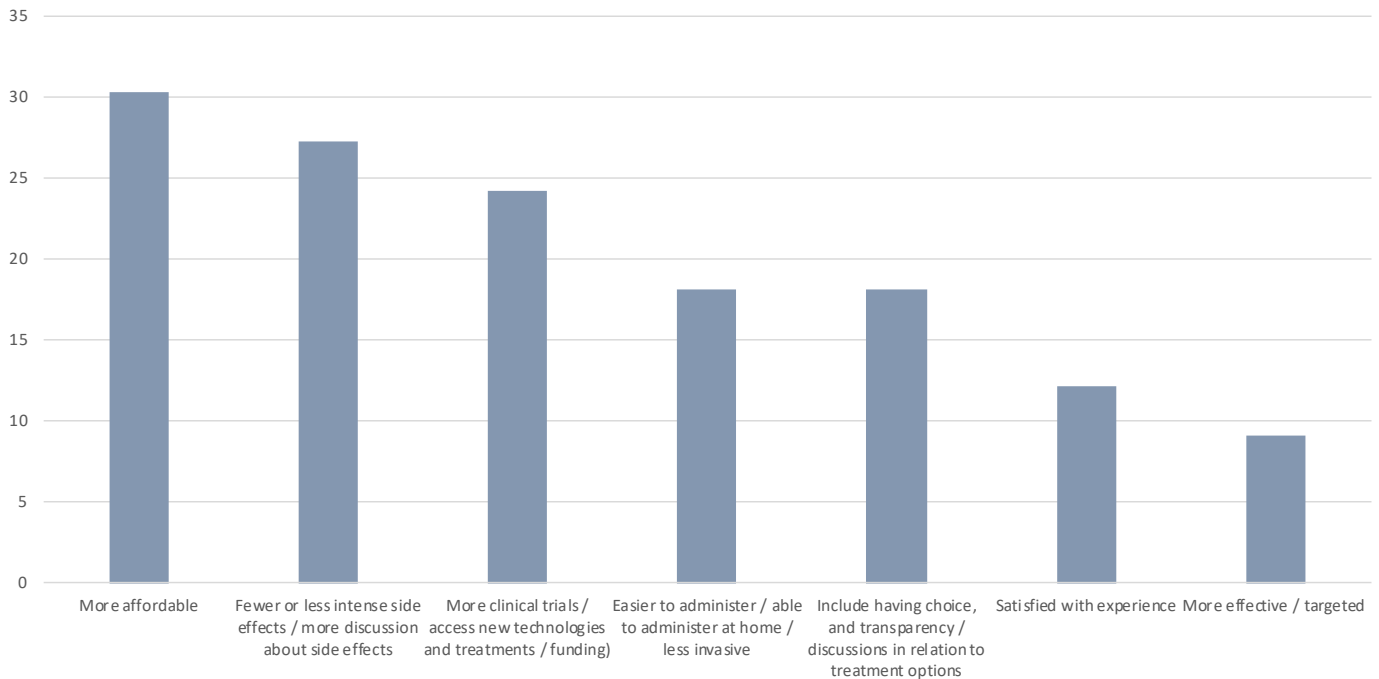
*I don't know that I'm qualified to answer that to be honest. What would be good overall is if the various parties could actually talk to each other and make it easier for people to navigate through the system to have an understanding of what's coming next. Because right through this whole process, I've had to ask, and what happens now? What happens next? Nobody offers that information. Participant 0\_2023AUCRT*

**Table 9.1: Expectations of future treatment**

Expectations of future treatments	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	%
Future treatment will be more affordable	10	30.30	4	57.14	3	30.00	3	18.75	9	34.62	1	14.29	7	46.67	3	16.67
Future treatments will have fewer or less intense side effects/more discussion about side effects	9	27.27	1	14.29	2	20.00	6	37.50	8	30.77	1	14.29	3	20.00	6	33.33
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	8	24.24	0	0.00	5	50.00	3	18.75	5	19.23	3	42.86	4	26.67	4	22.22
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	6	18.18	1	14.29	1	10.00	4	25.00	6	23.08	0	0.00	2	13.33	4	22.22
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	18.18	1	14.29	2	20.00	3	18.75	3	11.54	3	42.86	3	20.00	3	16.67
Participant describes being satisfied with the information they received	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	0	0.00	4	22.22
Future treatment will be more effective and/or targeted (personalised)	3	9.09	0	0.00	0	0.00	3	18.75	2	7.69	1	14.29	0	0.00	3	16.67

Expectations of future treatments	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	%
Future treatment will be more affordable	10	30.30	9	47.37	1	7.14	3	21.43	7	36.84	5	35.71	5	26.32
Future treatments will have fewer or less intense side effects/more discussion about side effects	9	27.27	6	31.58	3	21.43	5	35.71	4	21.05	4	28.57	5	26.32
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	8	24.24	7	36.84	1	7.14	5	35.71	3	15.79	3	21.43	5	26.32
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	6	18.18	3	15.79	3	21.43	2	14.29	4	21.05	2	14.29	4	21.05
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	18.18	2	10.53	4	28.57	2	14.29	4	21.05	1	7.14	5	26.32
Participant describes being satisfied with the information they received	4	12.12	1	5.26	3	21.43	2	14.29	2	10.53	2	14.29	2	10.53
Future treatment will be more effective and/or targeted (personalised)	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79



**Figure 9.1: Expectations of future treatment**

**Table 9.2: Expectations of future treatment – subgroup variations**

Expectations of future treatments	Reported less frequently		Reported more frequently	
	Subgroup	Percentage	Subgroup	Percentage
Future treatment will be more affordable	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older	18.18%	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64	30.30%
Future treatments will have fewer or less intense side effects/more discussion about side effects	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	27.27%	Multiple Myeloma	27.27%
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older	24.24%	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote	24.24%
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	CAR T-Cell therapy	18.18%	-	0%
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Mid to low status	18.18%	CAR T-Cell therapy Aged 65 or older	18.18%
Participant describes being satisfied with the information they received	Female	12.12%	Male	12.12%



## Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will provide more details about disease trajectory and what to expect (24.24%), include the ability to talk to/access to a health professional (12.12%), provide more details about new treatments or trials (12.12%) and provide more details on subgroups and specific classifications of their condition (12.12%). Other themes included be in a variety of formats (9.09%), and be more accessible/easy to find (9.09%). There were 6 participants (18.18%) that were satisfied with the information they received.

### Future information will provide more details about disease trajectory and what to expect

*I didn't have a problem with that at all from office because I presume I went looking for it. So maybe a booklet of some sort saying these are some of the complications. That might be associated with having chemotherapy to inform, although it's not just one thing.*

*Participant 024\_2023AUCRT*

*The emotional after-effects once you've been through the treatment, that I think is the most important, because I thought I'd just bounce back. I thought, "Great, I'm finished, get on with my life and I'll bounce back," but I didn't. I did and I didn't. I was always up and down. I wasn't prepared for that. I think it's like a shock, you go into a bit of a shock afterwards. You deal with it at the time, and then you go into shock later.*

*Participant 004\_2023AUCRT*

*PARTICIPANT: Yeah, more information about side effects. So side effects often kind of just get listed off. You might experience these, but what do they actually look like in your day-to-day life?*

*INTERVIEWER: Yeah, yeah, that practical.*

*PARTICIPANT: The stuff about the stuff around my libido like that and that can be quite. I would never talk to some people about that. I'm happy talking to the bone marrow transplant specialist about it. But those kinds of things can be quite difficult for people to talk about and then they don't get talked about and then it becomes something that just impacts you. But if you've got some stuff about what they look like, that would be great. What does it look like to live with*

*graft versus host disease? And you got what does it look like to go through hypercevad chemotherapy? It's a really commonly used one. What might that look like? Especially for your carer as well and your kids, so that they know what's coming?*

*Participant 016\_2023AUCRT*

### Participant describes being satisfied with the information they received

*No. I think everything was presented really well. None of these guys verbally explain things. They gave you a lot of paperwork and a proper folder that you could refer back to all the time. Your medication list, they updated that all the time. I think the information was pretty good. As I said, if you weren't sure, you could always ask someone. They'd always find out for you.*

*Participant 002\_2023AUCRT*

*No, no, I I think it's OK in terms of the information that's available it it's hard to cover without. Sort of becoming too overwhelming. I think they got the the balance right between being positive and being honest. Yeah, I think that was actually well done by both the the medical side and the things like the Leukemia Foundation.*

*Participant 009\_2023AUCRT*

*No. I think with certainly with multiple myeloma that the and I can only speak through Myeloma Australia here that the the, the, the the information is is very, very clear very very well put together there seems to be very accurate and and up to date and they they have quite 3 multiple alignment. They have regular online seminars with groups getting together online with talks and that sort of thing too. So no, I think I think the level of information that's given out in our particular cases is very good.*

*Participant 023\_2023AUCRT*

### Future information will include the ability to talk to/access to a health professional

*I don't really like watching seminars and and listen to video. Yeah like and they do have those things with the leukemia Foundation. You wanna join us for a you know we've got an online meeting. It doesn't interest me. I'm a sort of a one-on-one. Sit down and have a chat to somebody, but I've never had that from the Leukemia Foundation. The only thing that they offer is those online.*

*Participant 031\_2023AUCRT*

### **Future information will provide more details about new treatments and/or trials**

*I think they haven't told me anything about the other options of treatment so far, so I am still at the early stages of the treatment. It's only two years for me. But yeah, I would like to hear about the things that are available or the new medications that are coming into the market. If I receive something like an e-mail every month or every, I don't know a couple of months, six months about the new medications, the new options, getting more into details with CAR T cells with immunotherapy, I don't know that much about immunotherapy or the other treatments that are coming to the market. So this would be nice to receive them as. Yeah, to be notified, yeah, yeah.*  
Participant 017\_2023AUCRT

*Well, I think new treatments people people should know about new treatments and should know about clinical trials. And probably the best way for this to be done would be via the the treating clinician, but that certainly wasn't how my mine worked. I had to find out about new treatments, really the breadth of new treatments available. Not that I had to access access in the oven, but I found that out by myself.*  
Participant 014\_2023AUCRT

### **Future information will provide more details on subgroups and specific classifications of their condition**

*I think a lot more information. I guess it's hard for any doctors or nursing people to know every possible thing, but even the information that I was given at the hospital, a lot of it was other leukaemia, which, that's what DOCTOR was saying, they're totally opposite with outcomes and what you have to get done and all the rest of it. I would probably say more information on my condition. Leukemia in general with adults, and maybe exploring the word haematology, can be linked with cancer. That was me. Oncology, I just put with cancer. I never put hematology with cancer.*  
Participant 001\_2023AUCRT

*Not necessarily. There wasn't that much information just because not many people are diagnosed with this so there's not that much information out there as some of your other leukemia, like Hodgkin's lymphoma or AML. Yes, different, types of blood cancer like that. For it being quite rare, I think there is enough information if you go looking.* Participant 005\_2023AUCRT

### **Future information will be in a variety of formats**

*Yeah, I think it needs to be in multiple formats. I mean, I really like digital, obviously, but not everyone does and many and people need to be able to refer back. So paper form is critical, is important, and you know a booklet that is easy to read with further reading options. Because I think that that's often missing. You know, you can find out more about this or find out more about revaccination, where to go to the Australian government website for revaccination. It's fantastic.*  
Participant 036\_2023AUCRT

### **Future information will be more accessible/easy to find**

*I think that what they could have done more is giving out information was I didn't find out until afterwards, but there's a lot of the hospital has a lot of online stuff as well as the brochure. So it would have been more useful if right from the start they could have said, and I mean I probably should have looked at it, but go to go to the HOSPITAL to the website and then you'll be able to get more information about your treatments and your what's going on with you and what happens at hospital and that sort of thing. So yeah, if there was more available that that that way that would or if if I was made more aware of that.*  
Participant 006\_2023AUCRT

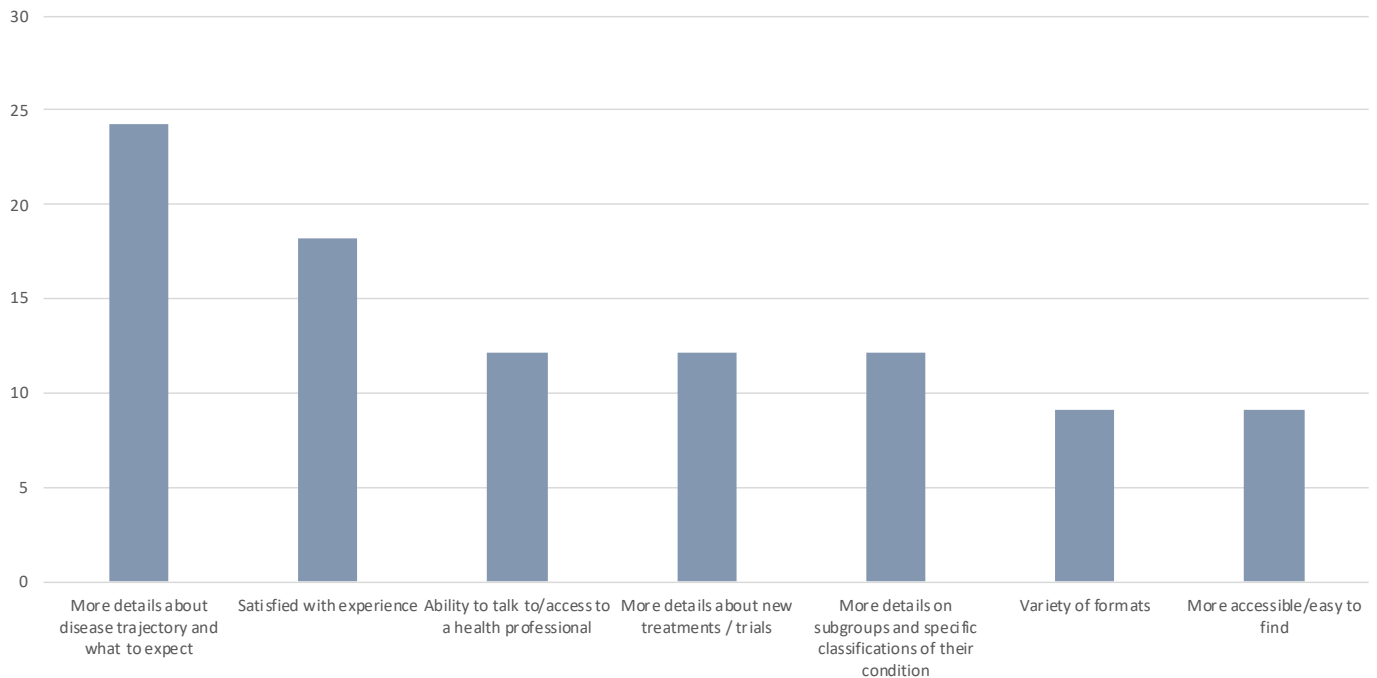


**Table 9.3: Expectations of future information**

Expectations of future information	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	%
Future information will provide more details about disease trajectory and what to expect	8	24.24	3	42.86	4	40.00	1	6.25	6	23.08	2	28.57	4	26.67	4	22.22
Participant describes being satisfied with the information they received	6	18.18	1	14.29	2	20.00	3	18.75	4	15.38	2	28.57	3	20.00	3	16.67
Future information will include the ability to talk to/access to a health professional	4	12.12	1	14.29	0	0.00	3	18.75	4	15.38	0	0.00	2	13.33	2	11.11
Future information will provide more details about new treatments and/or trials	4	12.12	0	0.00	0	0.00	4	25.00	3	11.54	1	14.29	0	0.00	4	22.22
Future information will provide more details on subgroups and specific classifications of their condition	4	12.12	2	28.57	2	20.00	0	0.00	4	15.38	0	0.00	3	20.00	1	5.56
Future information will be in a variety of formats	3	9.09	0	0.00	2	20.00	1	6.25	1	3.85	2	28.57	3	20.00	0	0.00
Future information will be more accessible/easy to find	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	3	20.00	0	0.00

Expectations of future information	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	%
Future information will provide more details about disease trajectory and what to expect	8	24.24	7	36.84	1	7.14	4	28.57	4	21.05	5	35.71	3	15.79
Participant describes being satisfied with the information they received	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	2	14.29	4	21.05
Future information will include the ability to talk to/access to a health professional	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
Future information will provide more details about new treatments and/or trials	4	12.12	1	5.26	3	21.43	2	14.29	2	10.53	1	7.14	3	15.79
Future information will provide more details on subgroups and specific classifications of their condition	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	4	28.57	0	0.00
Future information will be in a variety of formats	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	2	14.29	1	5.26
Future information will be more accessible/easy to find	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79



**Figure 9.2: Expectations of future information**

**Table 9.4: Expectations of future information – subgroup variations**

Expectations of future information	Reported less frequently	Reported more frequently
Future information will provide more details about disease trajectory and what to expect	Multiple Myeloma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Aged 25 to 64 Mid to low status CAR T-Cell therapy
Participant describes being satisfied with the information they received	-	-
Future information will include the ability to talk to/access to a health professional	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	-
Future information will provide more details about new treatments and/or trials	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Female	Multiple Myeloma Male
Future information will provide more details on subgroups and specific classifications of their condition	Multiple Myeloma CAR T-Cell therapy Higher status	B-cell acute lymphoblastic leukaemia (ALL) Mid to low status
Future information will be in a variety of formats	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Future information will be more accessible/easy to find	-	Female

## Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common response was that they were satisfied with the communication they had with healthcare professionals (45.45%). The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (21.21%), and will include a multidisciplinary and coordinated approach (15.15%). Other themes included that communication will be more empathetic (12.12%), will allow people more time to meet with their clinician (9.09%), and will be more understandable (9.09%).

### Participant describes being satisfied with communication

*No. I think from my experience, they've all been wonderful.*

*Participant 002\_2023AUCRT*

*No, not necessarily. The experience that I had was pretty positive with the communication. They were always quite open and answered the questions the best that they could.*

*Participant 005\_2023AUCRT*

*No, not really. I mean in general they've been, they've been very good and I haven't, I haven't had any any issues or anything that no that I would say that they would need to change so. No, no. That's all being good.*

*Participant 006\_2023AUCRT*

*No, not really. I think it just depends on the on the on the personal qualities of the doctor or the nurse or or whoever is treating you at the time. Because they're all human as well and if they had an argument before coming to work, they might not be in the best frame mindset or things like that. So I don't think I'll change anything.*

*Participant 024\_2023AUCRT*

### Future communication will be more transparent and forthcoming

*Yeah. Well, that that, that'll be it I think to to you know to to give information about the latest developments in the in the disease.*

*Participant 014\_2023AUCRT*

*Yeah, I think people, you know, for people's well-being mentally and physically, they need to be kept informed. Like a lot of people on people in the public system sort of get less, you know, get less sort of hanging out there to with no information, even though they've had a blood test or a scan. Or they might, they might have to wait three months for the results. Or they should be able to just get an e-mail or something or a quick Tele call to say stop worrying, everything is good. Or if there is a problem they should, they should should be acted on immediately. Like the three months can be a long time in and you can deteriorate a lot with myeloma in three months. If you're not, you know, say for example you were just picked up and you had no damage in three months time. Your level could be you know, from you know go from 20 to 100 and your bones are being affected before you even see the specialist again or the hematologist. That I was lucky because mine was always monthly. Initially when I was on smoldering it was six months here, but then when I got the symptoms, as I said previously, it was acted on straight away it. Wasn't just and my hematologist said if I would have left it for another three months for the next scheduled checkup, it would have been much worse. So that's the way I sort of. That's why I see people should be given more information quicker. Yeah, and the site mean people. It's the psychological, so not knowing it's terrible like.*

*Participant 032\_2023AUCRT*

### Future communication will include a multidisciplinary and coordinated approach

*The only thing I would like from the the medical system is is is basically to. And I don't know this is probably unrealistic, but I think the fact that where you're managing sort of three or four different sets of appointments in a week, that somehow your patient number ought to be, they should be able, for example, to print out all your appointments for that week that can be booked. Should you should be giving them once a week? Yeah. Because managing your equipments when various pieces of the system don't talk to each other like chemo and nuclear medicine. And I, I don't know that that all becomes a bit much. So yeah. Yeah, honestly, you it it was basically a lot of any energy that you had left went into managing those kind of things and that drove me mad. I thought it's got to be easier than this, even though I know medical systems*

*have to cope with the unexpected. That was that was a major source of stress for me.*

*Participant 009\_2023AUCRT*

*I mean public health system, operating in silos, that makes sense...Connection, connection between those silos is very limited in many ways. So the left hand doesn't talk to the right hand, you know. So OK, good example, I'm in hospital with massive back pain and I have to have an appointment with the oncology center in the exact same hospital.*

*Participant 027\_2023AUCRT*

#### **Future communication will be more empathetic**

*Yeah, my couple of my doctors are good, but I had some other ones there that need to learn how to talk to patients.*

*Participant 011\_2023AUCRT*

*Clear and balanced is probably all I really asked for is I like clear information. What, you know, when you say this, what does that actually mean? And yes, you don't have to pay rises and tell me I'm going to live to 150 and you know, yeah, this is all great. This is all going to be wonderful. You don't have to that. But you don't also have to be the other way and say, look, you have cancer, you're going to die sort of stuff. So try and try and realize there is a scared human being on the other end of the conversation and that scared human being just wants to know what's going on. It's no different from a, you know, a 5 year old kid first day of kindy sort of like what the hell is this? So it's the same thing we just to be older and a bit wiser and a bit grumpier. We just really wanna know what the hell's going on and what's the future is where we go from.*

*Participant 019\_2023AUCRT*

#### **Future communication will allow people more time to meet with their clinician**

*I probably needed to ask more questions in my follow-up visits. I always felt a bit guilty taking up too much time when I go in for my appointments because I know I'm just having a check-up and I know there's a lot of people who are in the middle of treatment and I feel like I shouldn't take up the doctor's time so that they have more time with him. I feel like I needed to talk about things a bit more with my hematologist, NAME, when I had some things. I'd sort of touched on them lightly, but I probably needed to talk more. That's something I needed to do, and I'm sure they would have been great. Participant 004\_2023AUCRT*

*Bit more time. I think this the hardest thing for health clinicians is the 10 minute appointment. You know when they look relaxed because you're there, you feel more inclined to ask the had a question and might have the appointment, but the 10 or 15 minute appointment is rushed for them. I don't know how they manage it. Getting the information systems to talk to each other between the health providers is still got a long way to go. It's there, it exists, and I'm on a committee that's looking at that at HOSPITAL. But getting them to actually talk HOSPITAL to talk to the GP, to talk to the cardiologist to talk to the dermatologist, you know, having all that stuff available now, I've set myself up so I fewer clinics involved. So you've got some hope, but it doesn't work. And my health record is a joke, you know? Does for. Some things are there. Some things aren't and. Hospital, some doctors included. Other doctors don't. It's fine. I end up entering stuff in there. So I've at least got that on the record. But I keep it all myself. I have my record.*

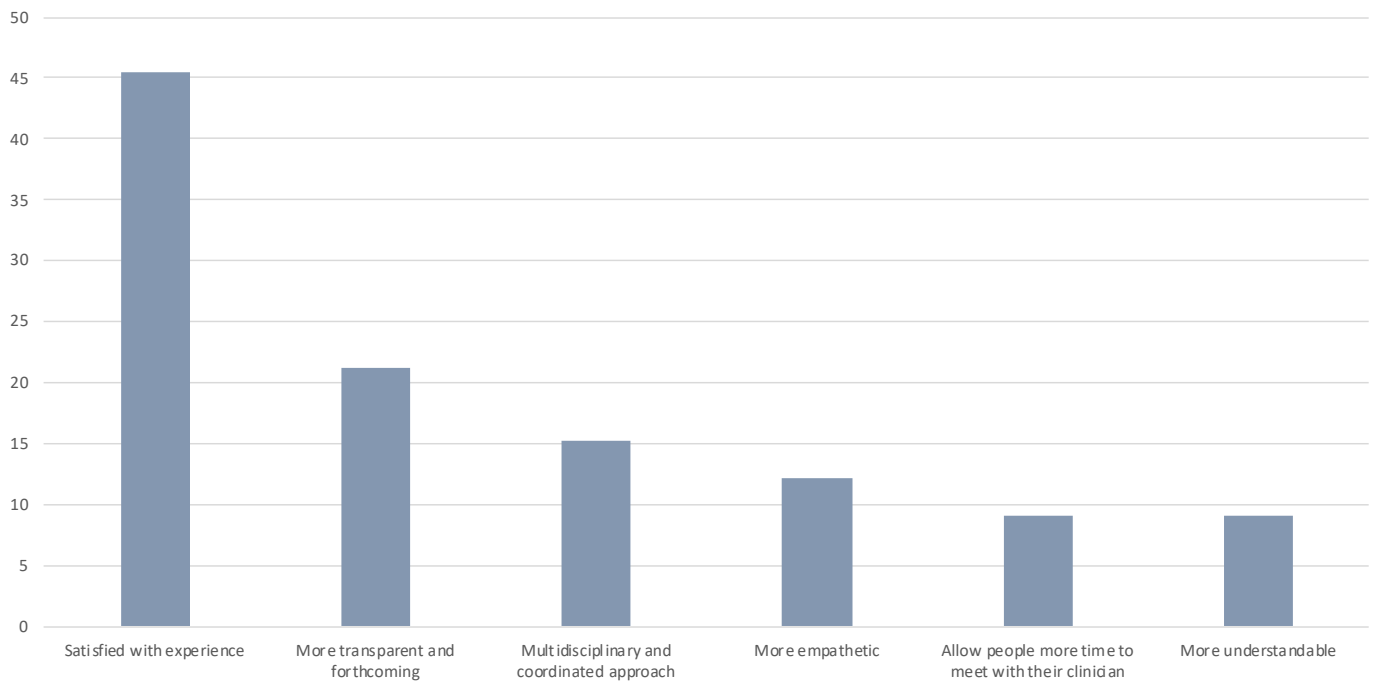
*Participant 036\_2023AUCRT*

**Table 9.5: Expectations of future healthcare professional communication**

Expectations of future communication	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 satisfied with communication	15	45.45	4	57.14	2	20.00	9	56.25	13	50.00	2	28.57	6	40.00	9	50.00
Future communication will be more transparent and forthcoming	7	21.21	1	14.29	1	10.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Future communication will include a multidisciplinary and coordinated approach	5	15.15	0	0.00	3	30.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Future communication will be more empathetic	4	12.12	0	0.00	2	20.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11
Future communication will allow people more time to meet with their clinician	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Future communication will be more understandable	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56

Expectations of future communication	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 satisfied with communication	15	45.45	9	47.37	6	42.86	6	42.86	9	47.37	6	42.86	9	47.37
Future communication will be more transparent and forthcoming	7	21.21	2	10.53	5	35.71	2	14.29	5	26.32	2	14.29	5	26.32
Future communication will include a multidisciplinary and coordinated approach	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	3	21.43	2	10.53
Future communication will be more empathetic	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	3	21.43	1	5.26
Future communication will allow people more time to meet with their clinician	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79
Future communication will be more understandable	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53



**Figure 9.3: Expectations of future healthcare professional communication**

**Table 9.6: Expectations of future healthcare professional communication – subgroup variations**

Expectations of future communication	Reported less frequently	Reported more frequently
Participant describes being satisfied with communication	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL) Multiple Myeloma
Future communication will be more transparent and forthcoming	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Future communication will include a multidisciplinary and coordinated approach	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Future communication will be more empathetic	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
Future communication will allow people more time to meet with their clinician	-	Diffuse Large B-Cell Lymphoma
Future communication will be more understandable	-	B-cell acute lymphoblastic leukaemia (ALL)

## Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common response was that they were satisfied with the care and support they received (27.27%). The most common expectations for future care and support were that it will include a multidisciplinary and coordinated approach (18.18%), will include more access to support services (15.15 %) and will be more holistic (including emotional health) (15.15%). Other themes included that care and support will include being able to connect with other patients through peer support (support groups, online forums) (12.12%), practical support (home care, transport, financial) (12.12%), and community awareness (9.09%).

### Participant describes being satisfied with the care and support they received

*I can't really think of anything. I mean, that probably would be, but there's nothing that sort of jumps out at me, no*

*Participant 006\_2023AUCRT*

*Can't think of anything. The transport service was great when we needed it. Remember the leukemia? Fantastic. Oh yeah, yeah, to and from hospital that was excellent. But that's all we needed.*

*Participant 013\_2023AUCRT*

### Future care and support will include a multidisciplinary and coordinated approach

*No, as aside from that coordination part of it. When you're in the the public system, I honestly think that if that could be somehow more streamlined that would that would have made the most difference to me.*

*Participant 009\_2023AUCRT*

*Yeah, more exercise physiology. The exercise physiologist was amazing at just getting me started when my balance was so shit and everything was really hard. I just yeah, I think that's probably the biggest one the the exercise Physiology and the and the allied health stuff to the physio that just that physical movement and again I'd say actually the the into the cognitive stuff. It's that kind of thing about oh you get cognitive deficit it it's temporary it's highly distressing especially for someone like me and and scary. So it'd be really great to have some things in*

*place that are less or they're just side effects put up with them. I would like to be proactive about those things to make them last less long.*

*Participant 016\_2023AUCRT*

*Yeah, probably access to exercise physiology for people in the public system. And also I've just done the practice where I am, has just done a pilot art therapy for six weeks, and that was, it wasn't just art therapy, it was there's there's different psychological exercises that you can do with with the art or with and they get a bit of poetry and there's quite a few I guess techniques that you can use to self improve self help. You know that can be that could be a big assistance and as I said exercise physiology is being recognized as it helps your helps the drugs sort of you know circulated because you're active and gives you more, gives you a positive, more of a positive angle on on the treatment because you're feeling better.*

*Participant 032\_2023AUCRT*

### Future care and support will include more access to support services

*So it might be through charities of the hospital system or like, I think when we first had that and the Leukemia Foundation, it was a lot of humming and haaring to see if we were eligible or not. And it turned out we were. But yeah, people need that reassurance that there's someone there to look up like to help you out where you're not just well with us. We just weren't left on our way. Like the Leukemia Foundation. They're just marvelous.*

*Participant 011\_2023AUCRT*

*The Leukemia Foundation was generous enough to offer my wife an apartment while I was in the HOSPITAL in CITY for two weeks and then one week for the expensive total 3 weeks. We were living in an apartment. I was in the hospital, She was living in an apartment nearby, so that was very generous, which was very helpful. And they offered some tax taxi vouchers and something like that, that we didn't didn't pick because she was just getting on the bus, 5 minutes later she was at the hospital. So we didn't want to bother about the other things. But I think, yeah, those kind of financial support for traveling for people who are living in more rural areas than us of course and would be critical. And I I came across this ad on the TV a few months ago and Medicare was telling that we have reduced all the prices of all the*



medication is below \$30.00 and don't postpone your treatment because of the expenses. So I then I realized that there are people who cannot afford even \$30,000 and they are postponing the treatment and that is that is unfair. Again, I think so, yeah. Considering these sort of patients, I think it would be good. I don't need too much support apart from very expensive treatments like \$150,000 or whatever that would be out of my imagination to pay for. But for a daily medication or my daily life, I'm still, thanks God, I'm still not in the situation that I need charity or yeah, financial.

Participant 017\_2023AUCRT

#### **Future care and support will be more holistic (including emotional health)**

I think there needs to be psychological help, definitely. The Leukemia Society came in for me, and they did offer me some help, but when I actually reached out to them it wasn't there. I think maybe they went off their feet or whatever. That's how we reason for it. I think it should be part of it. It's quite a hard thing to go through. I think you need to be treated as a whole person rather than just a body. A body that's sick.

Participant 003\_2023AUCRT

Yes, I think that's it mainly because all the other support's been there, but I think emotional support was lacking for me. It could have been there, but I wasn't-- I think it's something that they need to rather than say, "We're here if you need us," I think they need to say, "This is what you might feel." It could be in a pamphlet or-- and basic care for it to take longer than you think it's going to be, all of this like there's a clinical side which I think-- Of course, as my hematologist says, everyone reacts so differently.

At the time I went through it really well, but then I've had these lingering things which aren't serious, but they do interfere with my life, with me trying to get back on top, with me trying to earn a living because I'm self-employed, all those sorts of things. I think that there needs to be something about the after-effects. There's probably a bit of post-traumatic stress I imagine that most people go through from when I've spoken to all the other people online who have experienced similar. Someone will ask a question say, "Did you feel stress," or, "Did you have this," or, "Do you think you might have had this?" I think everyone is a bit frightened to talk about it, but it's something that needs to be talked about. I think also the primary care is too-- I had little burns in my arm, and he looked at me and he went, "Oh, you weren't worried?" I'm going, "No, it's fine. Look at my blood tests, they're all

fine." That's something I do if I'm in-between visits, if I'm not feeling 100%, that goes on for a little while, a couple of weeks, I'll just go and have a blood test, pick up the results, know everything is all right, so I find that quite reassuring to me and my husband.

Participant 004\_2023AUCRT

The support person seems to be the the biggest thing. It's like say we're we're tell someone they got cancer. It's pretty scary and the first thing is oh God, I'm going to die. Which to actually face mortality the first time is a bit like confronting and it changes a lot of perspectives in your life and you don't realize it. Well, from my point of view, like I was 46 or something at the time and yeah, bulletproof like I was just gonna conquer the world sort of thing. Then you actually have shoved in your face and say well in two months time you're potentially gonna not gonna be here. What's important to you now. So it's very, very scary.

Participant 019\_2023AUCRT

I think it's just that that after support if anything can you know probably the counseling support sort of things just depend on where people were on their journey with any form of catch. I think there's there's a big big need for for that. But probably, you know, just having access to it all all being sort of more front of mind because it said you you you're worried about the. The actual treatment itself, but obviously the psychological impacts of it, The aftermath is probably something that can get underestimated, I reckon.

Participant 026\_2023AUCRT

#### **Future care and support will include being able to connect with other patients through peer support (support groups, online forums)**

I don't know whether there's a thing even for children to go to with other children that have had parents affected. With my girls, it would have been nice for children to talk to other children in that same situation. My girls were very frightened in the beginning, but then in saying that, they actually got a lot of comfort from some of the nurses. After being there a month, and they'd come up every day. They explained it very basic in the beginning, and then they really got in depth to it, the nurses and my children. Maybe some way that the kids could probably go and talk to. For me, again, living on the border, the Leukemia Foundation did send me dates of catch up with other people with Leukemia in the area, but they're up the coast, not in STATE 1 where I'm living.



*The STATE 1 one are in CITY, but not where I am. I'm only minutes from the STATE 2 boarder.  
Participant 001\_2023AUCRT*

*Well, there was a support group here many years ago, which I did at hand, but I was possibly, well, 20 years younger than everybody else there. So it was I suppose a bit of A and you know that everybody was pretty well supported. But yeah, I didn't quite fit into any of that kind of area. And I think for younger people it's it's a lot harder. Not that I'm young now, but at the time I was a lot younger than most people. You could suffer from multiple myeloma, so yeah, but I'm not aware of any support group around this area anymore, so I'm not sure.  
Participant 015\_2023AUCRT*

*Well, I think with the Leukemia Foundation, I think if they could have the opportunity to have some discussions one-on-one or even a group, a group discussion, but in person not on, not a webinar.  
Participant 031\_2023AUCRT*

**Future care and support will include practical support (home care, transport, financial)**

*I would have loved help with transport so I wasn't so reliant on family all the time. When the Leukemia Foundation did contact me the one time, they said that nobody could help me because the person who looks after my area was on maternity leave and she had been replaced. Then COVID hit and so they*

*couldn't transport patients, but that would be what I would have really benefited from.  
Participant 002\_2023AUCRT*

*Absolutely. Financially is massive. Yeah. Charities, I don't know, just, yeah, can't survive without money. So we got through, but yeah. That was hard.  
Participant 037\_2023AUCRT*

**Future care and support will include community awareness**

*For more information on media. That would be really good. Because it's suddenly people were starting to talk about it and they didn't hadn't heard about it before.  
Participant 020\_2023AUCRT*

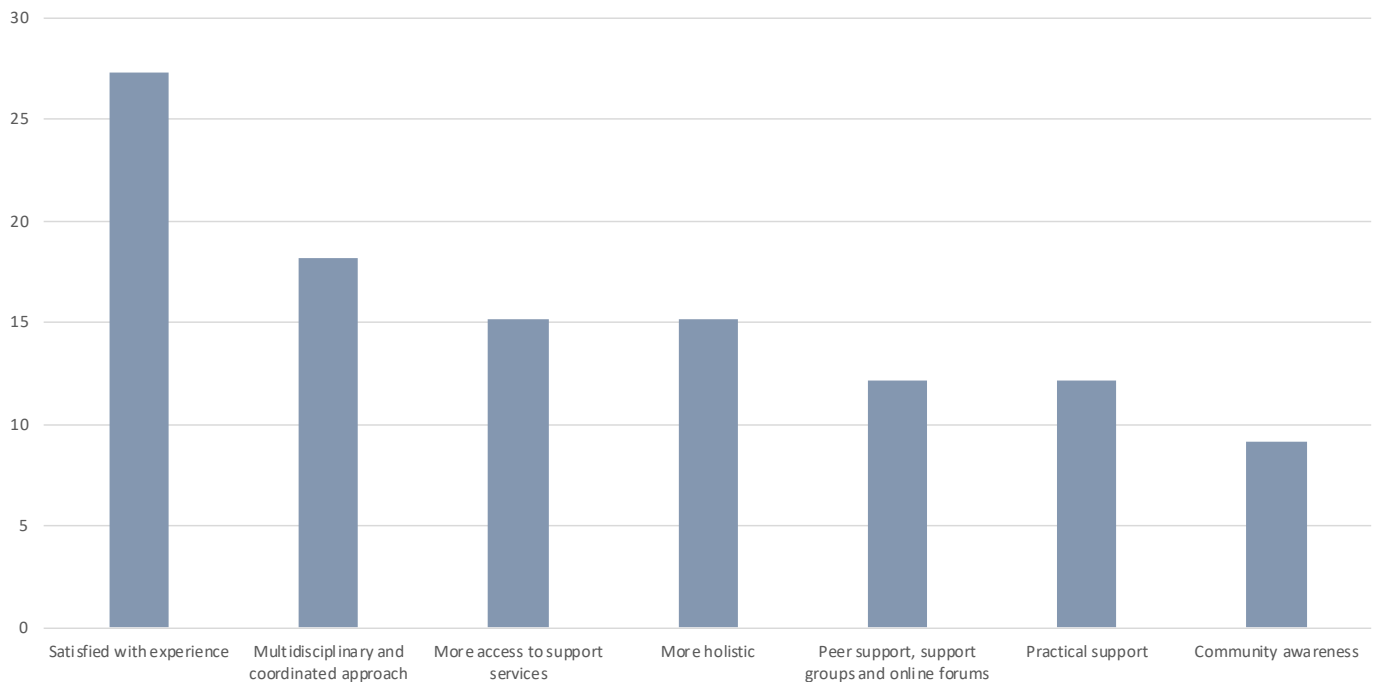
*Actually, Well, yeah, everyone I know has done the great shave and we've donated that way. I don't know. Sometimes I think about donating blood needs a bigger campaign because I certainly I went through my fair share of infusions and I don't think people realize the value and how easy it is. So I think, I think that that side could be pushed more and you know, especially when it's so easy for so many to give as far as yeah, leukemia seems. See, I don't know, like in CITY, they're quite well resourced, so it seems to me, well, they have a like, well, they have a lot of services anyway, so I'm not sure if they if they're finding their present fundraising significant. Seems like it might be enough at the moment, but I'm not sure.  
Participant 021\_2023AUCRT*

**Table 9.7: Expectations of future care and support**

Expectations of future care and support	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 satisfied with the care and support they received	9	27.27	3	42.86	2	20.00	4	25.00	6	23.08	3	42.86	4	26.67	5	27.78
Future care and support will include a multidisciplinary and coordinated approach	6	18.18	1	14.29	1	10.00	4	25.00	5	19.23	1	14.29	3	20.00	3	16.67
Future care and support will include more access to support services	5	15.15	0	0.00	1	10.00	4	25.00	5	19.23	0	0.00	1	6.67	4	22.22
Future care and support will be more holistic (including emotional health)	5	15.15	1	14.29	2	20.00	2	12.50	5	19.23	0	0.00	3	20.00	2	11.11
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	12.12	1	14.29	1	10.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11
Future care and support will include practical support (home care, transport, financial)	4	12.12	1	14.29	2	20.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Future care and support will include community awareness	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56

Expectations of future care and support	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 satisfied with the care and support they received	9	27.27	4	21.05	5	35.71	3	21.43	6	31.58	2	14.29	7	36.84
Future care and support will include a multidisciplinary and coordinated approach	6	18.18	3	15.79	3	21.43	2	14.29	4	21.05	2	14.29	4	21.05
Future care and support will include more access to support services	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	4	28.57	1	5.26
Future care and support will be more holistic (including emotional health)	5	15.15	3	15.79	2	14.29	2	14.29	3	15.79	3	21.43	2	10.53
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Future care and support will include practical support (home care, transport, financial)	4	12.12	4	21.05	0	0.00	3	21.43	1	5.26	3	21.43	1	5.26
Future care and support will include community awareness	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26



**Figure 9.4: Expectations of future care and support**

**Table 9.8: Expectations of future care and support – subgroup variations**

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant describes being satisfied with the care and support they received	Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy
Future care and support will include more access to support services	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	Mid to low status
Future care and support will be more holistic (including emotional health)	CAR T-Cell therapy	-
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	CAR T-Cell therapy	-
Future care and support will include practical support (home care, transport, financial)	CAR T-Cell therapy Aged 65 or older	-

### What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (36.36%), and low cost or free medical care through the government (33.33%). Other themes included the entire health system (30.30%), and timely access to treatment (9.09%).

#### Participant describes being grateful for healthcare staff (including access to specialists)

*I was really really really grateful for the care I received. It was outstanding, amazing staff, just such beautiful people. I'm really really grateful.*

**INTERVIEWER:** Yes. I'm glad that you had, despite what you went through, a good experience with that.

**PARTICIPANT:** Yes. They all deserve gold medals. The incredible patience that those nurses have is just amazing.

*Participant 003\_2023AUCRT*

*The people are amazing, from the cleaners and the ward staff, right through to specialists and nurses and doctors. I feel so safe and cared about and respected, you know, And grateful. Yeah, I've had. Yeah, I can't say that enough.*

*Participant 016\_2023AUCRT*

*I'm grateful for every bit of service that I get from the, from the people at HOSPITAL and their their associates who've been looking after me. And then I must under what I'm allowed to say this. But I reward them every, every every time I go there. Every month I take packets of biscuits, chocolates, bottles of wine at Christmas time. Every time I go there for the last eight years, I've rewarded everyone who looks after me. It'll be little little tokens. So I just it's an appreciation of me giving back, you know, I can afford that and I think they're very happy with it. I'll turn them all into diabetics.*

*Participant 018\_2023AUCRT*

**Participant describes being grateful for low cost/free medical care through the government (Public health system in general)**

*The financial side of the treatment, cost of the treatment, not costing anything, that's been amazing. Also, it was very accessible, everyone there is so accessible. I can still ring the center if I've got a problem or I'm worried about something and they'll pass the message on or whatever. The ongoing care is really good that way, clinical care.*

*Participant 004\_2023AUCRT*

*Well, I think I hinted at this before. I think the Medicare system is, although it's, you know, it's it's the cracks of widening in it now it really has been a marvelous thing for me. It, you know, I was able to get the treatment that I needed without having to worry about what it was costing, without it sort of, you know, affecting other aspects of my life any more than, you know, being unhealthy.*

*Participant 014\_2023AUCRT*

*I think just not outlaying any costs, I don't know if that was just all covered by my private health or if the public system was just that good that there was no outlay that was required but for the incredible treatment that I received, for not having to pay anything really is just out of this world. Also the Leukaemia Foundation, I think they do get a little bit of government support but the majority is fundraising and donations and the facilities there are just incredible. I think, yes, the public system and the Leukaemia Foundation just, yes, definitely, helped out immensely.*

**Participant describes being grateful for the entire health system**

*Yeah, I think it's excellent healthcare system. I've been treated very well. I can't complain at all.*

*Participant 015\_2023AUCRT*

*I think despite all the knockers, Australia has probably 1 or if not one of the best health systems in the world and it's not all American, which is just private only. But it's not all Scandinavian, which is just all state. We have a like education. We have a mix of public and private and it seems to serve us well. I think we've got*

*a pretty good system and I don't mind paying the Medicare levy all for private health insurance. So I do get annoyed when you get really sick. You can't use it for all that money you put. Yeah.*

*Participant 022\_2023AUCRT*

*Like we had a system like America's. There's no way known I could have. Yeah, I think we got pretty lucky with our health system. Medicare. It's, yeah, unreal.*

*Participant 037\_2023AUCRT*

**Participant describes being grateful for timely access to treatment**

*I think the speed at which it is all being dealt with has been something I've been grateful for, like I haven't had to wait a long time for things when I need a test. They've been organized quickly and I've been able to, you know, do everything quickly and get all the treatment moving quickly. That's good. You know you'll hear horror stories of people having to. Wait a year to see somebody, but I haven't had any of that. So I've been very grateful. And I think our health system, you know, obviously it's got its downsized and people who live remotely don't have good access and all that, but I think we are very lucky really.*

*Participant 012\_2023AUCRT*

*Yeah, When I think the the overall care was pretty good, like I've done both. I've done the public and the private, like private. We went private the first time and it was public the second time because I flew there. Probably we went public the first time. I wouldn't be here because the private sector, everything happened so quickly with all the tests and everything and if I would have been having to wait like a day for another test before they acted and all that, I wouldn't be here. Like it's something that I didn't know what happened to me and I certainly didn't write it on my bucket list. And I I just listened to the doctors and what I read and thought, you know what chance it, you know, if I don't have the treatment, what's going to happen? But I think the biggest thing like that is it's frustrating when you go because it is a public system and you're going to wait so long to see the doctor. And yeah, it's private sectors better. Like you have your appointment, you go there, you basically get straight in and there's a lot of waiting and yeah.*

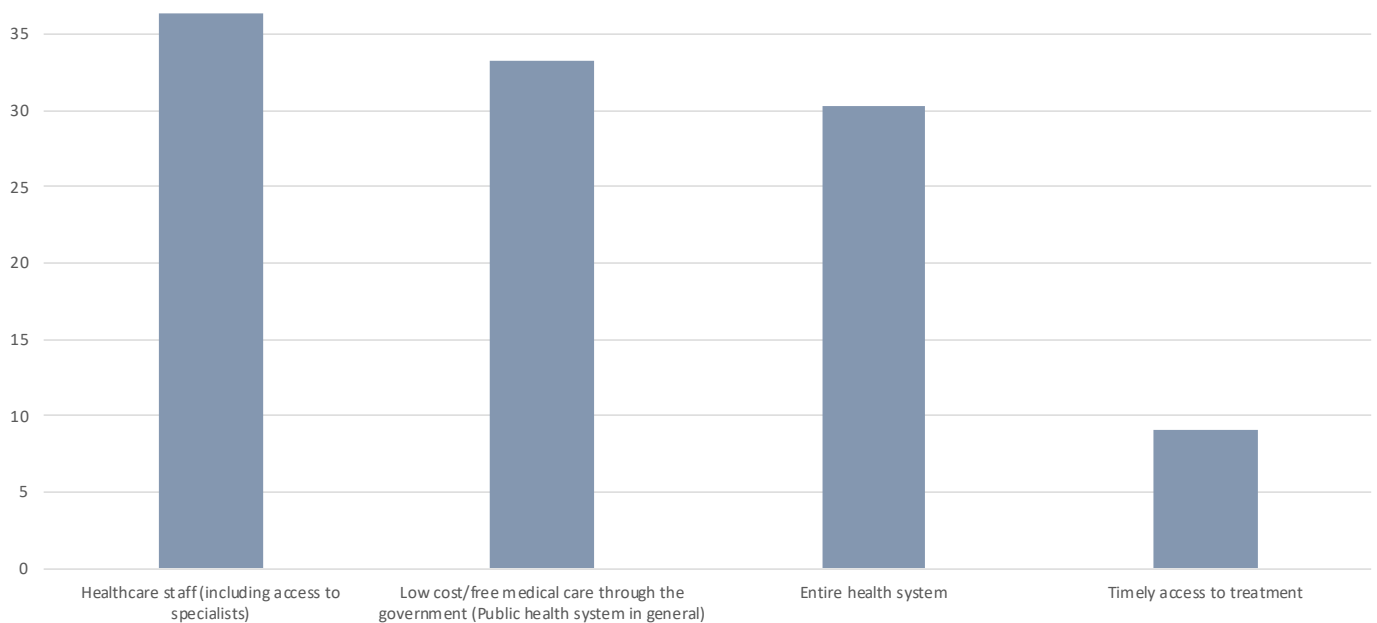
*Participant 011\_2023AUCRT*

**Table 9.9: What participants are grateful for in the health system**

What participants are grateful for in the health system	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 grateful for healthcare staff (including access to specialists)	12	36.36	4	57.14	3	30.00	5	31.25	8	30.77	4	57.14	5	33.33	7	38.89
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	11	33.33	4	57.14	3	30.00	4	25.00	10	38.46	1	14.29	6	40.00	5	27.78
Participant describes being grateful for the entire health system	10	30.30	2	28.57	4	40.00	4	25.00	7	26.92	3	42.86	3	20.00	7	38.89
Participant describes being grateful for timely access to treatment	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	2	13.33	1	5.56

What participants are grateful for in the health system	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 grateful for healthcare staff (including access to specialists)	12	36.36	6	31.58	6	42.86	5	35.71	7	36.84	3	21.43	9	47.37
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	11	33.33	8	42.11	3	21.43	3	21.43	8	42.11	4	28.57	7	36.84
Participant describes being grateful for the entire health system	10	30.30	7	36.84	3	21.43	6	42.86	4	21.05	4	28.57	6	31.58
Participant describes being grateful for timely access to treatment	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26



**Figure 9.5: What participants are grateful for in the health system**

**Table 9.10: What participants are grateful for in the health system – subgroup variations**

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for healthcare staff (including access to specialists)	Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Higher status
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	CAR T-Cell therapy Aged 65 or older Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes being grateful for the entire health system	Female	CAR T-Cell therapy Regional or remote

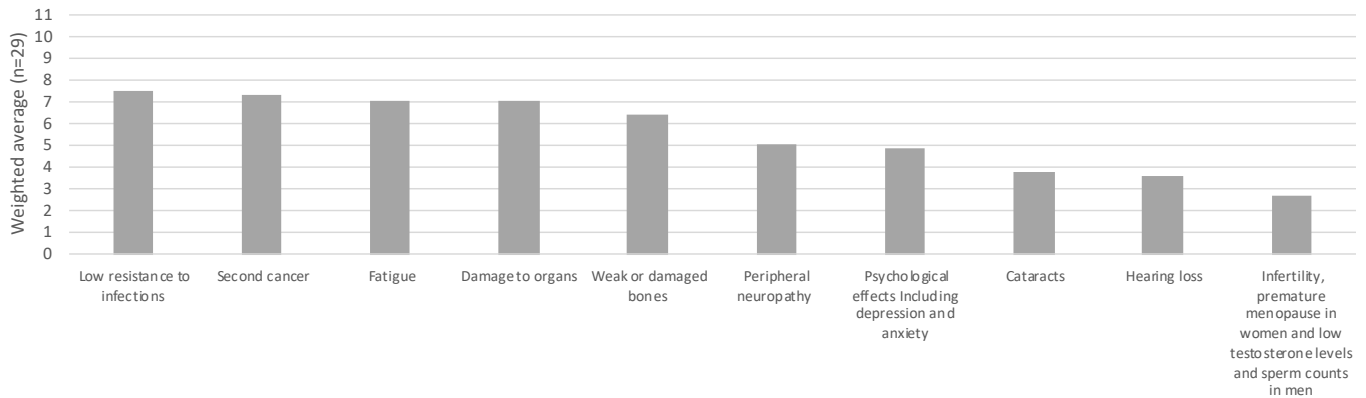
### Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 10 is the least important. A weighted average is presented in the table below. With a weighted ranking, the higher the

The most important aspects reported were fatigue pain, lymphoedema, and fertility. The least important were heart problems, memory loss and cognitive function, and effects on bones and joints.

**Table 9.11: Symptoms and aspects of quality of life**

Symptoms and aspects of quality of life	Weighted average (n=29)
Low resistance to infections	7.48
Second cancer	7.28
Fatigue	7.03
Damage to organs (heart, lung, thyroid)	7.03
Weak or damaged bones	6.38
Peripheral neuropathy (weakness, numbness, or tingling from nerve damage, usually in the hands and feet)	5.00
Psychological effects including depression and anxiety	4.83
Cataracts	3.72
Hearing loss	3.55
Infertility, premature menopause in women and low testosterone levels and sperm counts in men	2.69



**Figure 9.6: Symptoms and aspects of quality of life**

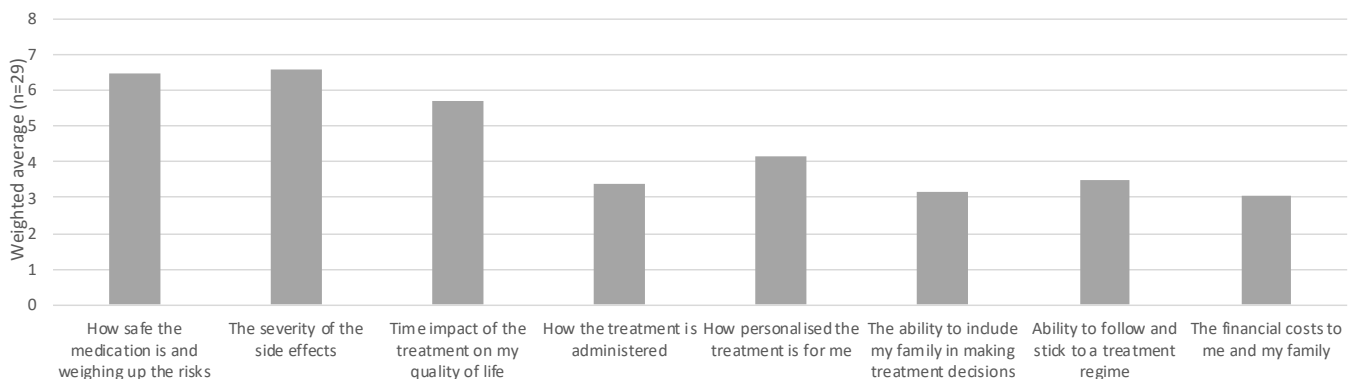
**Values in making decisions**

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in the table below. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "The severity of the side effects", and "How safe the medication is and weighing up the risks and benefits". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

**Table 9.12: Values in making decisions**

Symptom	Weighted average (n=29)
How safe the medication is and weighing up the risks and benefits	6.48
The severity of the side effects	6.59
Time impact of the treatment on my quality of life	5.69
How the treatment is administered	3.38
How personalised the treatment is for me	4.17
The ability to include my family in making treatment decisions	3.17
Ability to follow and stick to a treatment regime	3.48
The financial costs to me and my family	3.03



**Figure 9.7: Values in making decisions**

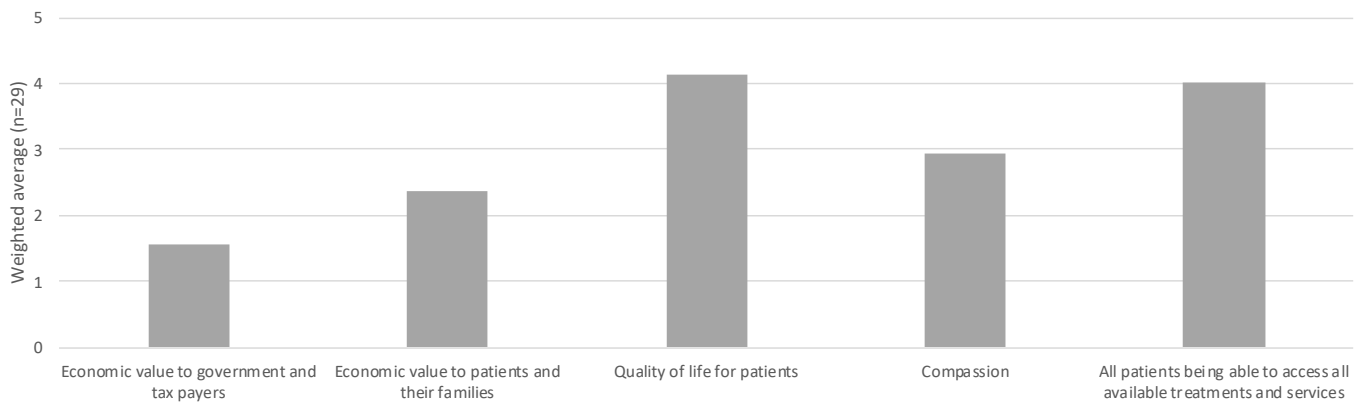
## Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in the table below. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

**Table 9.13: Values for decision makers**

Values for decision makers	Weighted average (n=29)
Economic value to government and tax payers	1.55
Economic value to patients and their families	2.38
Quality of life for patients	4.14
Compassion	2.93
All patients being able to access all available treatments and services	4.00



**Figure 9.8: Values for decision makers**

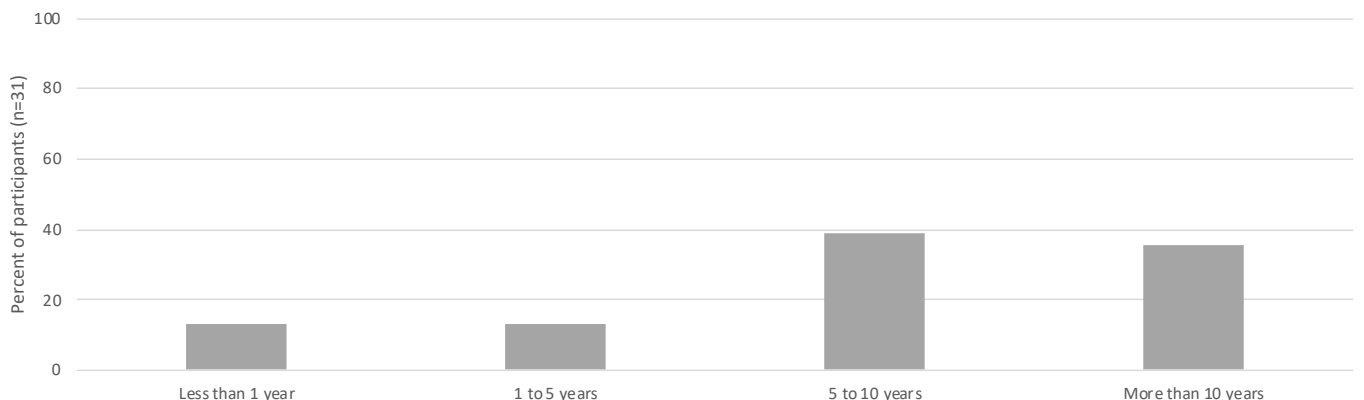
## Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

Most commonly participants would use a treatment for more than 5 to 10 years for a good quality of life even if it didn't offer a cure (n=12, 38.71%), or for more than 10 years (n=11, 35.48%).

**Table 9.14: Time taking treatment to improve quality of life**

Time taking medication to improve quality of life	Number (n=31)	Percent
Less than 1 year	4	12.90
1 to 5 years	4	12.90
5 to 10 years	12	38.71
More than 10 years	11	35.48



**Figure 9.9: Time taking treatment to improve quality of life**



## Most effective form of medicine

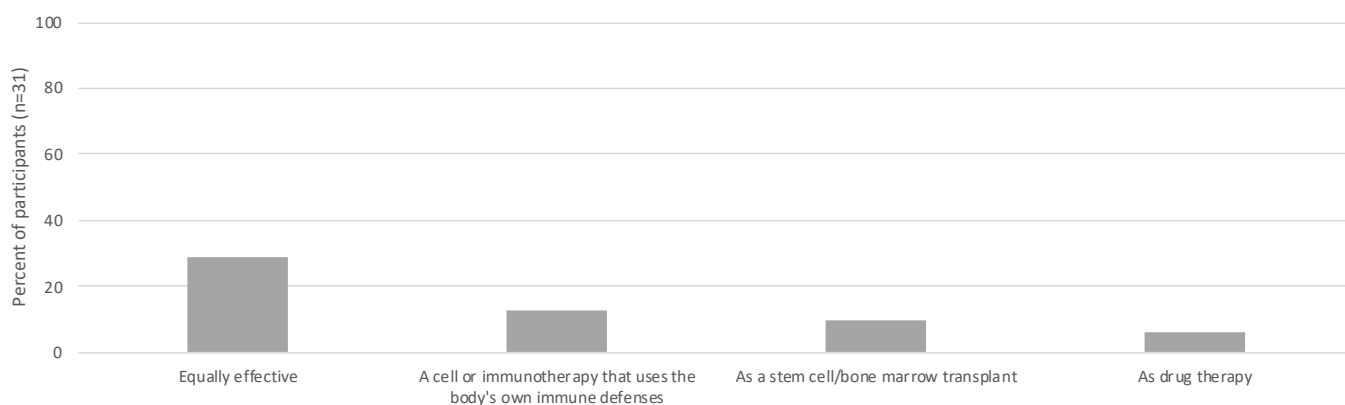
Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants most commonly responded that they did not know (n=17, 36.96%), followed by equally effective (n=15, 32.61%).

There were 9 participants (29.03%) that thought that medicine delivered by all forms were equally effective,

4 participants (12.90%) thought that q cell or immunotherapy that uses the body's own immune defense was most effective, and 3 participants (9.678%) that thought as a stem cell/bone marrow transplant was most effective. There were 11 participants (35.48%) that were not sure.

**Table 9.15: Most effective form of medicine**

Treatment most effective in what form	Number (n=31)	Percent
Equally effective	9	29.03
A cell or immunotherapy that uses the body's own immune defenses	4	12.90
As a stem cell/bone marrow transplant	3	9.68
As drug therapy	2	6.45
IV form (through a drip in hospital)	1	3.23
I'm not sure	11	35.48



**Figure 9.10: Most effective form of medicine**

## Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27%). Other themes included that treatments need to be affordable (21.21%), to invest in health professionals to service the patient population (18.18%), to help raise community awareness (12.12%), to improve rural services (12.12%), to have a holistic approach to the condition (including emotional support) (9.09%), and to increase investment (general) (9.09%).

### Grateful for the healthcare system and the treatment that they received

*I can't really complain about anything. I think they've been fantastic since diagnosis, the information. Also,*

*too, the good thing is, they've always given you their emails and their mobile number that you could call them at any time. Even the [unintelligible], it's a matter of a text message and you get your reply. You didn't feel like you were on your own. Especially, as I said, I forget a lot of things when the family would ask things. Even, they were never worried about speaking to a family member on my behalf, which was great.*  
Participant 002\_2023AUCRT

*I think I had the best access to care. I was in HOSPITAL. I think it was outstanding, really. I'd just say, "Thank you." Hopefully, everyone who gets leukaemia has the access to that care.*  
Participant 003\_2023AUCRT

*Well, I'm reminded of how well it works for me and that he needs to do everything he can to preserve the Medicare system and strengthen it so that it can do that for other people.*  
Participant 014\_2023AUCRT

*Yeah, yeah, I mean I think what we get here in Australia is amazing. My daughter's got a friend in America. She's head of, would you believe hematology LOCATION in America? And way back ages ago, years ago, she said to her, her friend in America, if mum, we can't have get things for Mum here, should we bring her over to America? And she said you leave her right way here, she's got the best treatment In the world.*

*Participant 025\_2023AUCRT*

### **More clinical trials and/or new treatments**

*It's always a money, money situation. I imagine so, but you certainly wouldn't hesitate on, yeah, going with the leading leading medical research and putting money behind it to make it available to as many people as possible.*

*Participant 021\_2023AUCRT*

*I think I would just say please give consideration to the new drugs as they come along that can help people who are living with the condition. You know, they always ask us when a new treatment's going before the TGA to write something in support of their submissions. And I know that there's a lot of things that different illnesses and rare cancers and so on that don't get the consideration that more common cancers do. But I'll just especially, I think I would say about cancers that affect children. Yeah, you know, that's what I where I think we really need to. It's bad enough when people my age get something, but you know, we've lived a good life. It's when small children or young people get things and if there's a treatment that could help them, give consideration and funding to that where possible and try and equalize things so that people who don't have as ready access to treatment as what I do have a better chance of getting it.*

*Participant 012\_2023AUCRT*

*Now when I say that you need to put more funding into research, well they probably that what they need to do is support like the likes of Leukemia Foundation more so they can look after the people. Medications need to be cheaper. You know, like I know when you get the healthcare card, it's only 7 bucks or anything, but you know when you go to when you when you crook. Like, even with all my healthcare card that I had with some medications, when you walk out, you go to the chemist, when you're on it, it's still like 60 or \$70.00 worth of pills that you know, sometimes more and like they should just, I don't know if there was funding there to make them even cheaper again.*

*Because, you know, like different people you spoke to. Like it was lucky that we had savings and that that there was an old fellow next to me. We were talking, sitting in the sun one day, getting there, just sitting at the hospital, and we were just chatting. And even with his healthcare card, he did his pension, he did his medication and like, he had like \$15 a week left for food after his medication and he had a healthcare card. And I mean, there's a lot of people like that. And that's what, yeah, they need to concentrate more on.*

*Participant 011\_2023AUCRT*

### **Invest in research (including to find new treatments)**

*I'd say pretty well done. Keep on looking for a cure. Keep on funding research.*

*Participant 013\_2023AUCRT*

*I would I would just be encouraging encouraging them to give all the all the support that was necessary in terms of dollars and and research given there's no there's no cure for multiple myeloma but like with with all with all with all cancers there's massive massive amount of research being done and eventually one day based on trials and all that that and that base is based on dollars with the research. So that continues to to to keep patients like me on a safe trip, but to improve the prove the life of others in the future with with research.*

*Participant 023\_2023AUCRT*

### **Treatments need to be affordable**

*Well I think in the present time it it it there's a lot of good treatment and and out there and you know it it it well for me it's worked and I I have I'm just the example of how how did the treatment system is but difficult one because I think can becoming more prominent than it used to be so and then that comes into it is the costing of how much it costs and you know how viable is especially in this day and age.*

*Participant 015\_2023AUCRT*

*Generally speaking, as I explained, there are there is not much that I know about the other medications for multiple myeloma that is in PBS or not. I know that the second line is Daratamabob as I said by talking to a few specialists overseas and I know that it since I came back two months ago. I just discussed that in my specialist and he said yes, this is included in PBS. So I'm happy that there is a second line of treatment, but we all know that it would fail again after a while. And then we need to go to the next stage and next stage, and this is the tough way that people like me have*

*ahead of their life to fail again and again and again. Still there is no more treatment. So I'm not quite sure if all of these third and 4th and 5th layers are covered in the PBS, but are hopeful that the minister could think about things ahead and yeah, make it fair and affordable for everyone to be able to have the treatment according to their needs. Yeah, I think Australia is a very wealthy country and looking at the number of the people who are living here, we can afford to support people who are sick with these unprecedented situations like me. So I think this is something that can be included in the expenses of the country.*

*Participant 017\_2023AUCRT*

### **Invest in health professionals to service the patient population**

*Oh God, I'd say look after your staff to make sure that the treatment is as optimal as it can be and staff are not exhausted by simply doing their jobs.*

*Participant 009\_2023AUCRT*

*I would. I would tell them to probably plan the nurses more, more money that you probably. I think they deserve it and forget about the interiors of the buildings and keep working on them on the facilities that are really important, you know the equipment that they need etcetera. But really we're very fortunate, we're on quite fortunate HOSPITAL. We've got a good hospital there. The facilities there are excellent. So you know, I'm sure people who work there would probably say they could, they could be improved. The regional areas, what I would think there's a lot of regional areas that are really missing out. They could, they can't do some of the trials. There's lots of things like that that I think that could be improved. Yeah, once you get outside the the CITY design, it doesn't, doesn't work that well. So, and I don't know how to, I don't know what I'd say, look, start to look after those people as well, but pay the nurses more money, but definitely.*

*Participant 018\_2023AUCRT*

### **Help raise community awareness**

*I'd just say, again, maybe just more make people are aware, whether it's on ads or things like that. Putting the word out there, different types of leukemias and that is associated with adults making more it aware, rather than you don't really hear much about, even on TV. I mean, the shaved one's just come up recently for leukaemia, but generally most people associate that.*

*I think people need to be aware that it can be an adult thing as well as a child thing, leukaemia. That there are different types of, leukemias and that when you do have any particular little signs, people need to be more aware and probably go to the doctor. If they play with fire like I was, I would've just went to sleep one night and that would have been it. So maybe just more awareness through media about leukaemia in general rather than just trusting people. I think, honestly, 8 out of 10 people would that I've spoken to and even after diagnosis, they've just associated it with an adult.*

*Participant 001\_2023AUCRT*

### **Improve rural services**

*So it would be to make it more available for people living in regional remote Australia and to be quicker off the mark to get new drugs and treatments through the PBS.*

*Participant 022\_2023AUCRT*

*INTERVIEWER: How do you make it so that it's more accessible to everybody? You know, it's the remote from the transplant game. You know, I found it hard going from RURAL LOCATION 1 to CITY. 1 I met someone who had to go to camp from RURAL LOCATION 2 to CITY. 2. How do you do that? So it's how do we get those support people who are regional and remote? That's the first thing. And the other one that comes up to me is people who are vulnerable with mental health issues or disability. Like if I was so hard to get diagnosed and I've struggled to get through this process, how do they get diagnosed? You know, people with intellectual disability die, have such low mortality rates, low high mortality rates and everyone else. And that would be why?*

*Participant 016\_2023AUCRT*

### **Holistic approach to the condition (including emotional support)**

*You can't explain fear and there is nothing available to help you come to terms with that. You watch nurses on cancer wards run 10 or 12 hours a day because there's not enough of them. My message would be you need to put money into mental health and you need to put more money into having good quality nursing care available. That would be my message.*

*Participant 008\_2023AUCRT*

*Yeah, look, support them. It's a dealing with HOSPITAL and no doubt there's other. Facilities around Australia, but yeah certainly, certainly that sort of*

things, yeah to support it for sure. But also look at strip it back would be the thing to look at the individual side of things. Where are they coming from for treatment, what are they made, what extra support and what's their their home sort of

demographic side of things. Because again sometimes it can just be unfortunately just be a number in the system.

Participant 026\_2023AUCRT

Table 9.16 Messages to decision-makers

Message to decision-makers	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	%
Grateful for the healthcare system and the treatment that they received	10	30.30	3	42.86	4	40.00	3	18.75	9	34.62	1	14.29	7	46.67	3	16.67
More clinical trials and/or new treatments	9	27.27	0	0.00	2	20.00	7	43.75	6	23.08	3	42.86	4	26.67	5	27.78
Invest in research (including to find new treatments)	9	27.27	1	14.29	5	50.00	3	18.75	6	23.08	3	42.86	5	33.33	4	22.22
Treatments need to be affordable	7	21.21	0	0.00	2	20.00	5	31.25	5	19.23	2	28.57	1	6.67	6	33.33
Invest in health professionals to service the patient population	6	18.18	0	0.00	2	20.00	4	25.00	3	11.54	3	42.86	1	6.67	5	27.78
Help raise community awareness	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00
Improve rural services	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	1	6.67	3	16.67
Holistic approach to the condition (including emotional support)	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11
Increase investment (general)	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	0	0.00	3	16.67

Message to decision-makers	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	%
Grateful for the healthcare system and the treatment that they received	10	30.30	5	26.32	5	35.71	3	21.43	7	36.84	3	21.43	7	36.84
More clinical trials and/or new treatments	9	27.27	4	21.05	5	35.71	3	21.43	6	31.58	3	21.43	6	31.58
Invest in research (including to find new treatments)	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Treatments need to be affordable	7	21.21	5	26.32	2	14.29	5	35.71	2	10.53	4	28.57	3	15.79
Invest in health professionals to service the patient population	6	18.18	1	5.26	5	35.71	3	21.43	3	15.79	1	7.14	5	26.32
Help raise community awareness	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	1	7.14	3	15.79
Improve rural services	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	1	7.14	3	15.79
Holistic approach to the condition (including emotional support)	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	1	7.14	2	10.53
Increase investment (general)	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

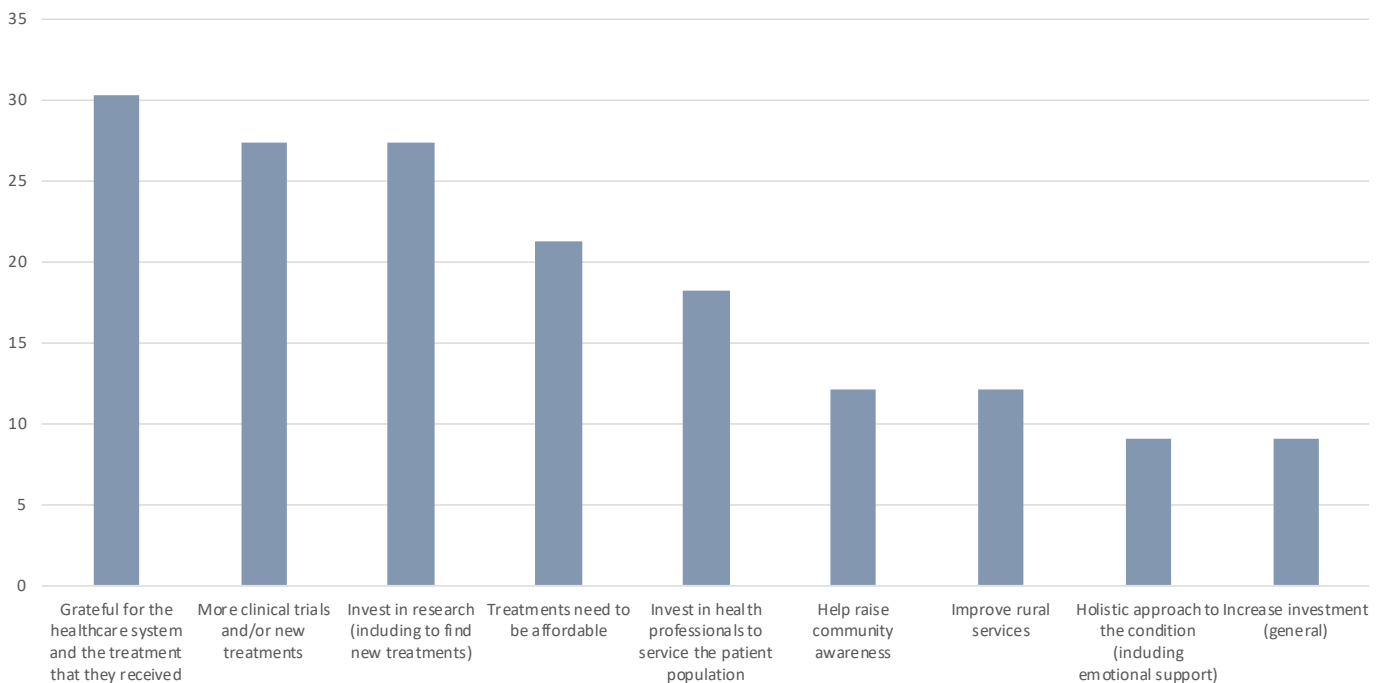


Figure 9.11: Messages to decision-makers

**Table 9.17: Messages to decision-makers – subgroup variations**

Message to decision-makers	Reported less frequently	Reported more frequently
Grateful for the healthcare system and the treatment that they received	Multiple Myeloma CAR T-Cell therapy Male	B-cell acute lymphoblastic leukaemia (ALL) Female
More clinical trials and/or new treatments	B-cell acute lymphoblastic leukaemia (ALL)	Multiple Myeloma CAR T-Cell therapy
Invest in research (including to find new treatments)	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Treatments need to be affordable	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan	Multiple Myeloma Male Regional or remote
Invest in health professionals to service the patient population	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64 Mid to low status	CAR T-Cell therapy Aged 65 or older
Help raise community awareness	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Female
Improve rural services	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Holistic approach to the condition (including emotional support)	-	B-cell acute lymphoblastic leukaemia (ALL)