

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were from a specific health charity (60.61%), from books, pamphlets and newsletters (51.52%), and from their treating clinician (48.48 %). Other themes included the internet (Including health charities) (42.42%), from other patient's experience (Including support groups) (27.27%), from nursing staff (12.12%), at conferences or webinars (12.12%), from journals (research articles) (9.09%), and family members (9.09%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were, talking to a doctor, specialist or healthcare team (36.36%), hearing what to expect (e.g. from disease, side effects, treatment) (33.33%), and other people's experiences (21.21 %). Other themes included scientific information, or information from medical journals (12.12%), and information from health charities (9.09%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information was not helpful (36.36%), worse case scenarios (18.18%), and other people's experiences (15.15 %). Other themes included being confident in deciding themselves (12.12%), and sources that are not credible (Not evidence-based) (12.12%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (39.39%), and talking to someone plus online information (21.21%). Other themes included online information (18.18%), written information (18.18%), and all forms (12.12%).

The main reasons for a preference for talking to someone were being able to ask questions (30.30%), that it was personalised or relevant (21.21%) and because it was supportive (12.12%). The main reasons for a preference for online information were accessibility (24.24%), that it was personalised or relevant (9.09%), and being able to digest information at their own pace (6.06 %). The main reason for a preference for written information was that they could easily refer back to it (12.12%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (36.36%), after the shock of diagnosis (15.15%), continuously (15.15 %), and after treatment (12.12%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having overall positive communication (75.76%), communication that was overall positive, with the exception of one or two occasions (18.18%), and overall negative communication (6.06 %).

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (60.61%), good, with no particular reason given (18.18%), good especially in

relation to multi-disciplinary communication (9.09 %). and good, yet limited in relation health to professionals not having a lot of time (6.06%). For those describing negative communication, this was because information was not forthcoming (9.09%) and limited in relation to their understanding of the condition (6.06%).

Partners in health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had very good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=26, 78.79%), disease management (n=24, 72.73%), dietary (n=21, 63.64%), and disease cause (n=17, 51.52%) were most frequently given to participants by healthcare professionals, and information about complementary therapies (n=5, 15.15%), psychological/ social support (n=5, 15.15%), and hereditary considerations (n=1, 3.03%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were complementary therapies (n=16, 48.48%), disease cause (n=14, 42.42%), interpret test results (n=14, 42.42%), and treatment options (n=12, 36.36%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=10, 30.30%), clinical trials (n=9, 27.27%), and hereditary considerations (n=8, 24.24%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=25, 75.76%) and psychological/ social support (n=19, 57.58%).

The topics that participants were given most information from both healthcare professionals and searching independently were treatment options (n=10, 30.30%) and dietary information(n=9, 27.27%).

The topics that participants did not search for independently after receiving information from healthcare professionals were disease management (n=17, 51.52%) and treatment options (n=16, 48.48%).

The topics that participants searched for independently after not receiving information from healthcare professionals were complementary therapies (n=14, 42.42%) and disease cause (n=9, 27.27%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Hospital or clinic where being treated was most accessed followed by information from the Non-profit organisations, charity or patient organisations. Information from Government and from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 17 participants (51.52%) had accessed My Health Record, 16 participants (48.48%) had not.

Of those that had accessed My Health Record, there were 3 participants (17.65%) who found it to be poor or very poor, 12 participants (70.59%) who found it acceptable, and 2 participants (11.76%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were from a specific health charity (60.61%), from books, pamphlets and newsletters (51.52%), and from their treating clinician (48.48 %). Other themes included the internet (Including health charities) (42.42%), from other patient's experience (Including support groups) (27.27%), from nursing staff (12.12%), at conferences or webinars (12.12%), from journals (research articles) (9.09%), and family members (9.09%).

Participant describes accessing information from a specific health charity

I struggled with the information, so Leukemia Foundation makes these fantastic booklets. Really love them. They're in plain language, they're easy to understand, so that's great. Where the gap is that I kind of wanted to know a bit more, so there's nothing in the middle. There's very high level kind of information and then it very quickly degenerates to academic articles and the only thing in the middle for me I found was, you know, Doctor Google, which I didn't want to access, and the academic articles I couldn't understand, but I wanted to know more. So for example, that Philadelphia chromosome, I wanted to understand more about that and I want to understand about more about how remission occurs or could occur once since I've had a bone marrow transplant. But that information is really hard to get. I understand that, you know, everyone's experience and illness is really diverse and that makes it hard. But there really is, I think, a lack of information. You know, there needs to be more depth of information than what's there.

Participant 016_2023AUCRT

Participant describes receiving information from books, pamphlets and newsletters

OK. I had lots of access for from the hospital so they would print out information about the type of chemo that I was having, the expected side effects, all of that sort of thing. Both hospitals were good at that. I also received information from the Leukemia Foundation, and I found that also excellent. I avoided Google, yes. So I generally went to the Leukemia Foundation, the Cancer Council, and my medical team.

Participant 009_2023AUCRT

Participant describes primarily accessing information through treating clinician

I remember DOCTOR told me never to Google anything about my symptoms. He said if you want any information to ask him directly, because he said a lot of people get it confused. He said, "Don't Google anything, unless you go to the Leukemia Foundation." I've never Googled anything.

Participant 01_2023AUCRT

I've read some of the pamphlets that I got given from hospital. They're informative but not of much use. I looked at some of the stuff on the Internet and I felt that that was misleading, so I haven't bothered. ... Oh, like I asked questions of my doctors and DOCTOR is pretty good at giving upfront answers. The hematologist DOCTOR, that I'm seeing doesn't like being questioned.

Participant 008_2023AUCRT

Participant describes accessing information through the internet in general

Oh yeah. Well, I read up quite a bit. I read the, there's quite a few websites out there and there's a myeloma website. There's the Mayo Clinic in America. And you know they give out lots of information, lots of people's stories, you know lots about treatments and what's available. Plus I was given a lot of lot of information by the hematologist and the oncologist about what's involved. So I was, I felt like I was pretty informed and knew knew what the the best treatment was for it.

Participant 015_2023AUCRT

Well, mostly for talking to the doctors and the nurses and then also reading the information that they give you and rereading it and then going through and thinking of questions to ask them and then asking questions. I look up a bit of stuff online, but I try to go to the things like the Queensland Health or NSW Health or the ones that are not the other, that are in Australia and that are proper medical ones as opposed to, you know, someone's crackpot theory or whatever, yeah.

Participant 006_2023AUCRT

Participant describes primarily accessing information through other patient's experience

I did actually join a support group, with the Leukemia Foundation, but that was later, I didn't know about it at the time and I really wished...Now I'm in touch with

quite a few people and we all share experiences. It makes you feel like, "Okay, it is pretty normal to be going through the things I'm still going through." You ask questions and people say, "Yes, that happened to me, and this happened to me."

Participant 004_2023AUCRT

Most of my information came from the medical library at the hospital, so I'd like I said I was just studying the drugs, looking at the statistics, things like that, looking at other people's other people's stories. I've read a story in in In Flight magazine, but a guy that had a, I think he had a lymphoma or some sort of lymphatic disease and was able to get back into his life afterwards. That's about it, basically.

Participant 024_2023AUCRT

Participant describes receiving information through nursing staff

Yes, the nurses, yes, probably more so the nurses rather than the doctors for providing information and peace of mind, yes.

Participant 005_2023AUCRT

And a couple of times when I've had questions, I've contacted the Leukemia Foundation nurses and spoken to them on the phone.

Participant 012_2023AUCRT

Participant describes receiving information through conferences or webinars

Oncologists at HOSPITAL, that was the best thing I saw about CAR-T on the web was him giving a 40 minute talk...and his talk was fantastic and he I'd still refer back to it and I send everyone there, but he said that's great, but most people find it too much. Which is fair enough. So there is somewhere in between where the facts there should be references or facts available or more information rather than...I don't want a one page thing that's warm and fuzzy.

036_2023AUCRT

Participant describes accessing information primarily through journals (research articles)

It would be my own Internet research, looking at medical papers, etc. and I sort of realized that anything that's in a few years old, it's probably out of date, especially CAR-T therapy, so recent research papers I guess.

Participant 021_2023AUCRT

Participant describes receiving information through family members

I speak to my dear wife who was a research oracle, I mean she's she's extremely intelligent researcher. Wisely, as I said at the beginning, perhaps one of the ways I manage my condition is to stick my head in the sand and not want to know about anything and just do what the specialist tells me. I see they research to the nth degree about multiple myeloma.

Participant 013_2023AUCRT

Table 6.1: Access to information.

Access to 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	%
Participant describes accessing information from a specific health charity	20	60.61	3	42.86	5	50.00	12	75.00	17	65.38	3	42.86	9	60.00	11	61.11
Participant describes receiving information from books, pamphlets and newsletters	17	51.52	3	42.86	5	50.00	9	56.25	12	46.15	5	71.43	7	46.67	10	55.56
Participant describes primarily accessing information through treating clinician	16	48.48	4	57.14	4	40.00	8	50.00	13	50.00	3	42.86	6	40.00	10	55.56
Participant describes accessing information through the internet in general	14	42.42	2	28.57	6	60.00	6	37.50	10	38.46	4	57.14	4	26.67	10	55.56
Participant describes primarily accessing information through other patient's experience	9	27.27	2	28.57	2	20.00	5	31.25	9	34.62	0	0.00	4	26.67	5	27.78
Participant describes receiving information through nursing staff	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00
Participant describes receiving information through conferences or webinars	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes accessing information primarily through journals (research articles)	3	9.09	0	0.00	2	20.00	1	6.25	0	0.00	3	42.86	2	13.33	1	5.56
Participant describes receiving information through family members	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	0	0.00	3	16.67

Access to 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	%
Participant describes accessing information from a specific health charity	20	60.61	10	52.63	10	71.43	9	64.29	11	57.89	9	64.29	11	57.89
Participant describes receiving information from books, pamphlets and newsletters	17	51.52	9	47.37	8	57.14	7	50.00	10	52.63	6	42.86	11	57.89
Participant describes primarily accessing information through treating clinician	16	48.48	12	63.16	4	28.57	9	64.29	7	36.84	7	50.00	9	47.37
Participant describes accessing information through the internet in general	14	42.42	9	47.37	5	35.71	9	64.29	5	26.32	7	50.00	7	36.84
Participant describes primarily accessing information through other patient's experience	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Participant describes receiving information through nursing staff	4	12.12	3	15.79	1	7.14	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes receiving information through conferences or webinars	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes accessing information primarily through journals (research articles)	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	1	7.14	2	10.53
Participant describes receiving information through family members	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26

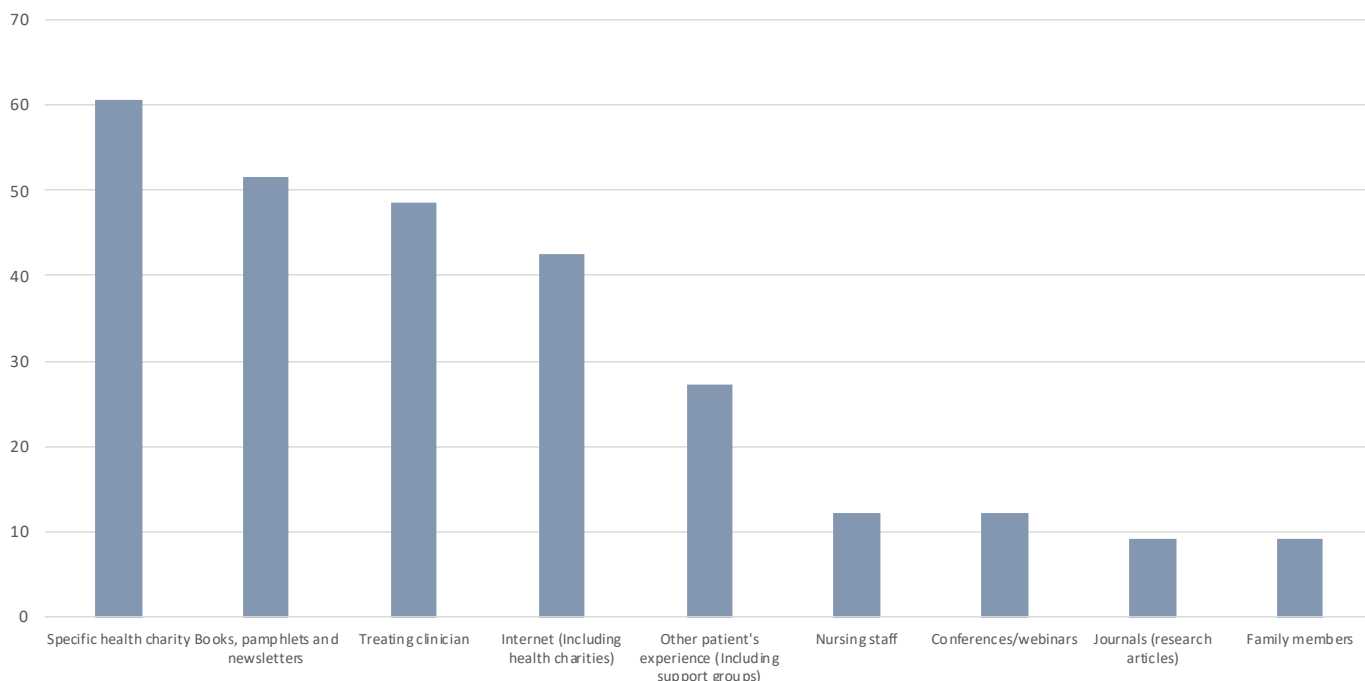


Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information from a specific health charity	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma Aged 65 or older
Participant describes receiving information from books, pamphlets and newsletters	-	CAR T-Cell therapy
Participant describes primarily accessing information through treating clinician	Aged 65 or older Metropolitan	Aged 25 to 64 Regional or remote
Participant describes accessing information through the internet in general	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote
Participant describes primarily accessing information through other patient's experience	CAR T-Cell therapy	-
Participant describes receiving information through nursing staff	CAR T-Cell therapy Male	B-cell acute lymphoblastic leukaemia (ALL) Female
Participant describes receiving information through conferences or webinars	B-cell acute lymphoblastic leukaemia (ALL)	-
Participant describes accessing information primarily through journals (research articles)	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were talking to a doctor, specialist or healthcare team (36.36%), hearing what to expect (e.g. from disease, side effects, treatment)(33.33%), and other people's experiences (21.21 %). Other themes included scientific information, or information from medical journals (12.12%), and information from health charities (9.09%).

Participant describes talking to their doctor or specialist as helpful

I find the information, I guess maybe I just trust my specialist. He's the only, probably, one I would trust out of all the doctors and nurses and everyone else that I've been with. Whatever his information is, is what I go by.

Participant 01_2023AUCRT

The most helpful Just the explanation really. I think of how how the disease came about and what happens and what my doctor actually did, which I thought was quite clever when he explained to me how the disease worked. You know, he drew funny little diagrams and arrows going everywhere, but he did all that. And then he said. I think it was at the next visit you said okay, I told you all that last time. Now I want you to explain it back to me what you understood from what I've told you before. So he got me to tell him what my understanding of it was. So I thought that was a good way of testing how much I understood because I have heard of some people who when they're told they have multiple myeloma, I think that they've got Melanoma.

Participant 012_2023AUCRT

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

I guess it was good to know what what the likely side effects were, the point at which you should call for help. So monitoring your temperature, all that kind of thing. Yeah, just just basically that kind of thing.

Participant 009_2023AUCRT

Just knowing what's available and knowing what to do and because the book of the initial book explained things in good detail and the processes and what you've got to do and and how to how to look after yourself. Really it's a matter of just looking after yourself, yeah.

Participant 018_2023AUCRT

Probably just bouncing back that getting back to your point earlier about some of those side effects. Hey look if I've gone to sort of the information I'm feeling really tired or fatigued does you know does it give you fatigue and what what's the side effects what's gee, you know all the radiation and chemo and all the drugs have had is that causing this that or the other yes it can cause this that now. So I suppose it's it's more not getting an overall thing, it's just probably based around some condition I'm feeling at the the time if I yeah, if it's fatigue or dizziness or you know if my blood pressure is high or or or something like that, yeah, for sure. That's probably what I'd I'd search for it.

Participant 026_2023AUCRT

Participant describes other people's experiences as helpful (Peer-to-peer)

I think the most helpful has been information from people who have also gone through the same thing, and their way of coping and dealing with it, small things like what to eat when you're vomiting. Yes, how you feel and what to expect from that.

Participant 003_2023AUCRT

Participant describes scientific information, or information from medical journals as helpful

The medical, the actual medical stuff, without a doubt

036_2023AUCRT

Most helpful would be like yeah, reading about clinical trials I guess and what the result, Yeah, somewhere you have results and what's worked and hasn't worked I guess.

Participant 021_2023AUCRT

Participant describes health charities information as helpful

The guidebooks they've got available. They're great. There's a whole guidebook on an autologous stem cell transplant. There's a guide book on living well with myeloma. There's a guide book on living with amyloidosis like Yep and also I've. I've also done some online webinars with Leukemia Foundation and and done some online support group stuff which has been good.

Participant 022_2023AUCRT

Table 6.3: Information that was helpful

Information that has been helpful	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 talking to their doctor or specialist as helpful	12	36.36	4	57.14	1	10.00	7	43.75	11	42.31	1	14.29	6	40.00	6	33.33
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	11	33.33	2	28.57	3	30.00	6	37.50	8	30.77	3	42.86	2	13.33	9	50.00
Participant describes other people's experiences as helpful (Peer-to-peer)	7	21.21	1	14.29	3	30.00	3	18.75	6	23.08	1	14.29	4	26.67	3	16.67
Participant describes scientific information, or information from medical journals as helpful	4	12.12	0	0.00	3	30.00	1	6.25	0	0.00	4	57.14	3	20.00	1	5.56
Participant describes health charities information as helpful	3	9.09	0	0.00	1	10.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Information that has been helpful	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 talking to their doctor or specialist as helpful	12	36.36	7	36.84	5	35.71	3	21.43	9	47.37	4	28.57	8	42.11
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	11	33.33	6	31.58	5	35.71	5	35.71	6	31.58	4	28.57	7	36.84
Participant describes other people's experiences as helpful (Peer-to-peer)	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	2	14.29	5	26.32
Participant describes scientific information, or information from medical journals as helpful	4	12.12	2	10.53	2	14.29	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes health charities information as helpful	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	2	14.29	1	5.26

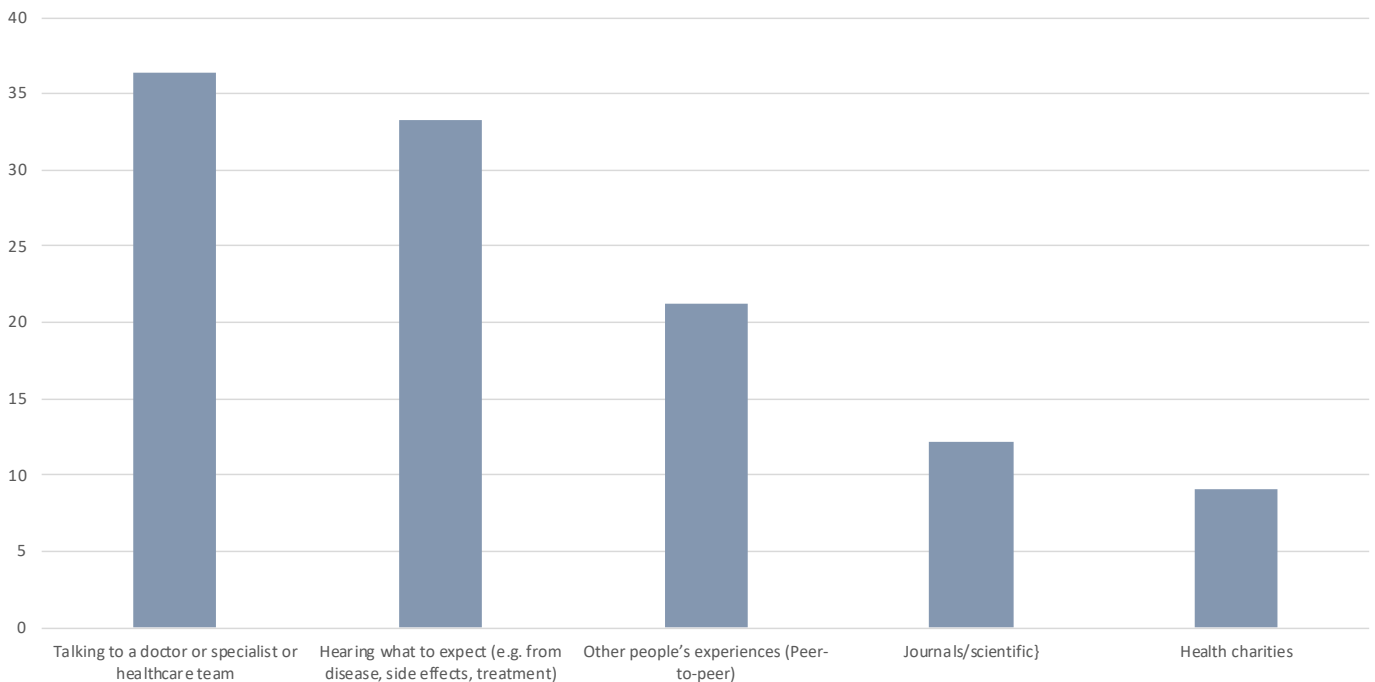


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes talking to their doctor or specialist as helpful	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Female	Male
Participant describes scientific information, or information from medical journals as helpful	B-cell acute lymphoblastic leukaemia (ALL) No CAR T-Cell therapy Regional or remote	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes health charities information as helpful		Regional or remote

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information was not helpful (36.36%), worse case scenarios (18.18%), and other people's experiences (15.15 %). Other themes included being confident in deciding themselves (12.12%), and sources that are not credible (Not evidence-based) (12.12%).

Participant describes no information being not helpful

*No. I think throughout my whole treatment, if you've asked the questions, you've always been given the answers, so I don't think so. I think it's just a matter of you as a person asking what you need to know. My problem is that I don't remember. No, I think everything's been going okay.
Participant 002_2023AUCRT*

No, I haven't. I couldn't say that I...I think everything that I've looked at seem really useful. I also did a lot of research on the different genetic markers with prognosis and things like that. I was really interested in that. I've learned a lot.
Participant 004_2023AUCRT

Participant describes information about worse case scenarios and negative information as being not helpful

Sometimes there's times when there's jargon and facts and figures that are sort of just too confusing that are not helpful for a layman. I guess you would say so, yeah, yeah, there's a certain level that. Yeah, that's easier to read than others. And in relation to and something, Sorry, something's not only cause you to panic, and maybe it's not worth reading some of the statistics anyway.
Participant 021_2023AUCRT

Participant describes other people's experiences as being not helpful

Yes. Some of those support groups have horror stories. Then you go, "No. Not going to go in there anymore." [laughs]
Participant 003_2023AUCRT

Participant describes feeling confident in deciding if something is not helpful (or not credible)

PARTICIPANT: Oodles of it out there, but we've just... try to zero in and concentrate on reliable sources. Probably an example of that, if there is as there is anything in social media, there's quite a while over Facebook page and all that and I got to a point after about two or three weeks and might not just have to turn the notifications of it just to keep out. It was just, yeah, just not helpful, yeah. On that and I just, you know some of the stuff that people are sprouting was you know, I knew was from from reliable and expert sources was complete rubbish
Participant 027_2023AUCRT

Participant describes information from sources that are not credible as not helpful (Not evidence-based/opinions)

Well meaning friends who think they're trying to help. But have no idea.
Participant 022_2023AUCRT

Table 6.5: Information that was not helpful

Information that has not been helpful	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 no information being not helpful	12	36.36	2	28.57	1	10.00	9	56.25	12	46.15	0	0.00	6	40.00	6	33.33
Participant describes information about worse case scenarios and negative information as being not helpful	6	18.18	2	28.57	3	30.00	1	6.25	5	19.23	1	14.29	4	26.67	2	11.11
Participant describes other people's experiences as being not helpful	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 feeling confident in deciding if something is not helpful (or not credible)	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 information from sources that are not credible as not helpful (Not evidence-based)	4	12.12	1	14.29	0	0.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67

Information that has not been helpful	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 no information being not helpful	12	36.36	5	26.32	7	50.00	2	14.29	10	52.63	4	28.57	8	42.11
Participant describes information about worse case scenarios and negative information as being not helpful	6	18.18	4	21.05	2	14.29	3	21.43	3	15.79	4	28.57	2	10.53
Participant describes other people's experiences as being not helpful	5	15.15	2	10.53	3	21.43	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	2	14.29	2	10.53

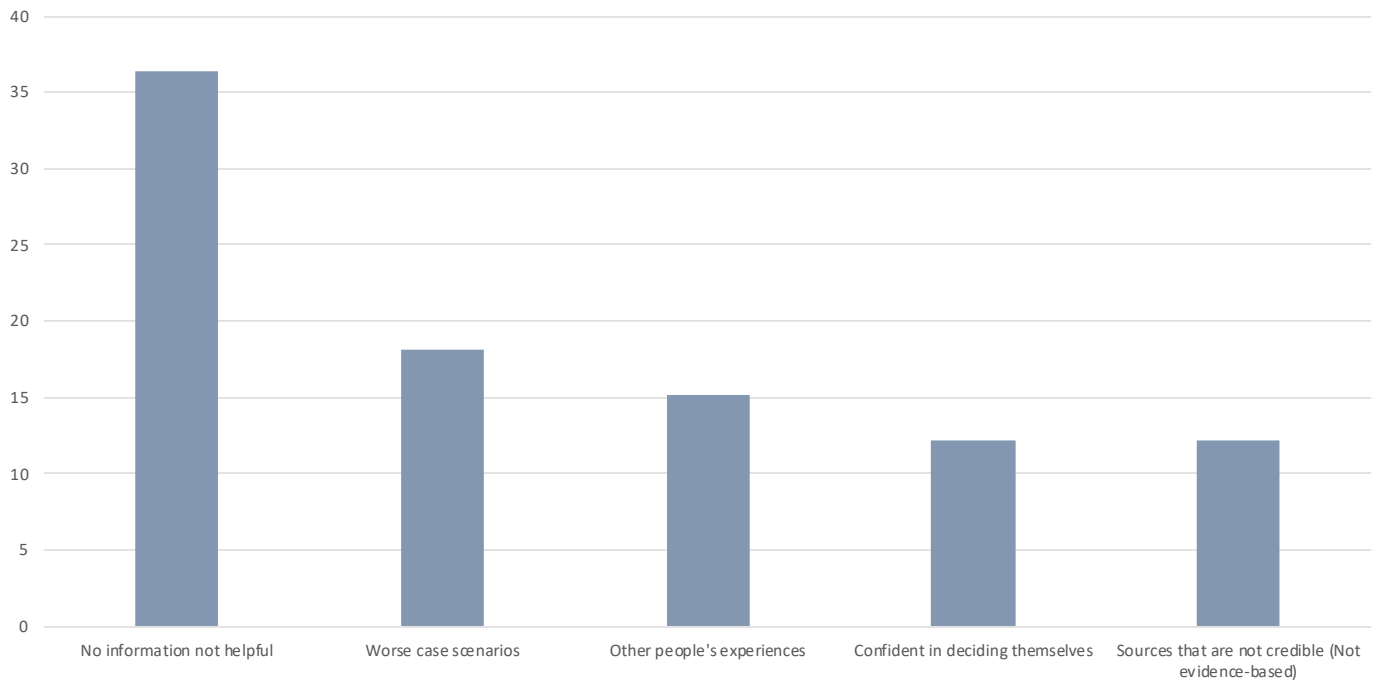


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote	Multiple Myeloma Aged 65 or older Metropolitan
Participant describes information about worse case scenarios and negative information as being not helpful	Multiple Myeloma	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Mid to low status
Participant describes information from sources that are not credible as not helpful. (Not evidence-based)	Diffuse Large B-Cell Lymphoma	

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (39.39%), and talking to someone plus online information (21.21%). Other themes included online information (18.18%), written information (18.18%), and all forms (12.12%).

The main reasons for a preference for talking to someone were being able to ask questions (30.30%), that it was personalised or relevant (21.21%). and because it was supportive (12.12%).

The main reasons for a preference for online information were accessibility (24.24%), that it was personalised or relevant (9.09%), and being able to digest information at their own pace (6.06 %).

The main reason for a preference for written information was that they could easily refer back to it (12.12%).

Participant describes talking to someone as main information preference

Probably maybe talking to someone, probably would be the best option rather than an app. An app or information like that, you could press or look on the wrong information and cross your wires a little bit. Whereas talking to someone, they could make things a lot clearer, so I'd probably go with the talking with someone option.

Participant 01_2023AUCRT

I prefer talking to someone because that way, you can make sure you understand what they're saying. I also do online, but then not a Google thing. It had to be from a reputable source. Basically, I prefer talking to people. That's why I think the group is so good.

Participant 002_2023AUCRT

Talking to someone who can explain it to me so you can actually question what they're saying.

Participant 008_2023AUCRT

Probably talking to someone who's had the experience would be good because they've been through it. Booklets is just basically general like it's how would you say it comes back to an average of every, I think everyone, every individual's different, how things would treat them are you know affect them. So mainly I think the best thing would be to talk to people.

Participant 011_2023AUCRT

Well, talking to someone would be good. I think it's quite a well for me it was quite a emotional stressful experience to go through. I mean I think everybody's experience is is different. So you know for me it was, it was difficult but I think it was that was exacerbated maybe possibly by my own personal kind of situation. So but you know I possibly should have sought more help in that area than I did again you know and I didn't. So I think that's an area which it's available, but I didn't utilize it and like you know, so that the hospital does provide those things that I didn't take them up on it.

Participant 015_2023AUCRT

Participant describes talking to someone plus online information as main information preference

PARTICIPANT: Probably something written down with but that you can talk to someone about as well. So so I guess in that first instance you're talking, but then you've also got that written note to refer back to. But yeah, it's it's also good to look things up if there's, if you know where you can go online to to find the right information. So yeah.

INTERVIEWER: And is there a reason you also prefer speaking to someone?

PARTICIPANT: Probably because you can based on what they say. Then you can interact back and say, oh, so why is that? Or does that mean if I did this I could do that or? Do you do you know what I mean?

Participant 006_2023AUCRT

Participant describes online information as main information preference

Probably prefer to do it by myself rather than talking to someone, so probably online on my phone for convenience.

Participant 005_2023AUCRT

Participant describes written information as main preference

I like booklets because I'm old enough not to be too computer savvy, so I like having a hard copy of

something I can look at so I can go back and revise. Yeah, so for me it's written.

Participant 009_2023AUCRT

I probably prefer personally booklets and talking that could be generational, but but the only thing I've found with with the Internet is is whoever pays the most gets up at the top. And a lot of it's American based, which again, I know myeloma is myeloma and whatever country you're in. But a lot of the American stuff, I don't know it just I didn't relate to it as well. And then it also somewhere in there there'd be something trying to sell you something and all that sort of stuff and that was just and and there's so much information on the Internet. It's like, well, you know it's just so just keep it simple. Keep it down to half a dozen different things, whatever it may be. And then I can sort of interpret what you've told me in those booklets or this person, if I unsure of something, talking to a person's a good way to get it explained to you because then I can bounced back to them in my way of understanding. They can correct me or or or tell me it's right, whatever.

Participant 019_2023AUCRT

Yeah, probably I always do like something written, I like talking to people, but I also like to follow up with something written so you can reread, reread and digest it again later. So I think, I think both two prong approach is good and I usually go to master points with my husband and I think that's been important because we often have sometimes we'll have a different understanding and then we of what something was said and I need to clarify it. So I do think that if someone people always have someone else that they can attend appointments with, it's useful.

Participant 021_2023AUCRT

I still, I still love to read, you know, from the paper. Yeah, but of course that will go on Google. But my preferred one, I took all those, you know, paper printed booklets and I kept reading them with me and referring to them again and again.

Participant 034_2023AUCRT

Participant describes preferring all forms of information

PARTICIPANT: All of those things have their place.

INTERVIEWER: Do you have a preference at all for one or the other or do you prefer a myriad, all of them?

PARTICIPANT: A myriad, different sorts of information.

Participant 003_2023AUCRT

PARTICIPANT: All of it. [laughs]

INTERVIEWER: Okay. What's the reason for that?

PARTICIPANT: I think it's good to read things. I think it's really good to talk to people, like online talking is really good. As I said that, the leukemia, support group has been fantastic, and everyone is so supportive of each other and encouraging and it's just been really good. We felt like everybody can help each other in some way, so I find that really good. Talking to someone, I think it's really good. I haven't really spoken verbally to people about it, it's more being online, and online is good.

INTERVIEWER: It sounds like as much information in different forms is great.

PARTICIPANT: Yes, different formats.

Participant 004_2023AUCRT

Oh, no, I think they all have their place. Yeah, I'm quite used to reading things online. But yeah, I don't mind if it's printed or I don't go into it, you know, in depth. Like, I know some people, when they have their blood tests done, they know every single thing that's being measured, what it means and what up and down and all that means in those different levels. And I haven't bothered going into that because my doctor goes through it with me and he goes, well, you know, your kidneys are working well, this is working well, that's working well. The white cells are low, but that just means you have to be careful of infection. It goes through it in a general way with me. And so I don't bother wanting to know all the ins and outs of what all those blood levels mean.

Participant 012_2023AUCRT

Table 6.7: Information preferences

Information preferences	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 talking to someone as main information preference	13	39.39	3	42.86	3	30.00	7	43.75	11	42.31	2	28.57	5	33.33	8	44.44
Participant describes talking to someone plus online information as main information preference	7	21.21	3	42.86	0	0.00	4	25.00	6	23.08	1	14.29	2	13.33	5	27.78
Participant describes online information as main information preference	6	18.18	1	14.29	3	30.00	2	12.50	4	15.38	2	28.57	3	20.00	3	16.67
Participant describes written information as main preference	6	18.18	1	14.29	3	30.00	2	12.50	2	7.69	4	57.14	4	26.67	2	11.11
Participant describes preferring all forms of information	4	12.12	0	0.00	2	20.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56

Information preferences	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 talking to someone as main information preference	13	39.39	8	42.11	5	35.71	6	42.86	7	36.84	7	50.00	6	31.58
Participant describes talking to someone plus online information as main information preference	7	21.21	4	21.05	3	21.43	2	14.29	5	26.32	2	14.29	5	26.32
Participant describes online information as main information preference	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	3	21.43	3	15.79
Participant describes written information as main preference	6	18.18	5	26.32	1	7.14	1	7.14	5	26.32	1	7.14	5	26.32
Participant describes preferring all forms of information	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	2	14.29	2	10.53

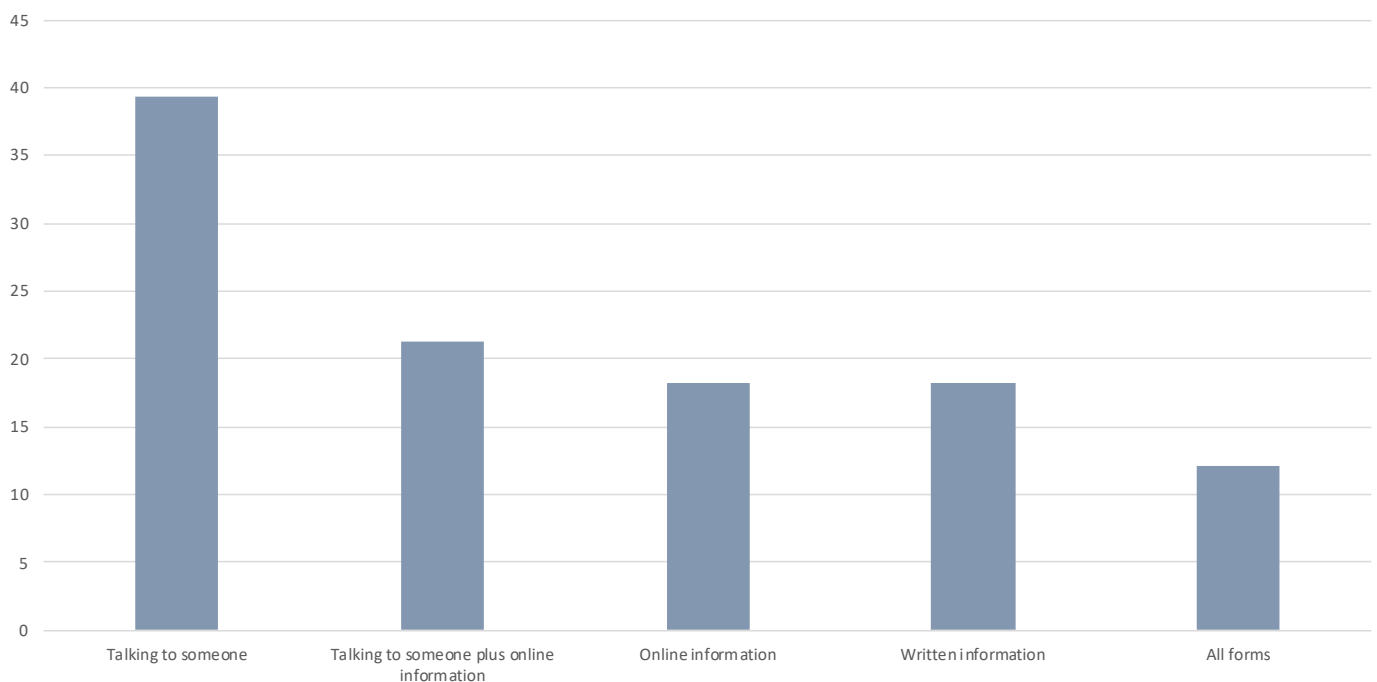


Figure 6.4: Information preferences

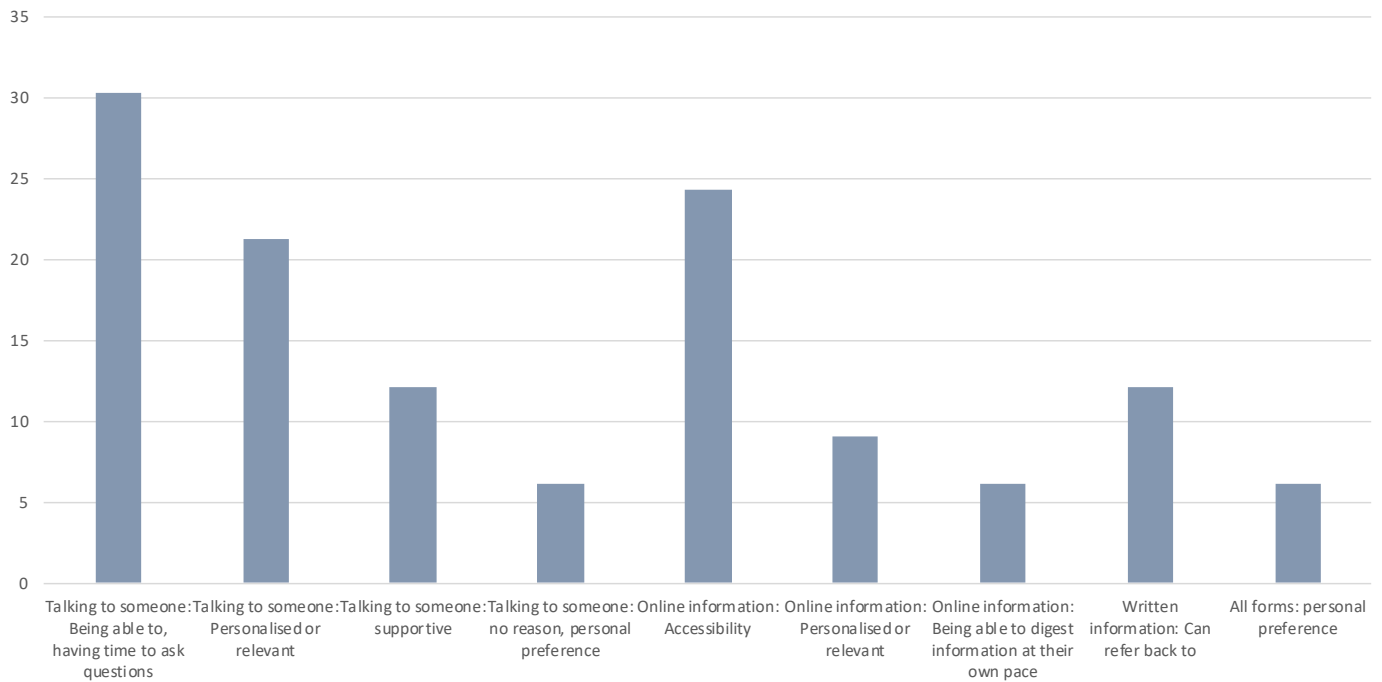


Figure 6.5: Reasons for information preferences by format

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone as main information preference	CAR T-Cell therapy	Mid to low status
Participant describes talking to someone plus online information as main information preference	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes online information as main information preference	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes written information as main preference	No CAR T-Cell therapy Aged 65 or older Regional or remote Mid to low status	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes preferring all forms of information	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-

Table 6.8: Information preferences – subgroup variations

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (36.36%), after the shock of diagnosis (15.15%), continuously (15.15%), and after treatment (12.12%).

Participant describes being receptive from the beginning (diagnosis)

I think straight away because I really wanted to know what was happening, but that's just the way I am. I wanted to be informed as much as possible, so I knew what I was dealing with so I took it in and read it, and read it, and read it. [laughs]
Participant 004_2023AUCRT

I think right from the word go, yeah. Yeah, Yeah. Right, Right from the word go. As soon as I got it.

That's fine. You know, as I said, nothing bothers me. I'm very happy to go and do anything, you know? Yeah.

Participant 018_2023AUCRT

Probably from day one, just cuz I just wanted to know what was going on. It's just the unknown is what's scary I suppose. It's unknown what's going to happen, what is this drug or what is, what is a biopsy or what is, you know, the the consequences of of taking all these drugs. What's going to happen to me? I don't have any family with me at the moment, things like that. So it's a bit scary at the time.

Participant 024_2023AUCRT

Probably at the very beginning.
Participant 025_2023AUCRT

Participant describes being receptive to information after the shock of diagnosis

*Probably a day or two after diagnosis, I guess after the initial shock had worn off.
Participant 005_2023AUCRT*

*Probably by about the 3rd or 4th day after I was diagnosed. I think the first day or two it was just such a shock and. I was having quite a bit of pain with my neck with that swollen bit and and just like Oh my God, what's happening. So it was it was probably a little bit of a blur then, but once I sort of got over that initial shock then I could was able to start reading the stuff and really talking to them about different options and what happens and that sort of thing.
Participant 006_2023AUCRT*

Yeah, that's a really good question. Initially it is a bit overwhelming, you know, always, you know, and my wife and daughter were there when I was diagnosed and when they said, you know, you got one to three years, they were kind of very upset and shit. So we actually sold the house and we moved. We lived very close to the hospital now...So you know, because I was going to the hospital six days a week or something, but now things have, so I'm more receptive. Sorry I got off track, more receptive to overwhelming in the beginning, but as I as my health started to improve and my mobility and also my mental focus, I was able to absorb information a bit better. Participant 031_2023AUCRT

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

*That never really stopped. I wasn't better or less on take it in all the way through.
Participant 022_2023AUCRT*

Yeah, that's tough. I think it was overwhelming, as you said, overwhelming to start with because there was so much information in the book and then. That's what it's virtually impossible to I guess recall everything that you've read you know regarding you know finer points of everything and you know how the how it all works. But I think as you get on the they seem the the topics for each zoom meeting you can choose. You don't have to access every meeting with it is relevant, yeah. It's that's the most helpful thing and it's and this and they actually do re reiterate the basics as well over now and then just so that you know you don't if you got something that's back back on the agenda again as far as the topic. So it's really helpful

*to have have a like a revision every now and then. And that's obviously the you know like the people, the two organizations that do most of the Zoom meetings are aware of how how to sort of structure the like with the with Leukemia Foundation.
Participant 032_2023AUCRT*

Participant describes being receptive to information after treatment

*Definitely more of the back end of treatment. In the beginning, I felt bombarded with information. I was overloaded too much. It just was too much. Whereas the middle to end of my treatment, I probably absorbed it a lot more, and I was able to observe it a lot more. I was a lot more clearer thinking than probably just all being bombarded even with, I might sound rude, but ignorant people that used to come into the hospital, like the social workers. I think there was help support and then I had my PICC dressing ladies. I had problems with my PICC. It wasn't smooth sailing. I just felt like there was constantly bombarding of people all the time in there with their information and then printed off the information they would give you. It was just too much.
Participant 01_2023AUCRT*

*Well, at the beginning of the diagnosis, my brain was too busy with other things. So the further I get from the treatment, from the diagnosis and now I'm learning how to live with the cancer day-to-day. My brain is more capable of absorbing more information now and from now onward. But the further I go, if I live longer, the more information would be more helpful. But at the beginning I was too scared, too shocked. I was not quite sure what's happening around me. I couldn't even imagine. Yeah, thinking about other things than chemotherapy and these kind of things. So, yeah, from now on. And yeah, after the diagnosis, it's getting more and more clear and more and more.
Participant 017_2023AUCRT*

Probably a couple of, well, you know, not not straight away. Obviously, the first week's just a blur. But yeah, probably a month or two into it because. Yeah. So the the first, you know, week or two, it's just simply just a blur. It's like, yeah, And that's what happened. I got diagnosed. So we're going to check in, you know, ambulance rushing off the hospital, start chemo the next day, run these tests. This is what the reliance is. And I was like whoa, because in in amongst that you've got painkillers which blow you a bit, make you bit cuddy as well. So any all the heavy ones, Oxy and that sort of stuff. So you'd be a bit foggy at first. And

there's also it is such a blur like you've got, you know I've got my wife and daughter crying on the in the bed and the doctor telling me that I won't live to Christmas and then my my extended family which is quite large

or ringing in from all over the country checking in, I mean it...and then to take it all in, it's almost secondary.

Participant 019_2023AUCRT

Table 6.9: Timing of information

Timing of 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	%
Participant describes being receptive from the beginning (diagnosis)	12	36.36	2	28.57	5	50.00	5	31.25	8	30.77	4	57.14	5	33.33	7	38.89
Participant describes being receptive to information after the shock of diagnosis	5	15.15	1	14.29	1	10.00	3	18.75	5	19.23	0	0.00	2	13.33	3	16.67
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	15.15	1	14.29	2	20.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Participant describes being receptive to information after treatment	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	3	20.00	1	5.56

Timing of 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	%
Participant describes being receptive from the beginning (diagnosis)	12	36.36	5	26.32	7	50.00	5	35.71	7	36.84	4	28.57	8	42.11
Participant describes being receptive to information after the shock of diagnosis	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes being receptive to information after treatment	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	3	21.43	1	5.26

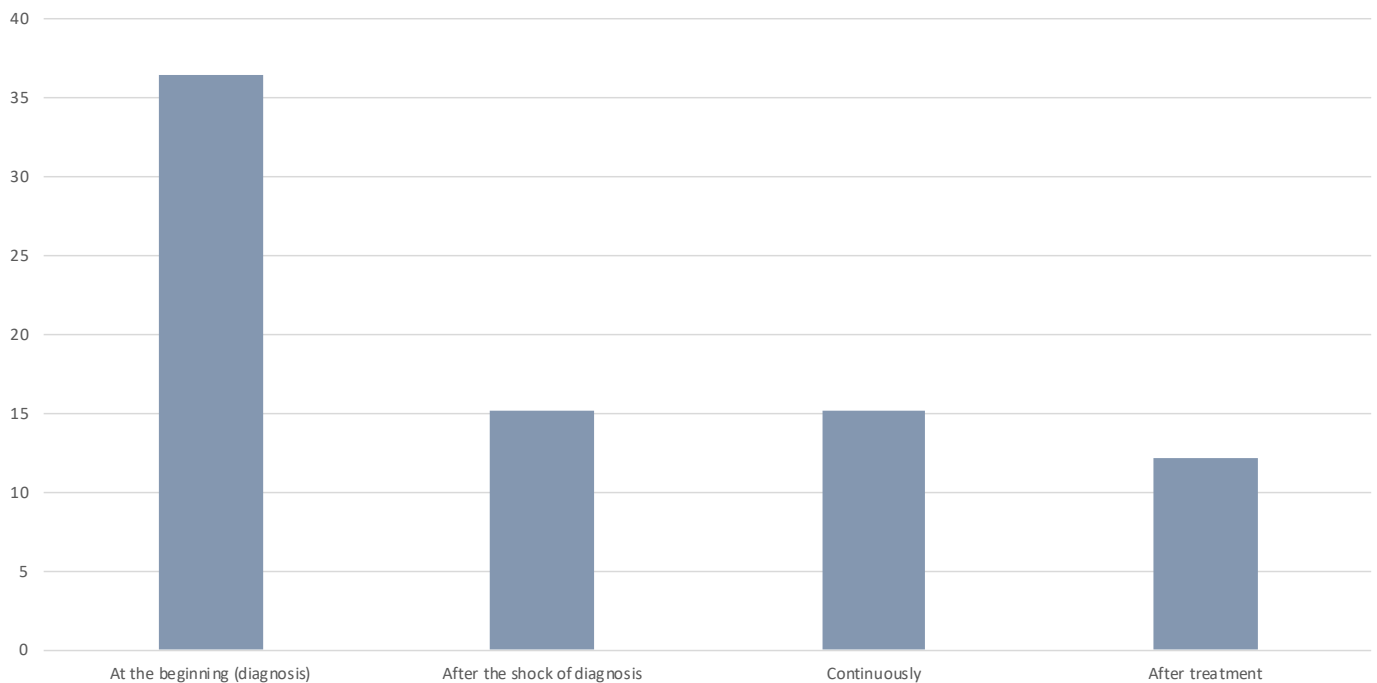


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Aged 25 to 64	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older
Participant describes being receptive to information after the shock of diagnosis	CAR T-Cell therapy	
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	-	CAR T-Cell therapy
Participant describes being receptive to information after treatment	Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having overall positive communication (75.76%), communication that was overall positive, with the exception of one or two occasions (18.18%), and overall negative communication (6.06 %).

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (60.61%), good, with no particular reason given (18.18%), good especially in relation to multi-disciplinary communication (9.09 %). and good, yet limited in relation health to professionals not having a lot of time (6.06%). For those describing negative communication, this was because information was not forthcoming (9.09%) and limited in relation to their understanding of the condition (6.06%).

Participant describes communication with healthcare professionals as overall positive

Overall, like I said, a 10 out of 10 with SPECIALIST. Even with my regular GP, she doesn't do anything without consulting with him either, now.
Participant 01_2023AUCRT

Yes, really good. Like I said before, any questions that I've had, they had answered or got back to me with an answer.
Participant 005_2023AUCRT

Generally speaking very good. I mean you have, I mean it's it's always hard of being a patient because you're always ready for answers and doctors are not always, they do their best, but they're you know they've got timetables and sometimes only see patients one or two days a week. So within the constraints of the system I think that been very forthcoming and available the most, the best for me has been having community nurses or a nurse overseeing your your case they always answer the phone and they can always get those an answer from the doctor and get back to you. So, yeah, so I've had a nurse that there's someone that sort of coordinates the CAR T that they're always available to talk and answer the phone. And I've had someone that I've

always been under, nurses, I've seen my case and now I can ring her number and she answers.
Participant 021_2023AUCRT

Fantastic. I cannot, I cannot praise them more than yeah they have been absolutely there. They they spend their time, they happy to spend time with you. They explain things in great detail. Again, it's a little bit over my head sometimes, but I always have NAME with me. So the two of us can usually put it together. And also I've always got NAME to re explain things.
Yeah.
Participant 018_2023AUCRT

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

I found the nurses really helpful, but they could only say so much. Hard to get information out of the doctors. I found the residents were easier to talk to than the specialists. I think this is a common complaint. They're very busy, and I understand that. Often I had no idea what was going on really.
Participant 003_2023AUCRT

Yeah, really good. No, I've I've found I've always asked questions to the extent that you would want them answered and have given me useful information. You're able to to to give you the realistic thoughts without being too too negative but that that sort of thing. I mean I I always ask a lot of questions as well. So I suppose I probably get better value than some people because because of that whereas if you're just waiting for them to tell you stuff you probably don't get told as much but. No, I've. I've found you that the information's been good and everyone's been great with oh, except for that. As I've touched on before when I was at that rehabilitation place, I didn't really like it.
Participant 006_2023AUCRT

Look, if I talk about, look, I'm going to say overall it's been amazing. I have the phone number of the mobile for my bone marrow transplant specialist and I'm to ring him if I'm worried or if I have to go to hospital or if or text him if I've got questions. So that's amazing. And the other services at HOSPITAL are all very accessible, although trickier on the weekends, but you know on the whole really accessible. The oncologist I had though in the start pretty hopeless really. Yeah. So I've got, I've got from one extreme to the other,

amazing and but you know for everyone but him, hopeless.

Participant 016_2023AUCRT

Participant describes communication with healthcare professionals as overall negative

About that communication overall, pretty poor. The only information I've got is because I ask the questions, not because they offer answers.

Participant 008_2023AUCRT

Well, because I didn't. No, it was because it was going outside of my my capability to un to understand I

suppose. You know there were I there were things that I didn't know and I wasn't going to be able to know. And it and it I think there was a brief period a couple a couple of brief periods where I was a little bit resentful about the fact that I that I didn't didn't understand everything and I guess I was I was wanting to be able to understand everything and and blaming the people who weren't weren't able to make me understand but that was that was brief and that then you know because I realized that that's that it was not really possible to for me to understand it properly in some ways they they they they just knew a lot more than I did they didn't know everything either.

Participant 014_2023AUCRT

Table 6.11: Healthcare professional communication.

Healthcare professional 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 communication with healthcare professionals as overall positive	25	75.76	5	71.43	9	90.00	11	68.75	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	6	18.18	2	28.57	1	10.00	3	18.75	6	23.08	0	0.00	3	20.00	3	16.67
Participant describes communication with healthcare professionals as overall negative	2	6.06	0	0.00	0	0.00	2	12.50	1	3.85	1	14.29	0	0.00	2	11.11

Healthcare professional 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 communication with healthcare professionals as overall positive	25	75.76	14	73.68	11	78.57	9	64.29	16	84.21	11	78.57	14	73.68
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	6	18.18	5	26.32	1	7.14	4	28.57	2	10.53	3	21.43	3	15.79
Participant describes communication with healthcare professionals as overall negative	2	6.06	0	0.00	2	14.29	1	7.14	1	5.26	0	0.00	2	10.53

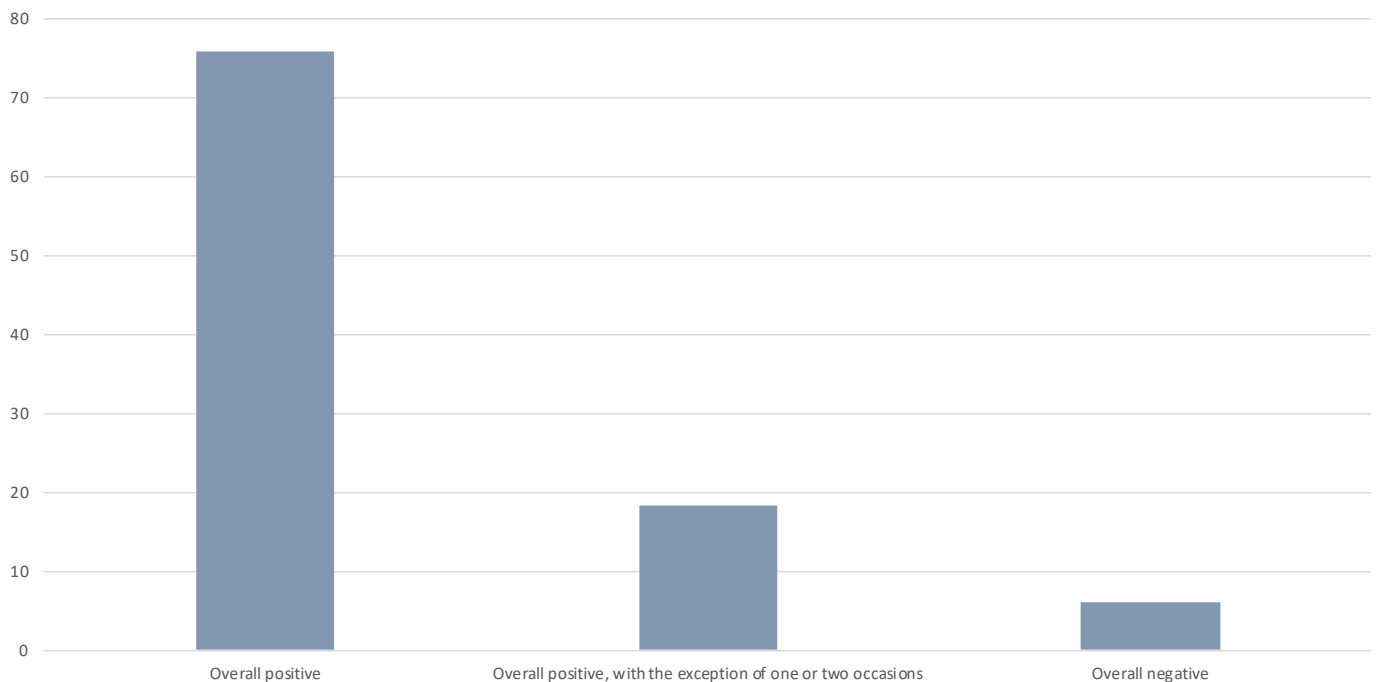


Figure 6.7: Healthcare professional communication

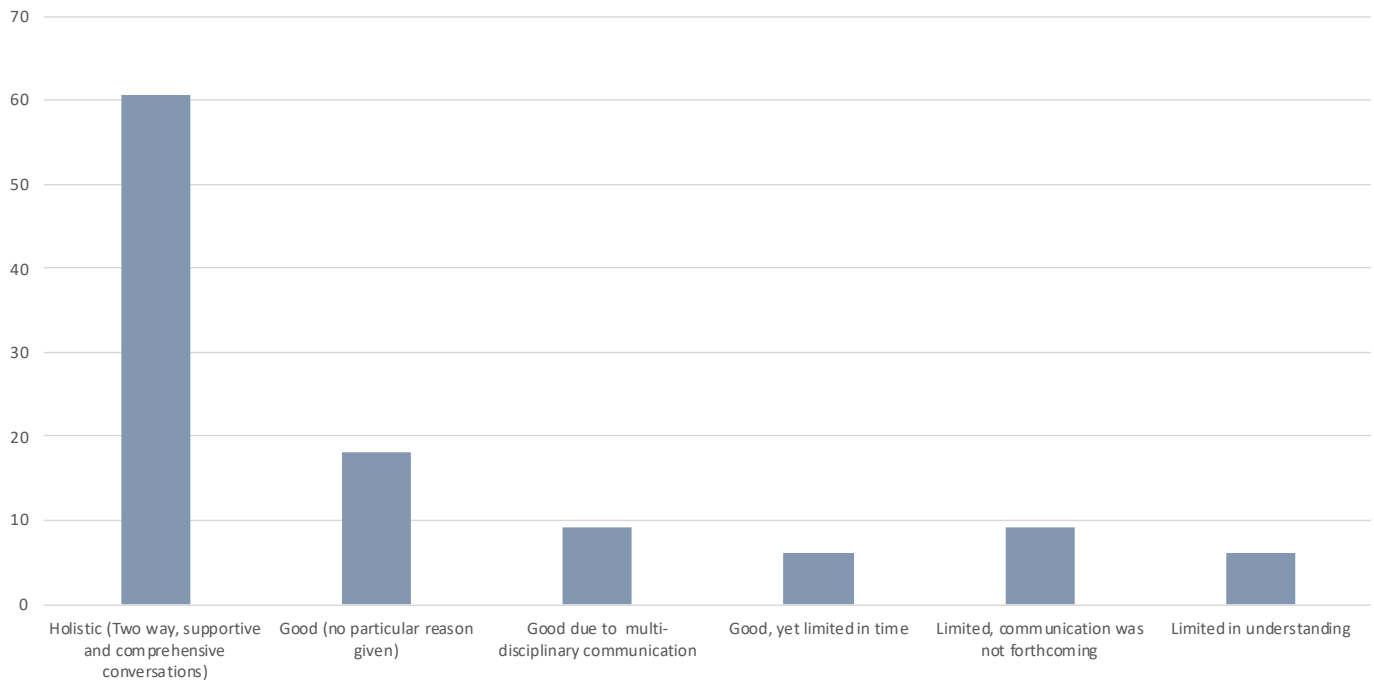


Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes communication with healthcare professionals as overall positive	Regional or remote	Diffuse Large B-Cell Lymphoma
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in the table below.

The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=30.00, IQR=4.00), Partners in health: Recognition and management of symptoms (median=22.00, IQR=5.50), Partners in health: Adherence to treatment (median=16.00, IQR=1.00), Partners in health: Total score (median=85.00, IQR=12.50) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health

The overall scores for the cohort were in the second highest quintile for Partners in health: Coping (mean=16.61, SD=4.58), indicating good coping.

Comparisons of Partners in health have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study

had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had very good overall knowledge, coping and confidence for managing their own health.

Table 6.13: Partners in health summary statistics

Partners in health scale (n=31)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	27.58	5.01	30.00	4.00	0 to 32	5
Coping*	16.61	4.58	18.00	6.00	0 to 24	4
Recognition and management of symptoms	20.71	3.66	22.00	5.50	0 to 24	5
Adherence to treatment	15.16	1.92	16.00	1.00	0 to 16	5
Total score	80.06	12.22	85.00	12.50	0 to 96	5

*Normal distribution use mean and SD as measure of central tendency

Partners in health by blood cancer type

Comparisons were made by type of blood cancer. There were 5 participants (16.13%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (32.26%) with Diffuse Large B-Cell Lymphoma, and 16 participants (51.61%) with Multiple Myeloma.

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used.

No significant differences were observed between participants by **blood cancer type** for any of the Partners in health scales.

Table 6.14: Partners in health by blood cancer type summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	16.20	3.11	Between groups	11.6	2	5.81	0.26	0.7700
	Diffuse Large B-Cell Lymphoma	10	32.26	17.50	3.63	Within groups	617.7	28	22.06		
	Multiple Myeloma	16	51.61	16.19	5.54	Total	629.3	30	27.87		

Table 6.15: Partners in health by blood cancer type summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	C ²	dF	p-value
Knowledge	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	30.00	3.00	0.31	2	0.8583
	Diffuse Large B-Cell Lymphoma	10	32.26	30.00	5.25			
	Multiple Myeloma	16	51.61	28.50	3.50			
Recognition and management of symptoms	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	24.00	5.00	2.46	2	0.2928
	Diffuse Large B-Cell Lymphoma	10	32.26	23.50	4.75			
	Multiple Myeloma	16	51.61	21.00	2.75			
Adherence to treatment	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	16.00	1.00	2.15	2	0.3405
	Diffuse Large B-Cell Lymphoma	10	32.26	15.50	1.75			
	Multiple Myeloma	16	51.61	16.00	0.00			
Total score	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	85.00	9.00	0.30	2	0.8607
	Diffuse Large B-Cell Lymphoma	10	32.26	86.00	9.00			
	Multiple Myeloma	16	51.61	78.50	14.25			

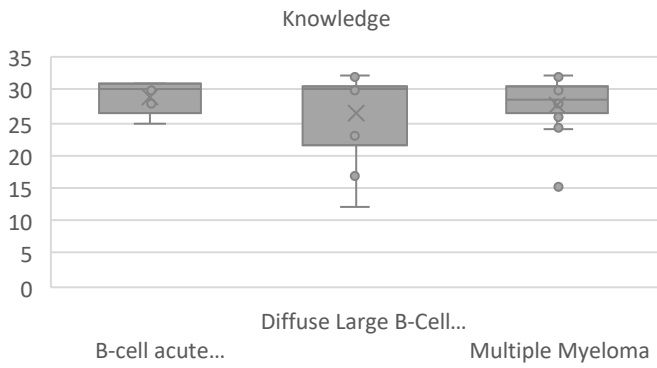


Figure 6.9: Boxplot of Partners in health: knowledge by blood cancer type

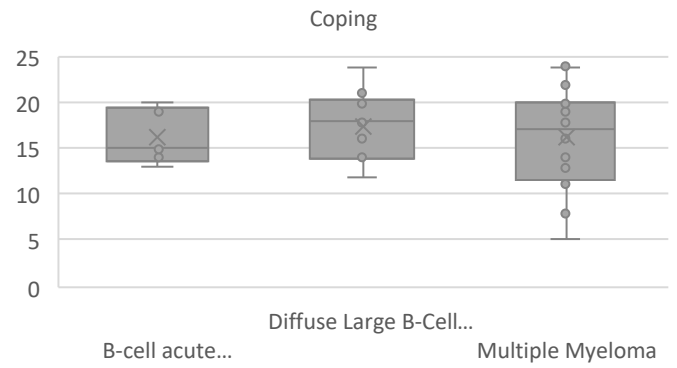


Figure 6.10: Boxplot of Partners in health: coping by blood cancer type

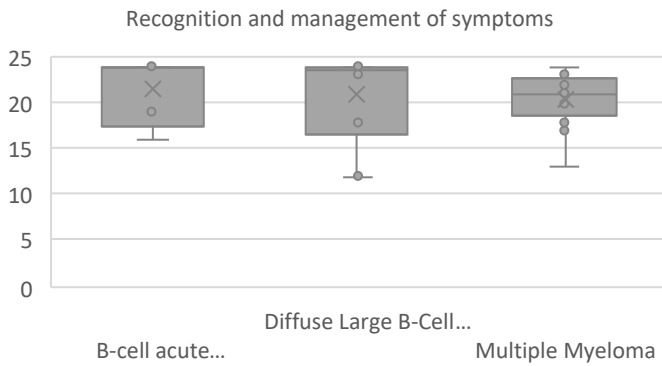


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by blood cancer type

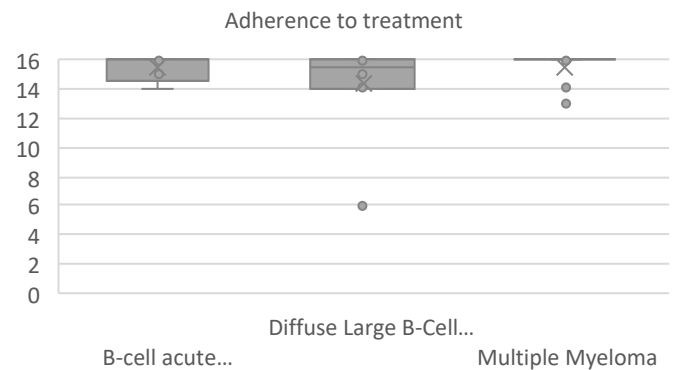


Figure 6.12: Boxplot of Partners in health: adherence to treatment by blood cancer type

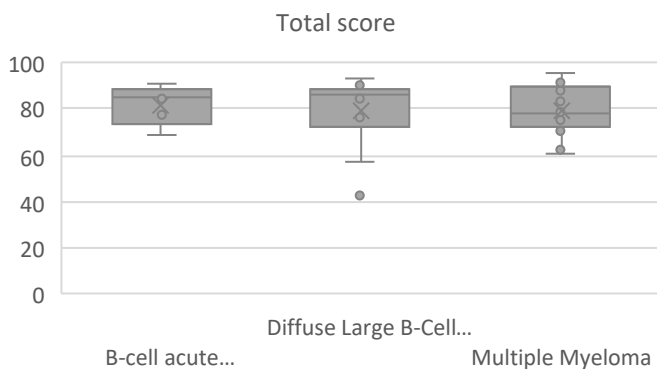


Figure 6.13: Boxplot of Partners in health Total score by blood cancer type

Partners in health by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 24 participants (77.42%) that had treatment with Car T-cell therapy and, 7 participants (22.58%) that did not .

A two-sample t-test was used when assumptions for normality and variance were met, or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Partners in health scales.

Table 6.16: Partners in health by CAR T-cell therapy summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	No	24	77.42	16.17	4.70	-1.00	29	0.3234
	Yes	7	22.58	18.14	4.10			

Table 6.17: Partners in health by CAR T-cell therapy summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	No	24	77.42	29.50	4.00	101.50	0.4164
	Yes	7	22.58	30.00	11.00		
Recognition and management of symptoms	No	24	77.42	22.00	4.25	92.50	0.7010
	Yes	7	22.58	22.00	6.00		
Adherence to treatment	No	24	77.42	16.00	1.25	93.00	0.6274
	Yes	7	22.58	16.00	1.00		
Total score	No	24	77.42	84.50	12.25	82.50	0.9623
	Yes	7	22.58	86.00	19.50		

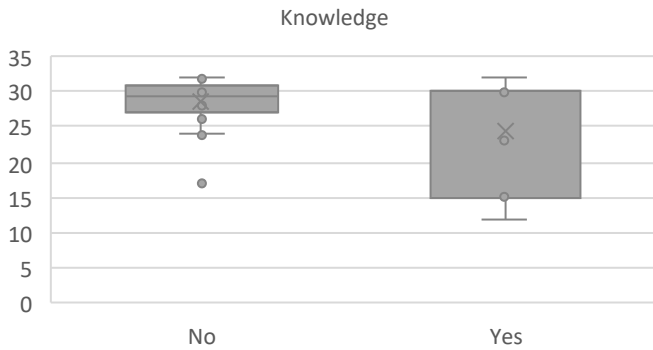


Figure 6.14: Boxplot of Partners in health: knowledge by CAR T-cell therapy

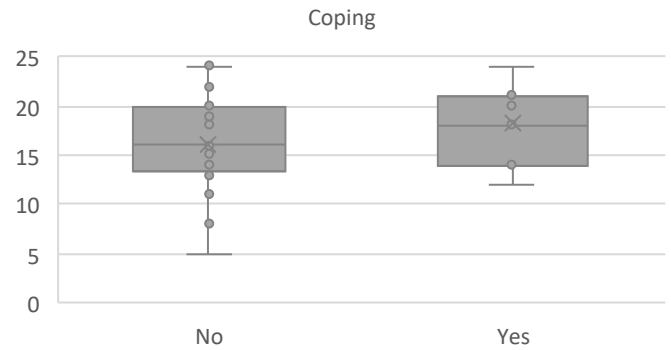


Figure 6.15: Boxplot of Partners in health: coping by CAR T-cell therapy

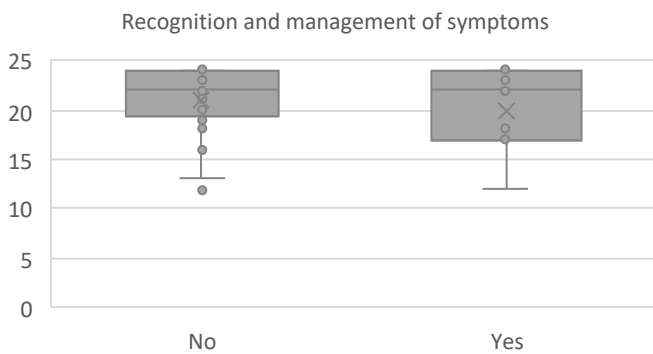


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by CAR T-cell therapy

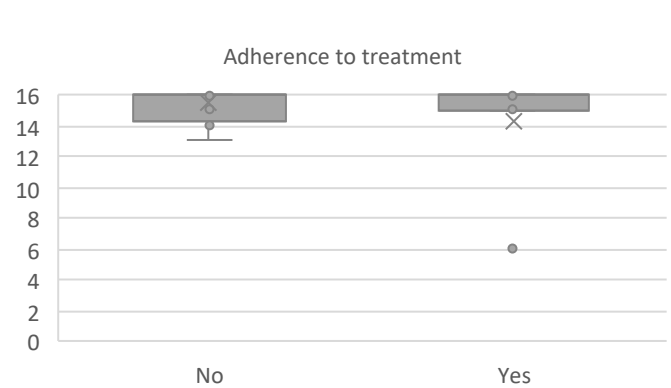


Figure 6.17: Boxplot of Partners in health: adherence to treatment by CAR T-cell therapy

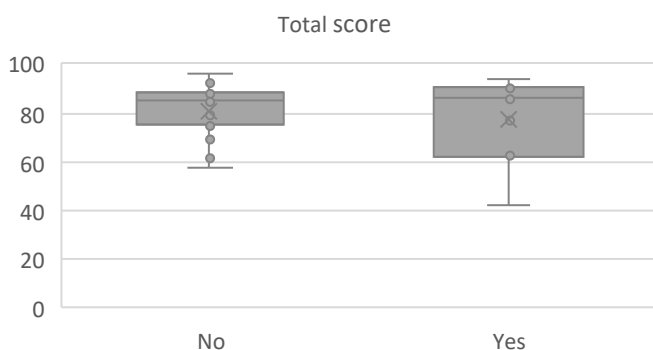


Figure 6.18: Boxplot of Partners in health Total score by CAR T-cell therapy

Partners in health by gender

Comparisons were made by gender, there were 13 female participants (41.94%), and 18 male participants (58.06%).

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met,

a Wilcoxon rank sum test with continuity correction was used

No significant differences were observed between participants by **gender** for any of the Partners in health scales.

Table 6.18: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Female	13	41.94	18.46	4.01	2.00	29.00	0.0546
	Male	18	58.06	15.28	4.60			

Table 6.19: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Female	13	41.94	30.00	1.00	146.50	0.2401
	Male	18	58.06	28.00	6.50		
Recognition and management of symptoms	Female	13	41.94	23.00	4.00	165.00	0.0534
	Male	18	58.06	21.00	5.50		
Adherence to treatment	Female	13	41.94	16.00	1.00	126.00	0.6809
	Male	18	58.06	16.00	1.75		
Total score	Female	13	41.94	86.00	10.00	165.50	0.0544
	Male	18	58.06	78.00	17.75		

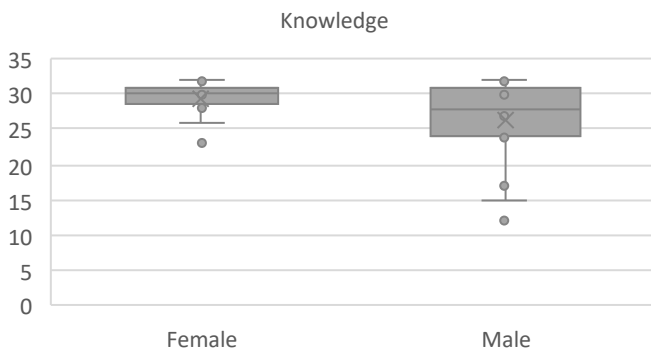


Figure 6.19: Boxplot of Partners in health: knowledge by gender

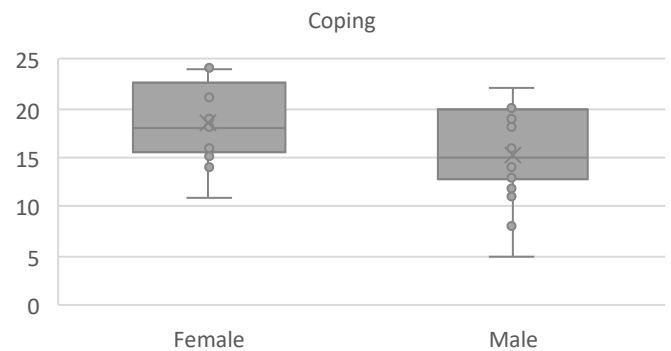


Figure 6.20: Boxplot of Partners in health: coping by gender

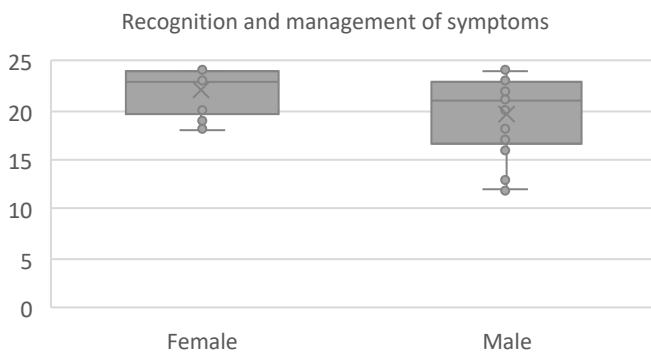


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by gender

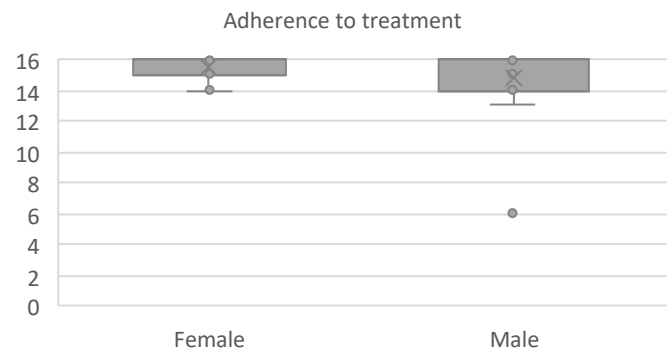


Figure 6.22: Boxplot of Partners in health: adherence to treatment by gender

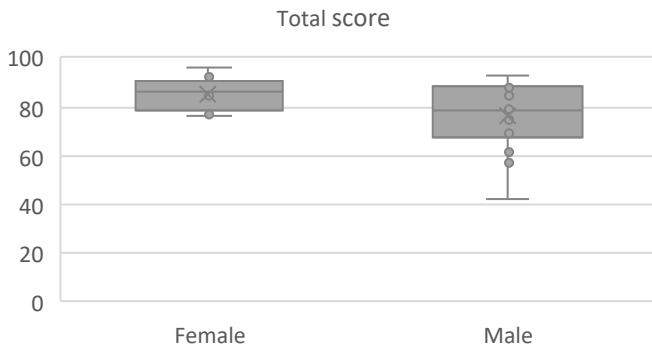


Figure 6.23: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=17, 54.84%), and participants aged 65 and older (n=14, 45.16%).

A two-sample t-test was used when assumptions for normality and variance were met, or when

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.20: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Aged 25 to 64	17	54.84	15.41	4.11	-1.65	29.00	0.1087
	Aged 65 and older	14	45.16	18.07	4.84			

Table 6.21: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 64	17	54.84	29.00	5.00	96.50	0.3769
	Aged 65 and older	14	45.16	30.00	4.50		
Recognition and management of symptoms	Aged 25 to 64	17	54.84	21.00	6.00	102.50	0.5188
	Aged 65 and older	14	45.16	22.50	3.25		
Adherence to treatment	Aged 25 to 64	17	54.84	16.00	2.00	85.00	0.1080
	Aged 65 and older	14	45.16	16.00	0.00		
Total score	Aged 25 to 64	17	54.84	78.00	11.00	80.00	0.1260
	Aged 65 and older	14	45.16	86.50	12.00		

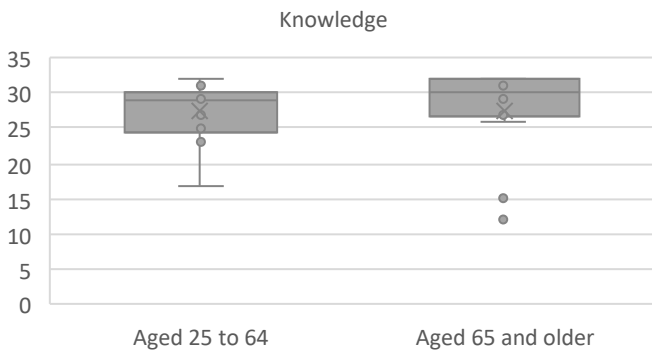


Figure 6.24: Boxplot of Partners in health: knowledge by age

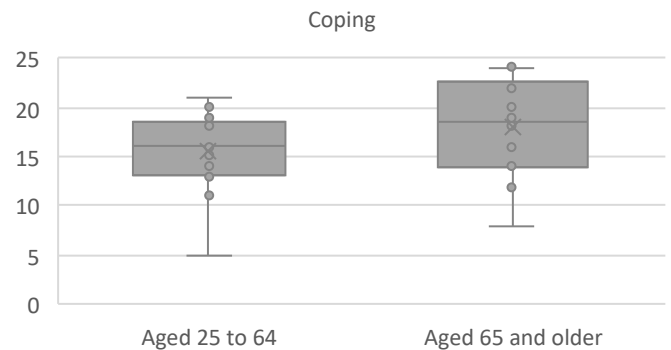


Figure 6.25: Boxplot of Partners in health: coping by age

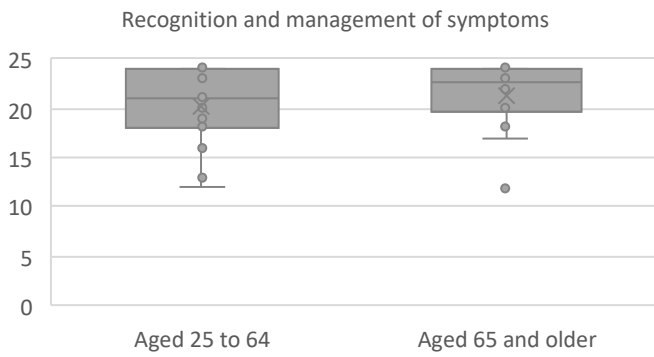


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by age

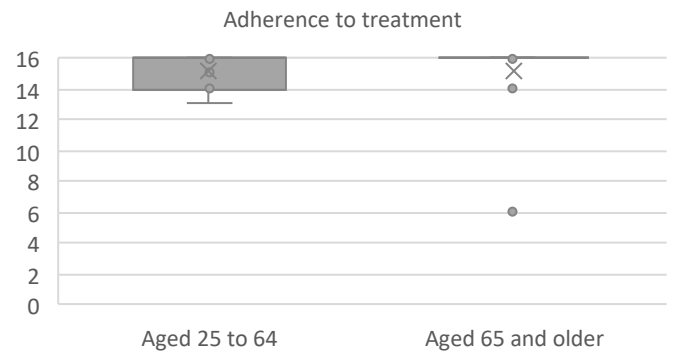


Figure 6.27: Boxplot of Partners in health: adherence to treatment by age

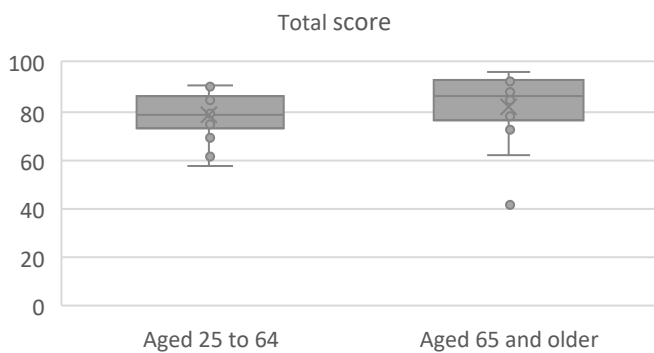


Figure 6.28: Boxplot of Partners in health Total score by age

Partners in health by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=15, 48.39%) were compared to those living in a major city (n=16, 51.61%).

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used

A two sample t-test indicated that the mean score for the Partners in health Coping scale [$t(29) = -2.80$, $p = 0.0090^*$] was significantly lower for participants in the Metropolitan subgroup (Mean = 14.47, SD = 4.61) compared to participants in the Regional or remote subgroup (Mean = 18.63, SD = 3.63.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in

health Recognition and management of symptoms scale [$W = 56.50$, $p = 0.0114^*$] was significantly lower for participants in the Metropolitan subgroup (Median = 20.00, IQR = 5.50) compared to participants in the Regional or remote subgroup (Median = 23.00, IQR = 2.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Total score scale [$W = 44.50$, $p = 0.0030^*$] was significantly lower for participants in the Metropolitan subgroup (Median = 76.00, IQR = 16.50) compared to participants in the Regional or remote subgroup (Median = 86.50, IQR = 5.75).

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Regional or remote subgroup scored higher than

participants in the Metropolitan subgroup, however, coping with their condition was good for both groups.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the Regional or remote subgroup had a higher total score for navigation compared to Metropolitan subgroup, however recognition and management of symptoms was very good for both groups.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Regional or remote subgroup scored higher than participants in the Metropolitan subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Regional or remote subgroup, and good for participants in the Metropolitan subgroup.

Table 6.22: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Metropolitan	15	48.39	14.47	4.61	-2.80	29.00	0.0090*
	Regional or remote	16	51.61	18.63	3.63			

Table 6.23: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Metropolitan	15	48.39	28.00	6.50	64.50	0.0278*
	Regional or remote	16	51.61	30.00	2.50		
Recognition and management of symptoms	Metropolitan	15	48.39	20.00	5.50	56.50	0.0114*
	Regional or remote	16	51.61	23.00	2.00		
Adherence to treatment	Metropolitan	15	48.39	16.00	2.00	84.00	0.0899
	Regional or remote	16	51.61	16.00	0.00		
Total score	Metropolitan	15	48.39	76.00	16.50	44.50	0.0030*
	Regional or remote	16	51.61	86.50	5.75		

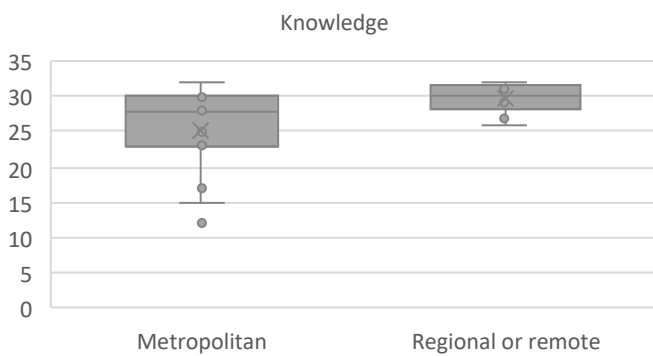


Figure 6.29: Boxplot of Partners in health: knowledge by location

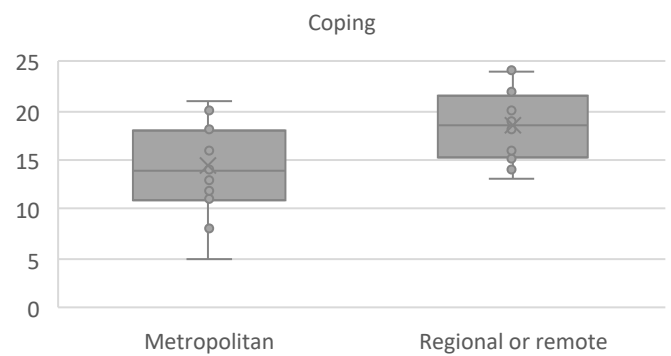


Figure 6.30: Boxplot of Partners in health: coping by location

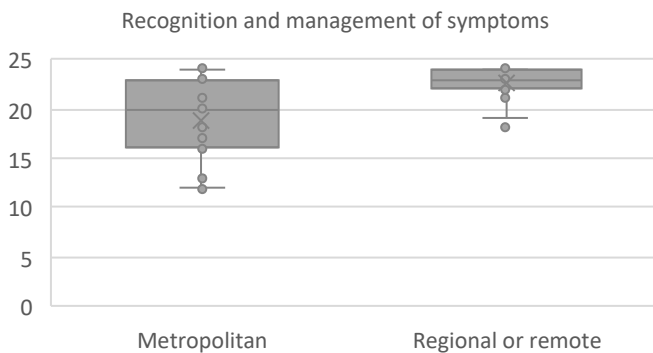


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by location

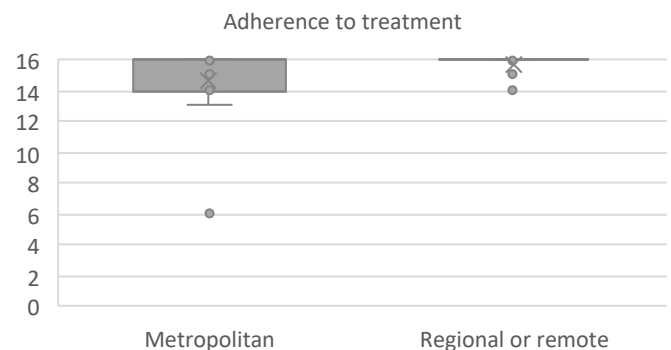


Figure 6.32: Boxplot of Partners in health: adherence to treatment by location

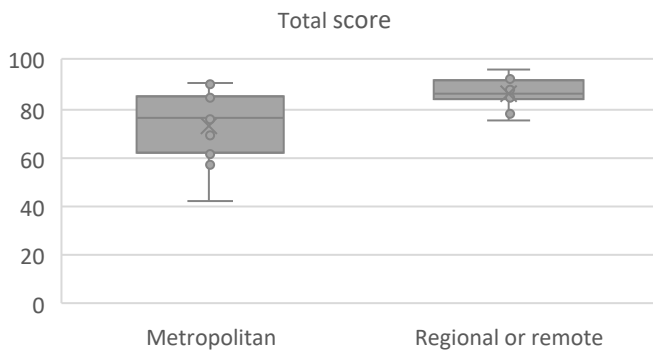


Figure 6.33: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=14, 45.16%) compared to those with a higher SEIFA score of 7-10 (n=17, 54.84%).

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used

A two sample t-test indicated that the mean score for the Partners in health Coping scale [t(29) = -2.86 , p = 0.0078*] was significantly lower for participants in the Higher advantage subgroup (Mean = 14.29, SD = 4.53) compared to participants in the Mid to low advantage subgroup (Mean = 18.53, SD = 3.74.)

A two sample t-test indicated that the mean score for the Partners in health Total score scale [t(29) = -2.19 , p = 0.0367*] was significantly lower for participants in the Higher advantage subgroup (Mean = 75.07, SD =

14.02) compared to participants in the Mid to low advantage subgroup (Mean = 84.18, SD = 8.98.)

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that participants in the Mid to low advantage subgroup were good at coping with their condition, and participants in the Higher advantage subgroup were average at coping.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Mid to low advantage subgroup, and good for participants in the Higher advantage subgroup.

Table 6.24: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Higher advantage	14	45.16	14.29	4.53	-2.86	29.00	0.0078*
	Mid to low advantage	17	54.84	18.53	3.74			
Total score	Higher advantage	14	45.16	75.07	14.02	-2.19	29.00	0.0367*
	Mid to low advantage	17	54.84	84.18	8.98			

Table 6.25: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Higher advantage	14	45.16	28.50	4.75	95.50	0.3556
	Mid to low advantage	17	54.84	30.00	4.00		
Recognition and management of symptoms	Higher advantage	14	45.16	20.00	5.00	83.50	0.1581
	Mid to low advantage	17	54.84	23.00	3.00		
Adherence to treatment	Higher advantage	14	45.16	15.50	2.00	78.00	0.0520
	Mid to low advantage	17	54.84	16.00	0.00		

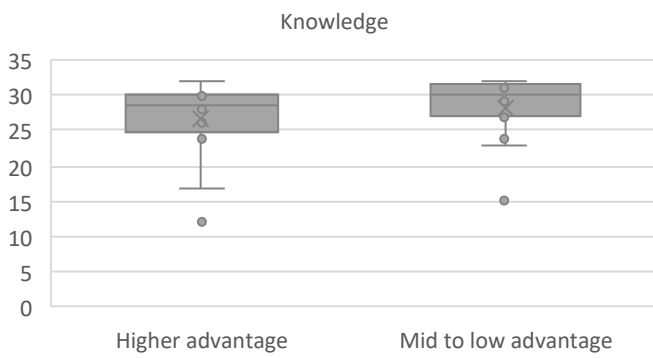


Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic status

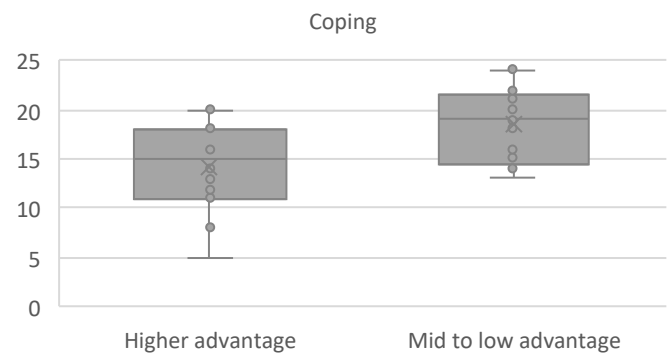


Figure 6.35: Boxplot of Partners in health: coping by socioeconomic status

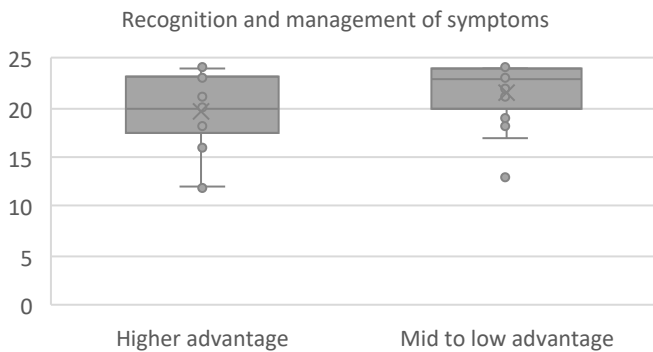


Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

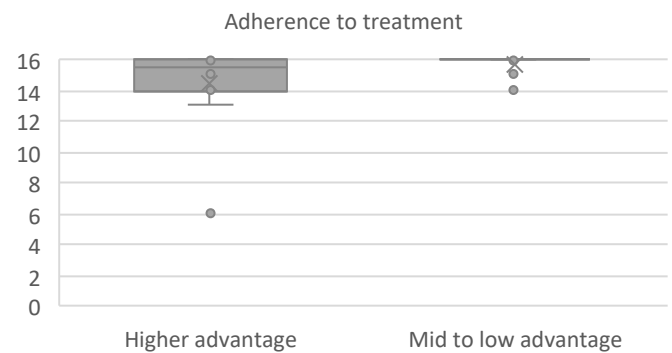


Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic status

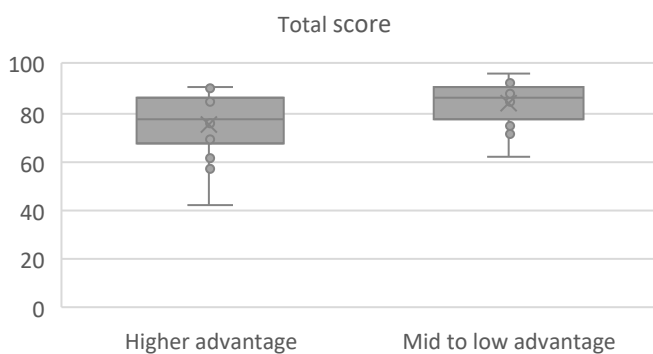


Figure 6.38: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as

prescribed all the time (n=22, 66.67%), and 11 participants (33.33%) responded that they took medicines as prescribed most of the time.

Table 6.26: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=33	
All of the time	22	66.67
Most of the time	11	33.33
Sometimes	0	
Rarely	0	

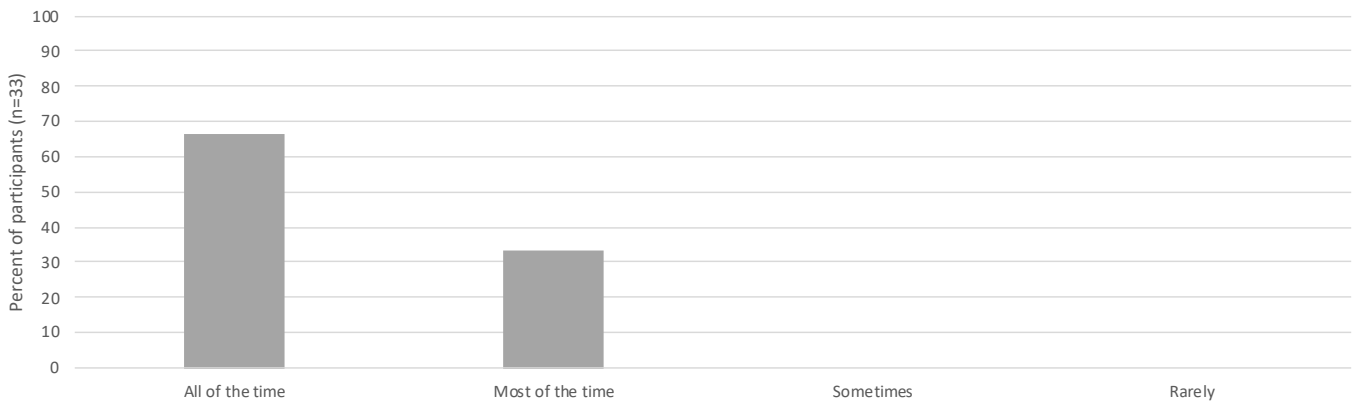


Figure 6.39: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=26, 78.79%), disease management (n=24, 72.73%), dietary (n=21, 63.64%), and disease cause (n=17, 51.52%) were most frequently given to participants by

healthcare professionals, and information about complementary therapies (n=5, 15.15%), psychological/ social support (n=5, 15.15%), and hereditary considerations (n=1, 3.03%) were given least often.

Table 6.27: Information given by health professionals

Information given by health professionals	Number (n=33)	Percent
Disease Cause	17	51.52
Treatment options	26	78.79
Disease management	24	72.73
Complementary therapies	5	15.15
Interpret test results	12	36.36
Clinical trials	9	27.27
Dietary	21	63.64
Physical activity	15	45.45
Psychological/ social support	5	15.15
Hereditary considerations	1	3.03

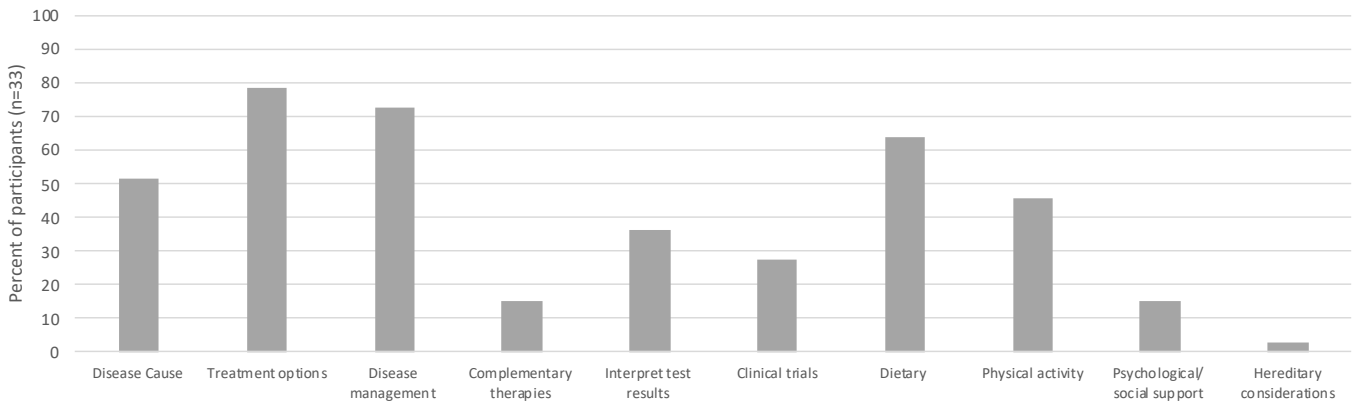


Figure 6.40: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were complementary therapies (n=16, 48.48%), disease cause (n=14, 42.42%), interpret test results (n=14,

42.42%), and treatment options (n=12, 36.36%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=10, 30.30%), clinical trials (n=9, 27.27%), and hereditary considerations (n=8, 24.24%) were searched for least often.

Table 6.28: Information searched for independently

Information searched independently	Number (n=33)	Percent
Disease Cause	14	42.42
Treatment options	12	36.36
Disease management	12	36.36
Complementary therapies	16	48.48
Interpret test results	14	42.42
Clinical trials	9	27.27
Dietary	12	36.36
Physical activity	12	36.36
Psychological/ social support	10	30.30
Hereditary considerations	8	24.24

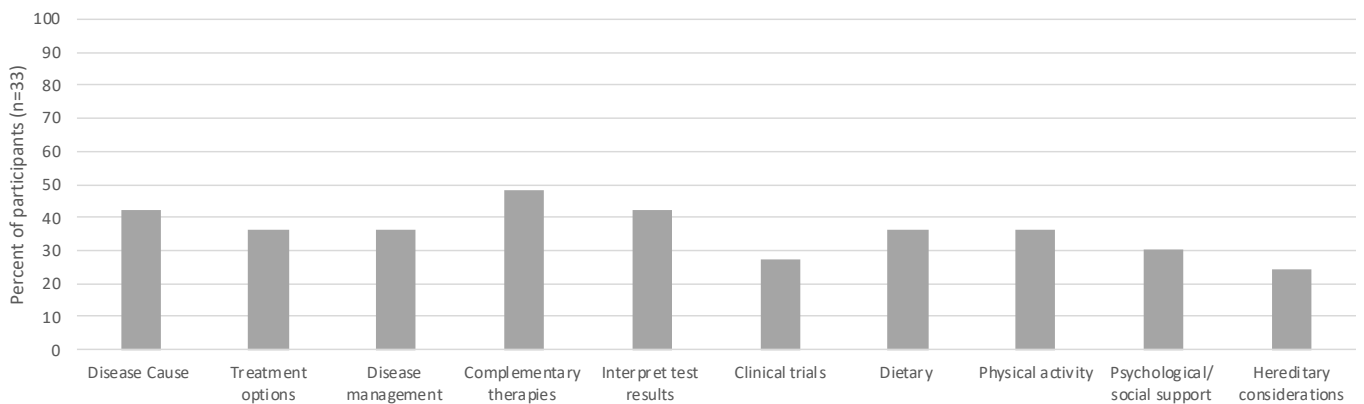


Figure 6.41: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=25, 75.76%) and psychological/ social support (n=19, 57.58%).

The topics that participants were given most information from both healthcare professionals and searching independently were treatment options (n=10, 30.30%) and dietary information (n=9, 27.27%).

The topics that participants did not search for independently after receiving information from healthcare professionals were disease management (n=17, 51.52%) and treatment options (n=16, 48.48%).

The topics that participants searched for independently after not receiving information from healthcare professionals were complementary therapies (n=14, 42.42%) and disease cause (n=9, 27.27%).

Table 6.29: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=33	%	n=33	%	n=33	%	n=33	%
Disease Cause	7	21.21	12	36.36	5	15.15	9	27.27
Treatment options	5	15.15	16	48.48	10	30.30	2	6.06
Disease management	4	12.12	17	51.52	7	21.21	5	15.15
Complementary therapies	14	42.42	3	9.09	2	6.06	14	42.42
How to interpret test results	13	39.39	6	18.18	6	18.18	8	24.24
Clinical trials	18	54.55	6	18.18	3	9.09	6	18.18
Dietary information	9	27.27	12	36.36	9	27.27	3	9.09
Physical activity	13	39.39	8	24.24	7	21.21	5	15.15
Psychological/social support	19	57.58	4	12.12	1	3.03	9	27.27
Hereditary considerations	25	75.76	0	0.00	1	3.03	7	21.21

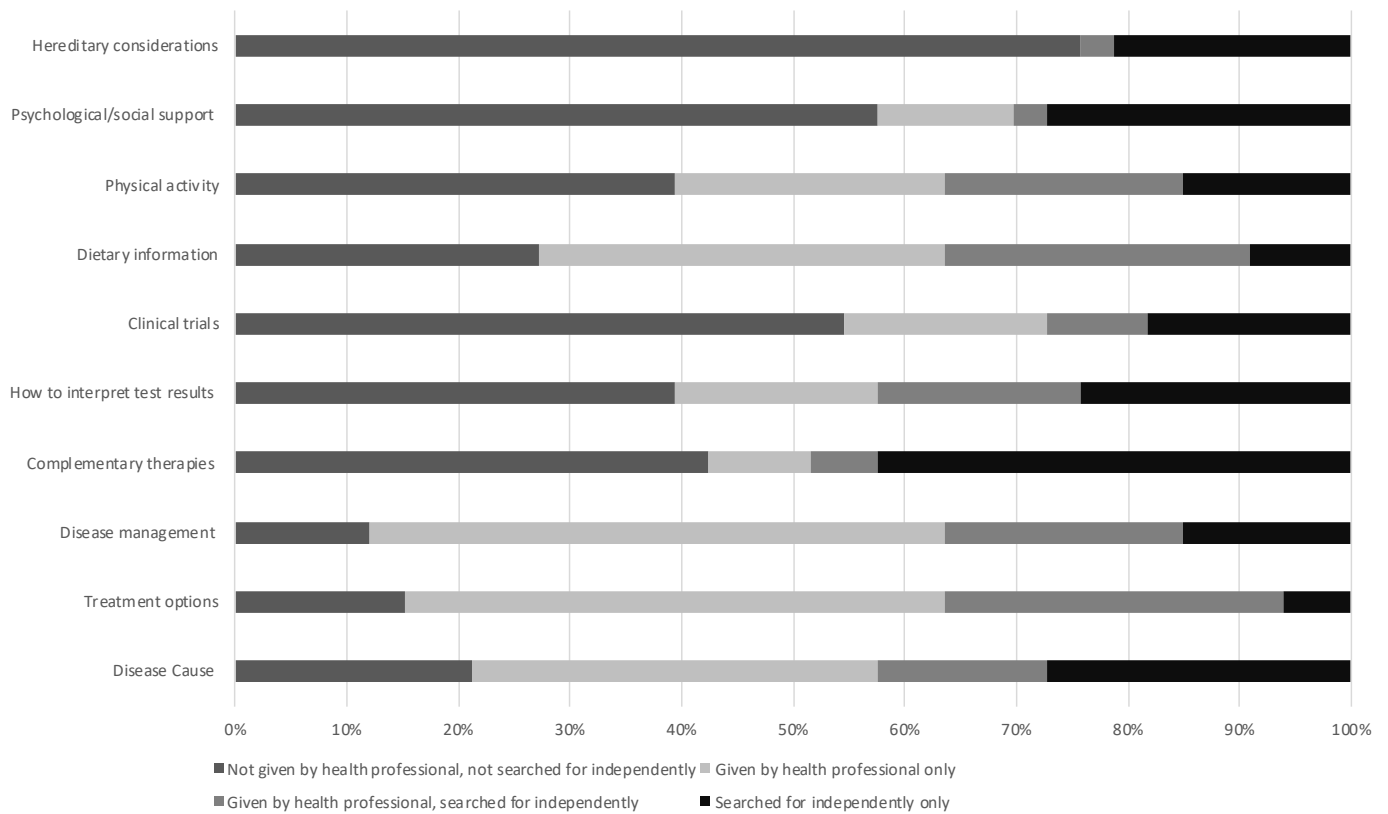


Figure 6.42: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most accessed and 5 is the least accessed. A weighted average is presented in the table below. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from Hospital or clinic where being treated was most accessed followed by information from the Non-profit organisations, charity or patient organisations. Information from Government and from Pharmaceutical companies were least accessed.

Table 6.30: Most accessed information

Information source	Weighted average (n=33)
Hospital or clinic where being treated	3.84
Non-profit organisations, charity or patient organisations	3.47
Medical journals	2.91
Government	2.81
Pharmaceutical companies	2.09

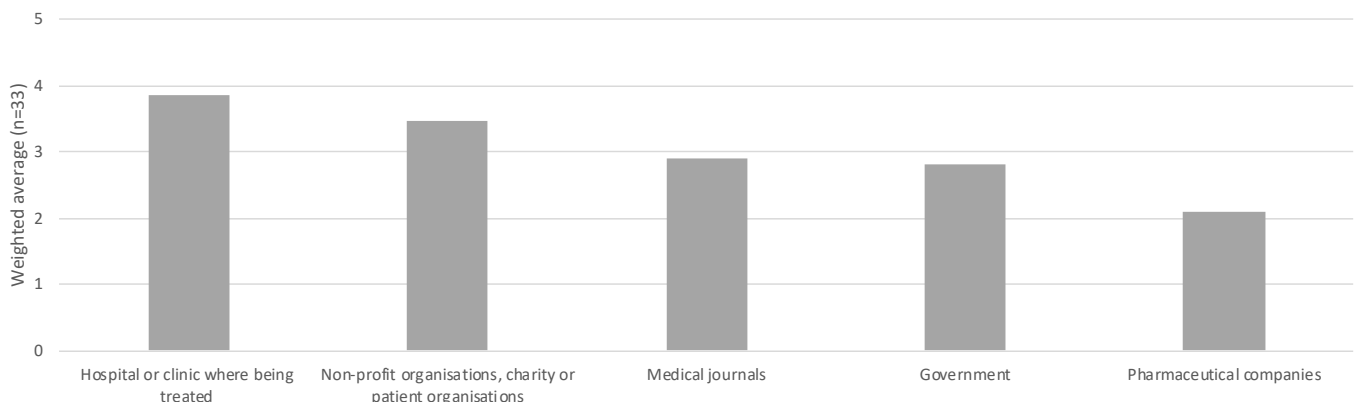


Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 17 participants (51.52%) had accessed My Health Record, 16 participants (48.48%) had not.

Of those that had accessed My Health Record, there were 3 participants (17.65%) who found it to be poor or very poor, 12 participants (70.59%) who found it acceptable, and 2 participants (11.76%) who found it to be good or very good.

Table 6.31: Accessed My Health Record

Accessed "My health record"	Number (n=33)	Percent
Yes	17	51.52
No	13	39.39
Not sure	2	6.06
Doesn't know what 'My Health Record' is	1	3.03

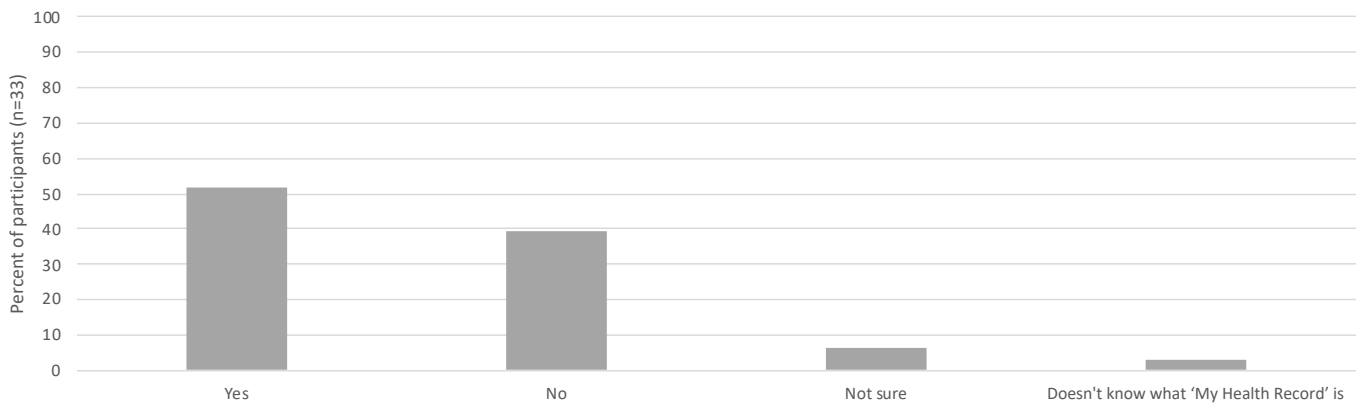


Figure 6.44: Accessed My Health Record

Table 6.32: How useful was My Health Record

How useful was "My health record"	Number (n=17)	Percent
Very poor	2	11.76
Poor	1	5.88
Acceptable	12	70.59
Good	2	11.76
Very good	0	0.00

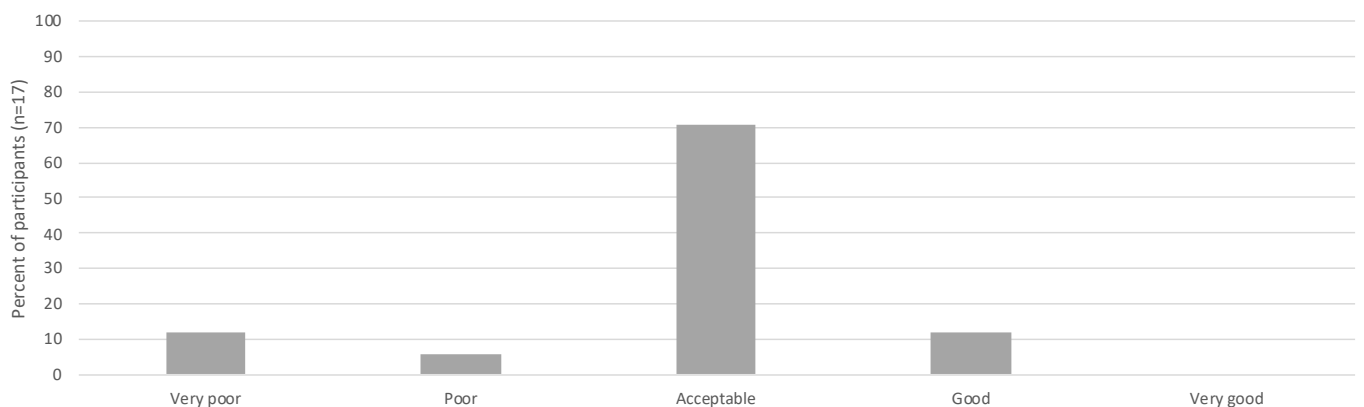


Figure 6.45: How useful was My Health Record