Section 6

Information and communication

Section 6 Summary: 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 type of information accessed by 20 participants (55.56%) was through the internet in general. This was followed by books, pamphlets and newsletters (n=15, 41.67%) and information from specific health charities (n=12, 33.33%). There were eight participants (22.22%) that described accessing information through their treating clinician and seven participants (19.44%) that described accessing information through Facebook and/or social media. Other types of information accessed included other patients' experiences (n=4, 11.11%) and primarily through journals or research articles (n=4, 11.11%).

Information that has been helpful

- In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 12 participants (33.33%) was information from reliable source, and this was followed by talking to their doctor or specialists (n=7, 19.44%). There were six participants (16.67%) that described health charities as being helpful and six (16.67%) that described information that's easy to understand as being helpful. Other types of information described as being helpful included information about what to expect (n=5, 13.89%), information specific to their condition (n=5, 13.89%) and other people's experiences (n=4, 11.11%).

Information that has not been 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 response by 18 participants (50.00%) was that no information was not helpful, and this was followed by GP and specialists as being not helpful (n=5, 13.89%).

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. Overall, the most common theme was talking to someone (n=10, 27.78%). There were seven participants (19.44%) that described a preference for talking to someone plus online information. There were also seven participants (19.44%) that described online information as their main preference.

- There were 12 participants (33.33%) whose rationale for their preference was simply a personal preference or gave no strong rationale for their preference. Among those who gave a rationale for their preference, seven (19.44%) described it as due to being able to digest information at their own pace and six (16.67%) described it as due to being able to, or having time to, ask questions.

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 time that participants described being receptive to receiving information was from the beginning/diagnosis (n=12, 33.33%) and this was followed by participants describing being receptive to information a specific amount of time after (n=7, 19.44%). There were six participants (16.67%) that described being receptive to information after the shock of diagnosis.

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.

- 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. Participants in this study had excellent 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). Participants in this study had very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

- 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. Participants in this study had an excellent 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. Participants in this study had excellent recognition and management of symptoms.

Information given by health professionals

- Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=27, 75.00%), disease management (n=26, 72.22%), and disease cause (n=22, 61.11%) were most frequently given to participants by healthcare professionals, and information about psychological/social support (n=8, 22.22%), and complementary therapies (n=4, 11.11%) 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. Information about disease management (58.33%) disease cause (55.56%), and treatment options (55.56%) were most often searched for independently by participants. Psychological/social support (27.78%), and hereditary considerations (30.56%) were least searched for.

Information gaps

- The largest gaps in information, where information was neither given to patients nor searched for independently were for psychological/social support (n=21, 58.33%), hereditary considerations genes or genomic biomarker information (n=21, 58.33%), and complementary therapies (n=20, 55.56%). Participants were given most information either from healthcare professionals or independently for disease management (n=16, 44.44%), and treatment options (n=15, 41.67%). The topic that was most searched for independently following no information from health professionals was complementary therapies (n=12, 33.33%).

Most accessed information

- Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. Across all participants, information from the hospital or clinic where treated was most accessed, followed by information from non-profit or charities or patient organisations.

My Health Record

- My Health Record is an online summary of key health information, an initiative of the Australian Government. Eleven participants (39.29%) had accessed "My Health Record". There were 15 (53.57%) who had not, two participants did not know what it is (7.14%), and four participants (4.00%) were not sure. Of those that had accessed "My Health Record", five participants (45.45%) found it good or acceptable, six participants (54.54%) found it poor, or very poor.

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 type of information accessed by 20 participants (55.56%) was through the internet in general, and this was followed by books, pamphlets and newsletters (n=15, 41.67%) and information from specific health charities (n=12, 33.33%). There were eight participants (22.22%) that described accessing information through their treating clinician and seven participants (19.44%) that described accessing information through Facebook and/or social media. Other types of information accessed included other patients experience (n=4, 11.11%) and primarily through journals or research articles (n=4, 11.11%).

In relation to subgroup variations, participants in the subgroups *Carer* (37.50%), *Aged 55 to 64* (25.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) described accessing information through the internet in general less frequently than the general population (55.56%), while those in the subgroups *Higher SEIFA* (60.00%), and *Aged 75 or older* (87.50%) described this more frequently.

Participants in the subgroup *AL amyloidosis* (60.00%) described receiving information from books, pamphlets and newsletters more frequently than the general population (41.67%), while those in the subgroups *Aged 55 to 64* (25.00%), and *Mid to low SEIFA* (27.27%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), and *Regional or remote* (44.44%) described accessing information through specific health charities more frequently than the general population (33.33%), while those in *ATTR-cardiac* (22.22%) and *Aged 55 to 64* (12.50%) subgroup described this less frequently.

Participants in the subgroups *Aged 55 to 64* (37.50%) and *Trade or high school* (35.71%) described accessing information through their treating physician more frequently than the general population (22.22%), while those in the subgroups *University* (7.14%) and *AL amyloidosis* (10.00%) described this less frequently.

Participants in the *Mid to low SEIFA* (9.09%) subgroup described accessed information through Facebook and/or social media less frequently than the general population (19.44%), whereas those in the *ATTR-cardiac* subgroup (33.33%) described this more frequently. Participants in the *Carer* (0.00%), *Aged 75 or older* (0.00%), and *Regional or remote* (0.00%) subgroups did not describe this at all.

Participants in the subgroups *AL amyloidosis* (30.00%), and *Aged 75 or older* (25.00%) described primarily accessing information through other patients' experiences, this is more frequently than the general population (11.11%). Participants in the *Mid to low SEIFA* (0.00%), *Aged 55 to 64* (0.00%) and *Carer* (0.00%) subgroups did not describe this at all.

Participants in the *Carer* (25.00%), *Female* (21.23%), and *Regional or remote* (22.22%) subgroups described accessing information primarily through journals and research articles more frequently than the general population (11.11%), while those in the subgroups *Trade or high school* (0.00%) and *Aged Aged 75 or older* (0.00%) do not describe this.

Internet (including health charities)

What type of information? I'm sorry, again, I don't know what you mean by type. I've read everything. I've looked up and read everything. I've got literature, internet. I've got stuff from the Amyloidosis association that I read a lot. I have, I think, read as much as I possibly can without getting too confused. Participant 001AL

Mainly going online. One thing, I find it a bit depressing to go online and read about stuff. Then also some of the case history that are written up by patients, some of the most recent new amyloidosis website in Australia, they are quite confronting some of the-- that I've mentioned before, some of the trials and tribulations that people have been through. Participant 011ATR

Just what's on the websites, and there's quite a bit of it there. I think there's quite a bit of information available there and talking to the people at the clinics I go to, and also, the woman that helps, NAME, who works with the Amyloidosis Society. They have been fantastic. Participant 017ATR

Books, pamphlets and newsletters

We got a pamphlet from the NAME hospital that gave us information on all the basics of the familial one and then we researched it online. There's a lot of stuff on the internet that when you drill right

down into it. You can pick up on the particular amyloid that I have. Participant 009ATR

Well, I've got a good little booklet. I think it's as much information as I need except, as I just said I don't think they're saying anything about the eye. I haven't heard much about that at all. No, I haven't really read anything about it. Participant 010ATR

Well, from the amyloid clinic in LOCATION METROPOLITAN, they give us some free data or information and read through a lot of literature. That was very good. Participant 014ATR

Specific health charity

We were very, very, very lucky. We were put in contact through Leukaemia Foundation, we literally spoke to a wonderful lady who helped us out not only via net but more or less with hypertension because we didn't know where to go but put us on to a lady who knew everything about amyloidosis. She was magnificent. The amount of brochures she gave me- literally sent out brochures. Basically, she met with us personally and not only one or two times but whenever we needed her. Participant 004CA

Yes, we're with the Australian Amyloidosis Association. We're members of that. In LOCATION here, they've brought their own group. We all get together and support each other, talk to each other, talk about our problem. Participant 009ATR

I did go into things like the Kidney Foundation, the Australian-- There's an Australian amyloidosis group too, but I don't really look at them now because, after two years, we're starting to feel comfortable with where things are at the moment. Participant 001CA

Facebook and/or social media

There are amyloid support groups both Australian based and international on different social media sites, I've got even a pamphlet for amyloid by the hospital in LOCATION METROPOLITAN where I was first diagnosed, I was given when I started-- yes that's pretty-- my doctors pretty much it. Participant 004ATR

There's a couple of decent YouTube videos that go through a couple of things as well. Aside from that, information used around- I've had a few different things, a couple of articles and things, but not much at all to be honest. Participant 006ATR

They have their Facebook groups and things, but I don't find them a good-- you get quite a lot of negativity and I understand that, but I don't bounce as well off that. I prefer to just go into facts and what is affecting me. That might sound selfish, but I think sometimes you have to protect yourself a bit, what you see and hear and not hear the negative stuff. Participant 012ATR

Treating clinician

I do go with NAME HUSBAND to the Amyloidosis Centre at the NAME HOSPITAL. That's usually with NAME CLINICIAN and two other cardiac specialists and a renal specialist. The cardiac and the renal specialist tend to be different each time you'd go. NAME CLINICIAN is the head of that centre and so he's the one that liaises, pulls everything together I suppose. Participant 001CA

I have read books on it, I've talked to doctors about it, I've researched on the Internet, I have been to seminars with the specialists in LOCATION METROPOLITAN. I've talked to a lot of people with it, I've talked with people who deal with it, I've talked to people who are active carers for it. Yes, I collect a lot of information on things like that. I like to know. Participant 002ALX

Yes. Apart from discussing it with the clinical team, and they gave me as much information as I wanted, I then went and confirmed through various websites to find out what is out there that way. I've also used a couple of Facebook groups to gain information that way as well, that's specific to the amyloid. Wide range of sources, and I use each one with a grain of salt until I get the information confirmed in other places. Participant 015ATR

Other patients' experiences

I talk to other patients and we have morning teas, and when we were not locked down with COVID, we used to have those three or four times a year. Participant 003AL

There's a lot of very informative information gleaned from the discussions from other patients. People are affected much worse than I am with their amyloidosis. The brochures that I've been given too, a guide to patients and families from the

Leukaemia Foundation, Amyloidosis, that's been very helpful. Participant 003ALX

I have read books on it, I've talked to doctors about it, I've researched on the Internet, I have been to seminars with the specialists in LOCATION METROPOLITAN. I've talked to a lot of people with it, I've talked with people who deal with it, I've talked to people who are active carers for it. Yes, I collect a lot of information on things like that. I like to know. Participant 002ALX

Journals (research articles)

I can't tell you now, but our daughter, actually, I think she saved the documents. It was out of medical paraphernalia, whatever medical libraries. She printed that and gave us a, I don't know, a 30-page document of very technical information, but there were pieces of it I was able to absorb and some of it, I had to get explained to me, but I think it was a collection of information. Then as time went on, I think I did too have an understanding of what the disease was and where it could go. Participant 001CA

It's the NAME CLINIC booklets. There's also the scientific journals that I was able to access at the time, there's websites in LOCATION and LOCATION. Participant 002AL

Apart from NAME DOCTOR giving us that information in 2014, and if she comes anything else, she sends it out, the medical camp have sent nothing. What we do is we do that ourselves. I go through London free cases; free Mayo clinic or PA have a few research cases. Free of cost, I don't pay for anything. Participant 005CA

Table 6.1: Access to information

Information accessed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes accessing information through the internet in general	20	55.56	10	55.56	14	56.00	7	70.00	3	37.50	13	59.09	7	50.00	4	44.44	16	59.26
Participant describes receiving information from books, pamphlets and newsletters	15	41.67	6	33.33	9	36.00	6	60.00	3	37.50	9	40.91	6	42.86	4	44.44	11	40.74
Participant describes receiving information from a specific health charity	12	33.33	4	22.22	8	32.00	5	50.00	3	37.50	6	27.27	6	42.86	4	44.44	8	29.63
Participant describes primarily accessing information through treating clinician	8	22.22	5	27.78	5	20.00	1	10.00	2	25.00	4	18.18	4	28.57	2	22.22	6	22.22
Participant describes accessing information primarily through Facebook and/or social media	7	19.44	6	33.33	6	24.00	1	10.00	0	0.00	5	22.73	2	14.29	0	0.00	7	25.93
Participant describes primarily accessing information through other patient's experience	4	11.11	1	5.56	2	8.00	3	30.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11
Participant describes accessing information primarily through journals (research articles)	4	11.11	1	5.56	2	8.00	1	10.00	2	25.00	1	4.55	3	21.43	2	22.22	2	7.41

Information accessed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes accessing information through the internet in general	20	55.56	2	25.00	11	57.89	7	87.50	9	64.29	8	57.14	5	45.45	15	60.00
Participant describes receiving information from books, pamphlets and newsletters	15	41.67	2	25.00	8	42.11	4	50.00	7	50.00	5	35.71	3	27.27	12	48.00
Participant describes receiving information from a specific health charity	12	33.33	1	12.50	8	42.11	2	25.00	5	35.71	4	28.57	4	36.36	8	32.00
Participant describes primarily accessing information through treating clinician	8	22.22	3	37.50	3	15.79	2	25.00	5	35.71	1	7.14	3	27.27	5	20.00
Participant describes accessing information primarily through Facebook and/or social media	7	19.44	2	25.00	4	21.05	0	0.00	4	28.57	3	21.43	1	9.09	6	24.00
Participant describes primarily accessing information through other patient's experience	4	11.11	0	0.00	2	10.53	2	25.00	2	14.29	2	14.29	0	0.00	4	16.00
Participant describes accessing information primarily through journals (research articles)	4	11.11	1	12.50	2	10.53	0	0.00	0	0.00	2	14.29	1	9.09	3	12.00

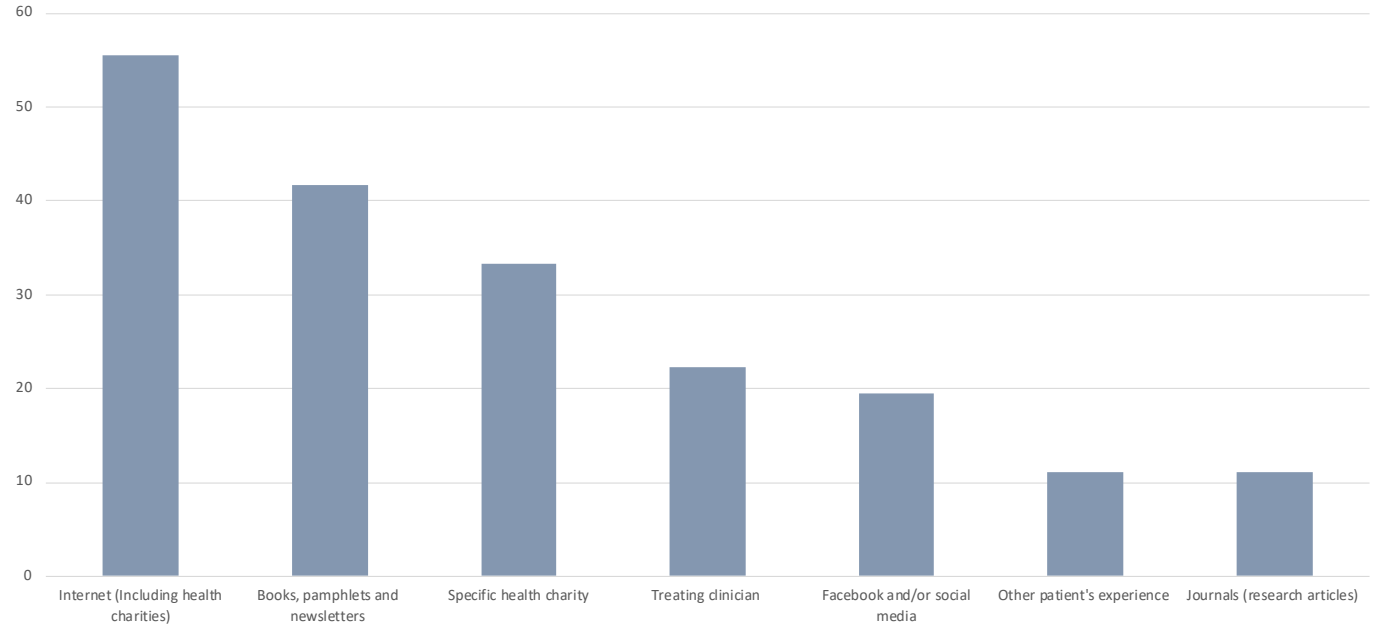

Figure 6.1: Access to information

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 type of information found to be helpful by 12 participants (33.33%) was information from reliable source, and this was followed by talking to their doctor or specialists (n=7, 19.44%). There were six participants (16.67%) that described health charities as being helpful and six (16.67%) that described information that is easy to understand as being helpful. Other types of information described as being helpful included information about what to expect (n=5, 13.89%), information specific to their condition (n=5, 13.89%) and other people's experiences (n=4, 11.11%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (50.00%), *Female* (50.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) subgroups described information from reliable sources as more frequently than the general population (33.33%), while those in the subgroups *AL Amyloidosis* (20.00%), *Aged 65 to 74* (21.05%), and *Male* (22.73%) described this less frequently.

Participants in the *AL amyloidosis* subgroup described talking to their doctor or specialist as helpful more frequently (50.00%) than the general population (19.44%), while those in the *Female* (7.14%) subgroup described this less frequently. Participants in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) subgroups did not describe this at all.

Participants in the subgroups *Trade or high school* (28.57%), *Regional or remote* (33.33%), and *Mid to low SEIFA* (27.27%) described health charities as helpful more frequently than the general population (16.67%).

Participants in the *University* (28.57%) subgroup described information that's easy to understand as helpful more frequently than the general population (16.67%), while those in the *Trade or high school* subgroup (0.00%), and *Mid to low SEIFA* (0.00%) did not describe this.

Participants in the *Regional or remote* subgroup described information about what to expect as helpful more frequently (33.33%) than the general population (13.89%), while those in the *Aged 55 to 64* (0.00%) subgroup did not describe this at all.

No participants in the *Regional or remote* subgroup (0.00%) described information specific to their condition (and sub-types) as helpful.

Participants in the *Regional or remote* subgroup (22.22%) described other people's experiences as helpful more frequently than the general population (11.11%), while those in the *Aged 75 or older* (0.00%), and *Carer* (0.00%) did not describe this at all.

Published information from reliable sources

The little booklet, 'Amyloidosis: A guide for patients and families', put out by the Leukaemia Foundation, I guess because they're more financially able to do these things, extremely informative, how is it treated. In my case, it says at this time there are no specific treatments that can directly clear amyloid deposits from tissues in the body, but for people like me with it in my skin, just see a skin specialist and they should do what they say. I've had a melanoma in the past, so I see a skin specialist once a year. That's very good information, this little booklet, full of information for me which I find very helpful and which I dip into every now and again just to refresh things in my mind. Participant 003ALX

Preferably the booklet about amyloid. Something that was written can be easily understood. I found that very helpful. Participant 003CA

What information's been most helpful? Probably the papers we've researched ourselves. Participant 005CA

Talking to a doctor or specialist

Probably talking to the professor in LOCATION METROPOLITAN and to NAME in LOCATION METROPOLITAN and talking to the scientific people. I'm interested in the science of the disease. Participant 002ALX

The doctors, you have to ask questions. You have to ask questions yourself. Doctors, they have a screen and they'll say, 'Oh, your numbers are good.' That's all they'll say unless you ask a specific question. When I had swollen feet, and then I knew my albumin count, and every time I went in there, I asked him, 'What's my albumin count?' They would tell me, so I knew when I was improving, or I wasn't improving. Everything, I ask a lot of questions. That's what I tell people, 'Look, you've got to ask questions. You've got to say--' There's three things, if you've got swollen feet, you've got to know what you albumin count is, and that's all related on blood pressure and different medical things, but if your albumin is increasing, that means your blood pressure's increasing, and you're getting some benefit from the treatment. The doctors really don't tell you. I mean they've only got a limited amount of time there too. Participant 005AL

I think doctor's input and me asking hopefully relevant questions. Anything else that may come to mind I'll make a note and bring that up in the next doctor's review. If, in fact, the doctor doesn't know, I'll speak to somebody else that may do or may know. I mentioned NAME DOCTOR before. He's been brought in and been able to answer my questions, so I think that that should answer your questions. Participant 006AL

Easy to understand information (layman's terms)

I like the way that a lot of information is being put into layman's terms because I think that helps a lot of patients that don't have a scientific background, and it should be easy to understand the most part of it. Participant 003AL

Preferably the booklet about amyloid. Something that was written can be easily understood. I found that very helpful. Participant 003CA

Information is being able to explain to me just gradually, gradually, otherwise because information sometimes isn't understood, at least for myself all at once. It's something like a study, it's something that gradually, gradually becomes clear in my mind just discovering something gradually, gradually, gradually. Participant 005ATR

Health charities

The little booklet, 'Amyloidosis: A guide for patients and families', put out by the Leukaemia Foundation, I guess because they're more financially able to do these things, extremely informative, how is it treated. Participant 003ALX

The information that has been the most helpful. I'm sorry, I should have mentioned The Leukaemia Foundation, even though it's an orphan disease and they adopted it. NAME, a health staff has given us ongoing support, but she had more knowledge of AL and AA. I got a bit mixed up in the beginning, but regardless of that she said, 'We can't tell you what to do but we can give volunteer financial person. Aside from that-- Can I have that question again. Participant 005CA

I've got a couple of newsletters that come out, one from the Leukaemia Foundation and another one from NAME HOPSITAL, in the amyloid clinic. I would take those, been pretty close to true and correct. I would sort of, read them whenever they come out, maybe once a month. Participant 008ATR

Condition-specific (including sub-types)

I did the other day specifically look at this one I've got, the hereditary one. More so that with symptoms and the family history and all the rest of it. But other than that no. I just generalize the information. Participant 001ATR

I really found the scientific papers useful for my purpose, but I think also the NAME CLINIC booklets and there's one I'm not sure that it's out of LOCATION METROPOLITAN in LOCATION. 'Understanding Amyloidosis'. They were really good because they laid out in layman's terms, but it is pretty comprehensively at the same time about the different amyloidosis and how we know what was happening. I think for even someone who can understand the science, it's good to have it laid out more simply. It's like the skeleton of the disease and the information and then you can add things to that from the science if you want to. Participant 002AL

Probably the brochures that we actually received that literally went into the amyloidosis, which explains all different types of amyloidosis, which literally shows us what our amyloidosis was. We didn't realise at that stage that we thought that all amyloidosis was treated normally, but it's not, and that's why they basically have to work out which amyloidosis you have because one treatment or one type may kill the other type. We literally believed everything from the brochures and most of those brochures came to us through leukaemia that helps us on amyloidosis. Participant 004CA

Hearing what to expect (e.g. from disease, side effects, treatment)

The description of the condition and the side effects mostly and how you might go about managing some of those. Just the description of the disease, the background, and the side effects. That's largely where the clinics or the network meetings have gone as well. They tend to offer a three-span schedule. One is new drugs or new treatments that have come about. Then, a general discussion on managing your life or lifestyle issues. What's the third one? Often a specialist like the stem cell transplant process or similar. They're doing very good. I'm quite impressed. Participant 004AL

We've had a workshop each year and I think the information there, it's been good overview information. I've not had carpal tunnel syndrome. I understand 50% of people with amyloidosis can have that. I've not really had any problems with nerves. It's useful to know that that can occur. Participant 011ATR

Gee, that's difficult. In terms of understanding the disease, the initial videos and things that I saw from the mail and from-- There's a video by the act of Michael York. It's just amazingly simple, but it puts it all in perspective. Generally, for the people before we talk anymore about it, have a look at the video… It tells you what things are happening there and it's not a medical slick. It's a cartoon type of thing, the people with hammers on the production line smashing amyloid stuff, and others, and that thing. It brings the message home. Yes. Participant 013ATR

Other people's experiences

I think what the AAN and NAME is going a fair way to improving the information that gets out to patients. Also, a number of patient groups that talk quite really with the clinic at NAME HOSPITAL and I've been invited to some of the meetings with NAME and a number of the specialists that are associated with that. Participant 003AL

Other than that, I don't really know anyone. I've spoken with a couple of people on my phone that have had the same problem. I've obviously got a cousin, my first cousin, up in LOCATION, that's got the same problem. Participant 008ATR

It's interesting hearing from other patients' journeys but in a positive way, if that makes sense. As I said, at NAME HOSPITAL they give you as much, as I guess, they think you can handle and things with follow-ups and things like that. Participant 012ATR

Table 6.2: Information that was helpful

Information that has been helpful	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes information from reliable sources as helpful	12	33.33	7	38.89	8	32.00	2	20.00	3	37.50	5	22.73	7	50.00	4	44.44	8	29.63
Participant describes talking to their doctor or specialist as helpful	7	19.44	2	11.11	6	24.00	5	50.00	0	0.00	6	27.27	1	7.14	1	11.11	6	22.22
Participant describes health charities information as helpful	6	16.67	3	16.67	4	16.00	2	20.00	1	12.50	3	13.64	3	21.43	3	33.33	3	11.11
Participant describes information that's easy to understand (layman's terms)	6	16.67	2	11.11	4	16.00	2	20.00	2	25.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes information about what to expect as helpful (Disease progression)	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	4	18.18	1	7.14	3	33.33	2	7.41
Participant describes information specific to their condition (and sub-types) as helpful	5	13.89	2	11.11	3	12.00	2	20.00	1	12.50	1	4.55	4	28.57	0	0.00	5	18.52
Participant describes other people's experiences as helpful (Peer-to-peer)	4	11.11	3	16.67	4	16.00	1	10.00	0	0.00	3	13.64	1	7.14	2	22.22	2	7.41

Information that has been helpful	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes information from reliable sources as helpful	12	33.33	4	50.00	4	21.05	3	37.50	4	28.57	5	35.71	5	45.45	7	28.00
Participant describes talking to their doctor or specialist as helpful	7	19.44	0	0.00	4	21.05	2	25.00	4	28.57	3	21.43	2	18.18	5	20.00
Participant describes health charities information as helpful	6	16.67	1	12.50	4	21.05	1	12.50	4	28.57	1	7.14	3	27.27	3	12.00
Participant describes information that's easy to understand (layman's terms)	6	16.67	1	12.50	4	21.05	1	12.50	0	0.00	4	28.57	0	0.00	6	24.00
Participant describes information about what to expect as helpful (Disease progression)	5	13.89	0	0.00	4	21.05	1	12.50	1	7.14	3	21.43	1	9.09	4	16.00
Participant describes information specific to their condition (and sub-types) as helpful	5	13.89	1	12.50	3	15.79	1	12.50	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes other people's experiences as helpful (Peer-to-peer)	4	11.11	1	12.50	3	15.79	0	0.00	2	14.29	2	14.29	2	18.18	2	8.00

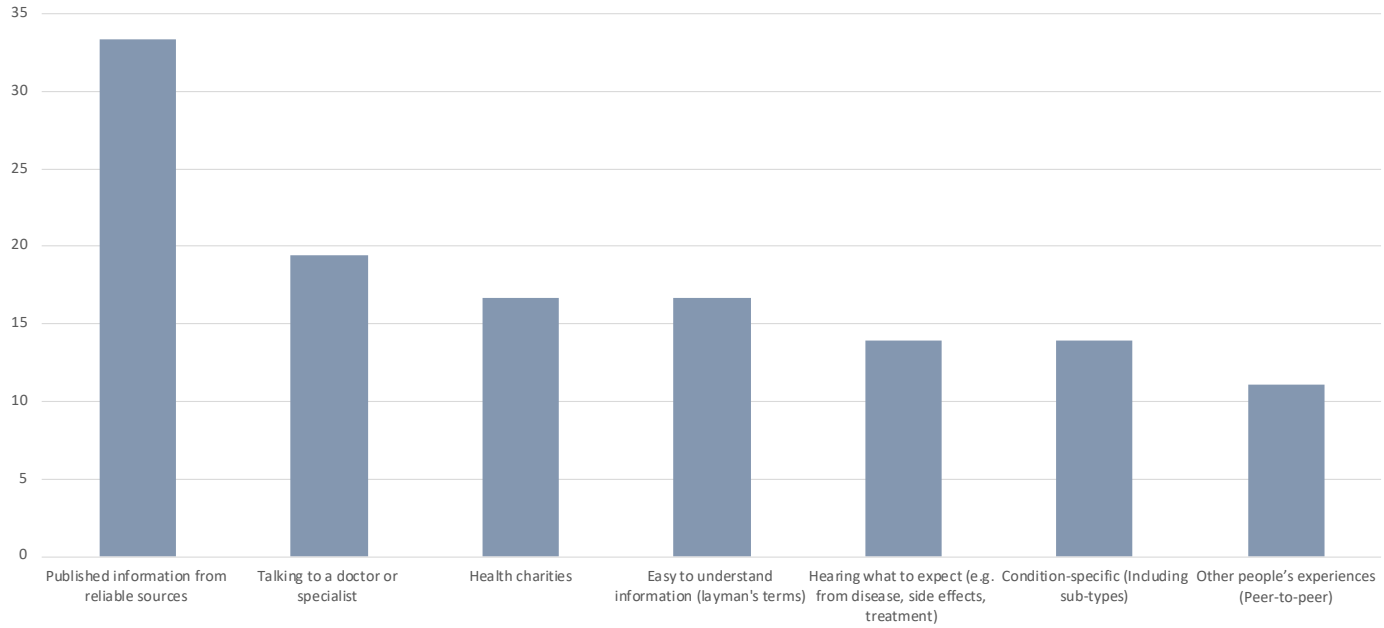

Figure 6.2: Information that was helpful

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 response by 18 participants (n=18, 50.00%) was that no information was not helpful and this was followed by GP and specialists as being not helpful (n=5, 13.89%).

In relation to subgroup variations, participants in the subgroups *Carer* (37.50%), *Aged 55 to 64* (25.00%) and *University* (28.57%) described no information as not helpful less frequently than the general population (50.00%), while those in the subgroups *Aged 75 or older* (62.50%), *Trade or high school* (78.57%), *Regional or remote* (66.67%), and *Mid to low SEIFA* (63.64%) described this more frequently.

Participants in the *AL amyloidosis* (30.00%), *Aged 55 to 64* (25.00%), *Aged 75 or older* (25.00%), and *University* (28.57%) subgroups described their GP and specialist as not helpful more frequently than the general population (13.89%), while those in the *Carer* subgroup (0.00%) and *Female* subgroup (0.00%) did not describe this at all.

No information not helpful

No. I'm trying to think. No, I haven't had any ideas myself. Participant 001ALX

No, not really. I can't say that I have. Participant 001ATR

That has not been helpful? No, I think most of the stuff that I read because, again, I'm only reading stuff and things like the Boston Uni hospital and stuff like that. I don't bother reading-- well, again it's not too much individual stuff because everybody is so different. I don't try to down the track of reading other people's experiences as such. Participant 003ATR

GP/specialist

Yes, a couple of GPs in time that told me there is no such thing. Federal government bureaucrats that want to know if I was pregnant when I was taking thalidomide. I had to explain to him the difficulties of me actually conceiving. I was being very sarcastic, I thought it was a stupid bloody question. Participant 002ALX

I sought help from my GP initially and then I sought help from a specialist recognised by him. Then I raised the issue with my oncologist specialist some months late. Clearly, the condition was getting worse and the blood analyses show that. I had a bunch of tests in early 2017, had one in mid-2017 with my usual CML check-up. Then one in November, a six-monthly check-up for CML again and then another one when the GP ran the numbers again. Yet, there was no explanation for the condition. The signs were there clearly with the scan of the heart showing a slight thickening and my inability to manage urine and the compromised kidney functions. It's clearly there and yet it really took something like 15 months to get it. Why was that the case? Participant 004AL

The thing that has been the least helpful, you were probably going to ask me this question a little bit down the line anyway, is the lack of knowledge at GP level. Participant 015ATR

Table 6.3: Information that was not helpful

Information that has not been helpful	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes no information being not helpful	18	50.00	10	55.56	13	52.00	5	50.00	3	37.50	12	54.55	6	42.86	6	66.67	12	44.44
Participant describes the GP/specialist as being not helpful	5	13.89	2	11.11	4	16.00	3	30.00	0	0.00	5	22.73	0	0.00	2	22.22	3	11.11

Information that has not been helpful	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes no information being not helpful	18	50.00	2	25.00	10	52.63	5	62.50	11	78.57	4	28.57	7	63.64	11	44.00
Participant describes the GP/specialist as being not helpful	5	13.89	2	25.00	1	5.26	2	25.00	1	7.14	4	28.57	1	9.09	4	16.00

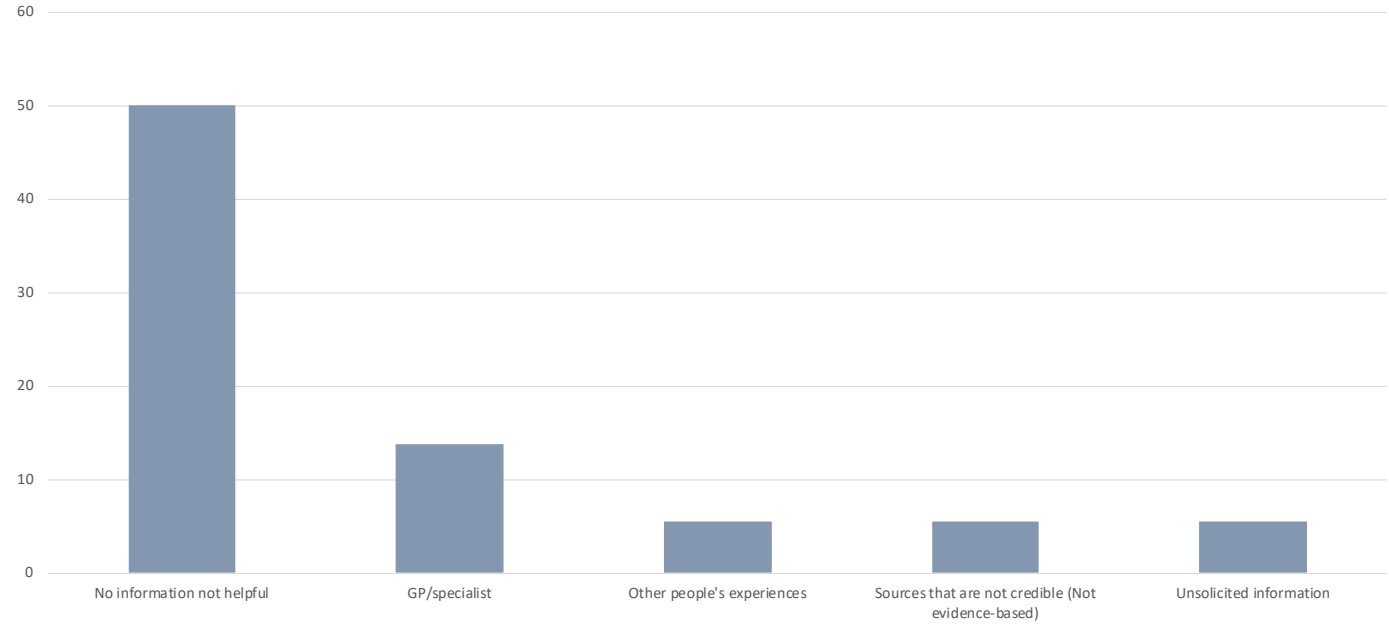

Figure 6.3: Information that was not helpful

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. Overall, the most common theme was talking to someone (n=10, 27.78%). There were seven participants (19.44%) that described a preference for talking to someone plus online information. There were also seven participants (19.44%) that described online information as their main preference.

There were 12 participants (33.33%) whose rationale for their preference was simply a personal preference or gave no strong rationale for their preference. Among those who gave a rationale for their preference, seven (19.44%) described it as due to being able to digest information at their own pace and six (16.67%) described it as due to being able to, or having time to, ask questions.

In relation to subgroup variations, participants in the *University* subgroup (14.29%), and *Regional or remote* subgroup (11.11%) described talking to someone as their main preference less frequently than the general population (27.78%), while those in the *Trade or high school* subgroup described this more frequently (42.86%).

Participants in the general population (19.44%) described talking to someone plus online information as their main preference, while those in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *Aged 75 or older* subgroup described online information as their main preferences more frequently (37.50%) than the general population (19.44%), while those in the *Female* (7.14%), and *Mid to low SEIFA* (9.09%) subgroups described this less frequently. Participants *Aged 55 to 64* (0.00%) did not describe this at all.

Participants in the *AL amyloidosis* (50.00%), *Male* (45.45%), and *Trade or high school* (50.00%) subgroups described their rationale for their preference as simply a person preference or had no strong rationale more frequently than the general population (33.33%), while those in the subgroups *Regional or remote* (11.11%), *Female* (14.29%), and *Carer* (12.50%) described this less frequently.

Participants in the subgroup *Regional or remote* (33.33%) described their rationale for their preference as due to being able to digest information at their own pace more frequently than the general population (19.44%).

Participants in the *Female* (35.71%) subgroup described their rationale for their preference as due to being able to/have time to ask questions more frequently than the general population (16.67%), while those in the *Male* (4.55%) subgroup described this less frequently. Participants in the *Regional or remote* (0.00%) did not describe this at all.

Talking to someone

Face-to-face. It's just the way that I've always dealt with that sort of-- In the scientific world, the work I do, over my years, I much prefer face-to-face and I can see from the person whether they-- I guess I get the feel as to whether they're legit or whether I'm beating the wind. I must admit, I don't trust a lot of the stuff on the internet. I usually always second guess it. Participant 002ALX

If I were to arrange them, I would say talking with someone first and phone app probably second and the journal and the net. Talking with someone, you can ask questions that are more specific to you rather than figuring out if it applies to you, or if it doesn't apply to you. Talking to someone and say, 'This drug would, or this treatment would, be just fixing this.' Then I can say, 'That's great for them, but what about this?' Then they can answer that. I think that's handy whether it's via phone call or video conferencing or even a chat, online chat. It's so much better than trying to cycle through loads and loads of information. Participant 002ATR

First thing I prefer face-to-face, I think that's just my generation, preferring face-to-face but I'm not-- I'm cynical of website information. When I first got diagnosed, I went online and the first thing you read is, 'You're not going to live 12 months.' You go, 'Yes, right.' Then you go and talk to your haematologist and he says, 'No, I'll be buying you a birthday card when you turn 89.' You get the two extremes. Participant 004ATR

Talking to someone plus online

Probably initially I like online stuff just because I can absorb it at my own time and when I might feel like it, as opposed to generally I don't want to talk about it, to be honest. As much as you can forget about it sometimes, so I go with that. But if it's important, I'd prefer to talk to someone in person. Initial stage something online that I can read through your phone or computer or whatever. When it gets into actually asking, I'd like to be able to ask questions and you're replying, and talk to someone in real life, as opposed to on the phone. That's really important. Participant 006ATR

I quite like the online ones, the network started a couple and they've been really good, interesting to hear the different peoples' journey and things of how they all got to where they are and that's been quite interesting. I like listening to the doctors but the ones that are able to explain it in a non-medical word way. Some of them are fantastic at what they do, but they can't share it in a palatable or easy way that everyone can understand, it gets too technical. I've always done seminars and things of nutrition I suppose, and I'm used to all that and I enjoy all that, I enjoy good speakers. I have to be able to feel I can relate to the person I'm talking to. That they are interested, I guess is the other thing, that they're interested because just going through the numbers and doing the motions. Yes, I enjoy that. Participant 012ATR

Initially, I liked the web. My initial research is web-based where I'll go pick up a heck of a lot of information and get things straight in my mind. Then I like to have it confirmed or refuted by talking to somebody about it. The two things, when working like that, allow me to get things straight in my mind about what it is and where we're going. Those are the two things I prefer. Participant 015ATR

Online

I suppose online would be the first place of choice because that's where we all go now for information and it's accessible at your own time. Participant 002CA

I don't have an app, but I certainly just go online and type in amyloidosis, and a whole lot of things comes up from the USA and on specific AL amyloidosis that always comes up. This ATTR medication, that came up last year. One of the other patients that I know quite well, one of his relatives in the UK sent him that information, which I was then able to access and read through. It's just like doing any other scientific research, you need to find information on new things, and I just follow that principle. Participant 003AL

I prefer online. I think that's the nature of the beast in a way. I prefer to access it in my own time and be able to digest it at my own pace and to explore further when necessary. If I don't get the answers, I'm happy to ask the question of someone in the discussion, but I like to cover all the bases as it were at my own tempo, when it's convenient, when I'm in the right mood, or when it's necessary. Participant 004AL

No strong reason for preference

Well, my generation does go to the computer, et cetera, and I know how to use the computer. I know how to look up the information, et cetera, et cetera, but I'm not what I would call a technical person. My reading of anything, and that means leisure reading or whatever it is, is much preferred in the written form and also in the discussion forum. When I talk to people in a discussion forum, I talk to people and see what happens, whether it's other patients with amyloidosis or at the clinic at NAME HOSPITAL, which I go to, or to the various professions. I find that is the most effective and preferred form of communication. Participant 001AL

All three of them, I have a preference. Talking to doctors, it would be my preferred option. I read about it somewhere, 'If it's affecting you, go then ask the doctor, 'I read this, what do you think about that?''. That's the approach I'm taking. Participant 001ALX

First thing I prefer face-to-face, I think that's just my generation, preferring face-to-face but I'm not-- I'm cynical of website information. When I first got diagnosed, I went online and the first thing you read is, 'You're not going to live 12 months.' You go, 'Yes, right.' Then you go and talk to your haematologist and he says, 'No, I'll be buying you a birthday card when you turn 89.' You get the two extremes. Participant 004ATR

Being able to digest information at their own pace

I'm a great reader, so I like getting booklet-type literature where I can read it and absorb it at my time and reread it again. Conversation phoning is also good because you can do the toing and froing ideas, discussions, thoughts that come up, you can pose a question to the person at the other end of the line, so to speak, so all of those, WhatsApp or probably booklets I probably prefer than phoning up for clarification or whatever. Participant 003ALX

I prefer online. I think that's the nature of the beast in a way. I prefer to access it in my own time and be able to digest it at my own pace and to explore further when necessary. If I don't get the answers, I'm happy to ask the question of someone in the discussion, but I like to cover all the bases as it were at my own tempo, when it's convenient, when I'm in the right mood, or when it's necessary. Participant 004AL

I now and then search online for a good article, something that I can process, to read, to learn, especially when I got them to me, I lot to choose. Just I can find my time and educating myself and understanding better. Yes, I do that. I go online, I don't talk with anybody else, I don't know anybody who is experiencing the same diseases that I have, so I haven't done that. The only thing I'm doing is to talking family, to talk with my doctor, to educate myself to read articles, to go online searching something that I can trust to really find the truth about what I don't know. I think when I find, and one can go. I even tried with some information like that, and sometimes it must read more than once to be understood properly and I go back to them and then I ask and explain. This is what I'm doing. Participant 005ATR

Being able to have time to ask questions

I think sometimes you have specific questions to yourself where it's good to talk to someone who's got the knowledge. I personally like a combination of sources of information. Participant 002AL

Talking with someone, you can ask questions that are more specific to you rather than figuring out if it applies to you, or if it doesn't apply to you. Talking to someone and say, 'This drug would, or this treatment would, be just fixing this.' Then I can say, 'That's great for them, but what about this?' Then they can answer that. I think that's handy whether it's via phone call or video conferencing or even a chat, online chat. It's so much better than trying to cycle through loads and loads of information. She probably knows much more, because people try so self-diagnose their-- A lot of hearsay and inconclusive treatment options. Participant 002ATR

Talking to someone that knew about, my preference was talking to someone. I think if you talk to someone that knows about the disease and can answer your questions and I think if it's someone that basically you can actually get has what the human touch rather than reading about something. Participant 004CA

Table 6.4: Information preferences

Information preferences	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Talking to someone as main preference	10	27.78	5	27.78	6	24.00	3	30.00	2	25.00	6	27.27	4	28.57	1	11.11	9	33.33
Talking to someone plus online information as main preference	7	19.44	5	27.78	6	24.00	1	10.00	1	12.50	5	22.73	2	14.29	2	22.22	5	18.52
Online information as main preference	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	6	27.27	1	7.14	2	22.22	5	18.52

Information preferences	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Talking to someone as main preference	10	27.78	3	37.50	5	26.32	2	25.00	6	42.86	2	14.29	3	27.27	7	28.00
Talking to someone plus online information as main preference	7	19.44	1	12.50	5	26.32	0	0.00	3	21.43	3	21.43	2	18.18	5	20.00
Online information as main preference	7	19.44	0	0.00	4	21.05	3	37.50	2	14.29	4	28.57	1	9.09	6	24.00

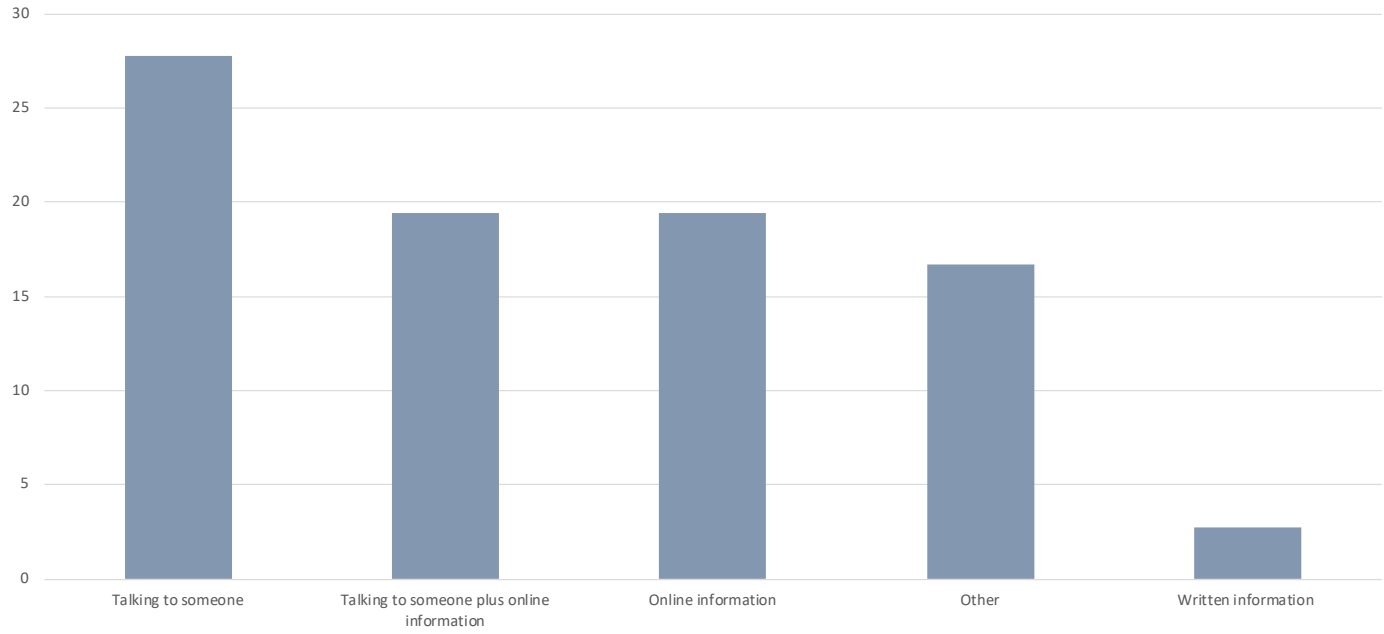

Figure 6.4: Information preferences

Table 6.5: Reasons for preference

Rationale for preferences	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Rationale for preference is simply a personal preference/no strong rationale	12	33.33	6	33.33	10	40.00	5	50.00	1	12.50	10	45.45	2	14.29	1	11.11	11	40.74
Rationale for preference is due to being able to digest information at their own pace	7	19.44	4	22.22	5	20.00	2	20.00	1	12.50	5	22.73	2	14.29	3	33.33	4	14.81
Rationale for preference is due to being able to/have time to ask questions	6	16.67	3	16.67	4	16.00	2	20.00	1	12.50	1	4.55	5	35.71	0	0.00	6	22.22

Rationale for preferences	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Rationale for preference is simply a personal preference/no strong rationale	12	33.33	2	25.00	7	36.84	3	37.50	7	50.00	4	28.57	3	27.27	9	36.00
Rationale for preference is due to being able to digest information at their own pace	7	19.44	2	25.00	3	15.79	1	12.50	2	14.29	4	28.57	2	18.18	5	20.00
Rationale for preference is due to being able to/have time to ask questions	6	16.67	1	12.50	2	10.53	2	25.00	2	14.29	3	21.43	1	9.09	5	20.00

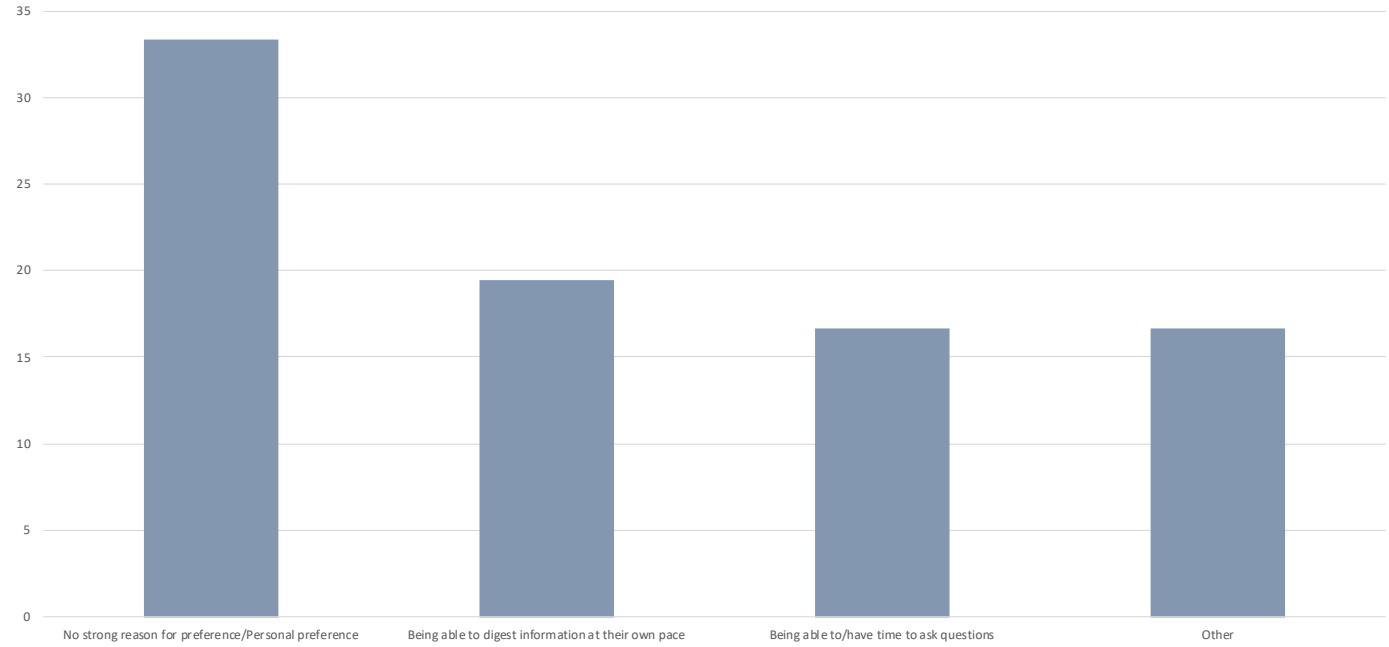

Figure 6.5: Reasons for preference

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 time that participants described being receptive to receiving information was from the beginning or at diagnosis (n=12, 33.33%). This was followed by participants describing being receptive to information a specific amount of time after (n=7, 19.44%). There were six participants (16.67%) that described being receptive to information after the shock of diagnosis.

In relation to subgroup variations, participants in the *AL amyloidosis* (20.00%) subgroup described being receptive to diagnosis from the beginning or at diagnosis less frequently than the general population (33.33%), while those in the subgroups *ATTR-cardiac* (44.44%), and *University* (50.00%) described this more frequently. Participants in the *Aged 75 or older* (50.00%) subgroup did not describe this at all.

Participants in the *Trade or high school* (28.57%) subgroup being receptive to information after the shock of diagnosis more frequently than the general population (16.67%), while those in the *University* (0.00%) subgroup did not describe this at all.

From the beginning (diagnosis)

Well, at initial diagnosis, of course, I was more receptive to information, because I had never heard of amyloidosis, and I knew nothing about it. Initially, I was all out getting in every bit of information that I could. Participant 001AL

When was I most receptive? Probably, on initial diagnosis really. Because of it being new beforehand, but it hadn't been formalised, I had done a little bit of reading and-- But as I said, there was absolutely no point in talking to a medical person, because like I was in NAME HOSPITAL one day with a MEDICAL PROFESSIONAL who knows me really well, and we were just chatting. I said something about, 'Geez, how have you been and blah, blah, blah? Well, you know what? I've just been diagnosed with amyloid.' She went, 'Oh my God, I haven't heard of that word since I was in TRAINING.' Participant 001ATR

I think initially, I was. I was a bit traumatised, obviously, it was a very emotional time because we thought the prognosis was not good. However, at that stage, I just wanted to seek as much information as I possibly could. I really understood exactly what it was and that we weren't being at all misled that the prognosis wasn't good. Then saying that his specialist never ever said, I give people 6 months, 12 months or 18 months because they're not going to do that anyway. Everybody responds to these treatments differently, but I think at the very beginning I wanted an easily accessible, and easy to understand, and easy to interpret information that was not too directed at the medical clinic, but more maybe directed towards the layperson understanding the intricacies of the disease. Participant 001CA

After a specific amount of time

Probably two or three months, I think before I really started to sort it out. Participant 010ATR

This time I really understood it better. I really started taking and trying to prepare my own sets of questions and the like. I suspect if I look back through my notes, I'll see that I sent notes to NAME CLINICIAN and to NAME CLINICIAN and they're basically asking a whole bunch of questions because I'd done the research, I'd understood as much as the layman does or the partial scientist does, the issues around AL and the side effects and the management of it, and with melanoma to ask to the informed questions I guess. It was probably, I think, 8, 10, 12 weeks before I really got on top of it, understood it, and ask a sensible series of questions. Participant 004AL

Not at the beginning, because at the beginning it was just an absolute shock. I think probably after that six weeks, when it finally more or less pivots that this is happening to us and because we waited for such a long time for a diagnosis. Participant 004CA

After the shock of diagnosis

Well, it was overwhelming at the beginning because it was, as I said, the future comes out and hits you in the face, and then as you get used to the idea and you start on treatment. I don't know. Maybe for somebody who's new into the whole journey, giving them a little bit of time to get used to the idea of the diagnosis and that there are treatments available, so people have calmed down a bit maybe, or accepted maybe a bit more, and then you're more receptive, maybe, to more information. Participant 002CA

Probably after I've seen-- I was very anxious before I saw NAME DOCTOR. Between the diagnosis and seeing him, I had no idea having been told that I had nodular amyloidosis. Before I had any brochures or booklets or anything like that, that was a very anxious time. After I'd seen NAME DOCTOR, he gave me all the information, he spoke with my husband and I very clearly and concisely in an unhurried manner, and I went actually with a little dot point list of questions. He allayed any fears that I had, expanded my knowledge greatly, of course, of what it was, and after that while I came home and then digested all of that information, I was more receptive into absorbing the information and coming to terms with it and settling down in myself what it was, what I'm faced with, how to deal with it, and that made me comfortable. Participant 003ALX

Probably reasonably soon after getting the diagnosis, once he got the hit of the diagnosis. For me, it's, 'Okay, right. What can I do? What is this all about? I need to know about this. I need to know what to look for.' Probably reasonably quickly, I would have thought after getting the diagnosis, the next visit back to the doctor would have been the best time to have a session on, 'Okay, so here's some information and work it from there.' Participant 003CA

Table 6.6: Timing of information

Timing of information	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being receptive from the beginning (diagnosis)	12	33.33	8	44.44	10	40.00	2	20.00	2	25.00	7	31.82	5	35.71	3	33.33	9	33.33
Participant describes a specific amount of time after diagnosis	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	4	18.18	3	21.43	2	22.22	5	18.52
Participant describes being receptive to information after the shock of diagnosis	6	16.67	3	16.67	3	12.00	1	10.00	2	25.00	3	13.64	3	21.43	2	22.22	4	14.81

Timing of information	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being receptive from the beginning (diagnosis)	12	33.33	3	37.50	4	21.05	4	50.00	3	21.43	7	50.00	3	27.27	9	36.00
Participant describes a specific amount of time after diagnosis	7	19.44	1	12.50	4	21.05	2	25.00	4	28.57	2	14.29	3	27.27	4	16.00
Participant describes being receptive to information after the shock of diagnosis	6	16.67	2	25.00	3	15.79	1	12.50	4	28.57	0	0.00	2	18.18	4	16.00

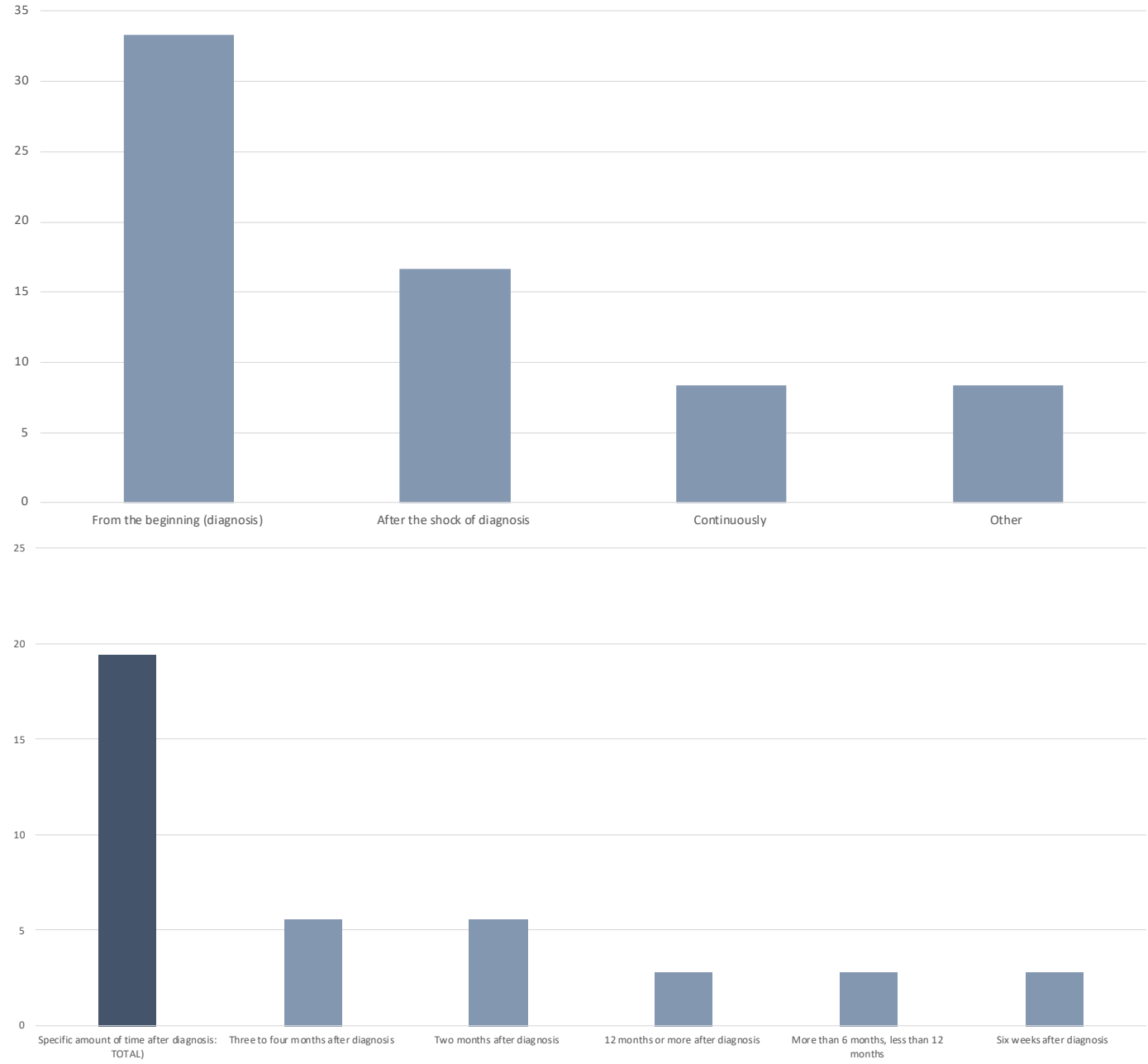

Figure 6.6: Timing of information

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 an overall positive experience (n=15, 41.67%). There were eleven participants (30.56%) that described an overall positive experience with the exception of one or two occasions and five participants (13.89%) who described an overall negative experience.

Where participants described a positive experience, this related to health professional communication as holistic (two way, supportive and comprehensive conversations (n=12, 33.33%). Where participants described a negative experience, this related to health professional communication being limited in relation to their understanding of the condition (n=11, 30.56%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (12.50%), *ATTR-cardiac* (22.22%), and *Regional or remote* (22.22%) subgroups described health professional communication as holistic less frequently than the general population (33.33%), while those in the *AL amyloidosis* (60.00%) subgroup described this more frequently.

Participants in the *Mid to low SEIFA* subgroup described health professional communication as limited in relation to their understanding of the

condition less frequently (18.18%) than the general population (30.56%).

Overall, participants in the subgroups *ATTR-cardiac* (55.56%), *All cardiac* (52.00%), and *Male* (54.55%) described health professional communication as overall positive more frequently than the general population (41.67%), while those in the subgroups *Female* (21.43%), and *Carer* (12.50%) described this less frequently.

Participants in the *Female* subgroup described health professional communication as positive with the exception of one or two occasions more frequently (42.86%) than the general population (30.56%).

Overall positive

Good. Everyone is trying to do their best, and the conveyance of that information from various people-- I'm talking about cardiologists. I'm talking about haematologists. I'm talking about other specialists, which I've gone to them. We've talked about exercise. We've talked about all these things. I've found it to be good, helpful, and receptive. I have no complaints, not at all. Participant 001AL

The ones that I'm dealing with? Supportive and informative, but not with information overload. Only enough to maybe make me think a little bit more about the disease and do a little bit of research myself. They've not been holding back information, but not wanting to alarm me, basically. Participant 001ATR

Well, I think the medical treatments been first class. I think to the time of my having a problem, which was really when I had the February check-up to diagnosis since September is just a bit over six months and that's kind of-- Based on the information I saw in one of the workshops I attended, that's probably best, best on outcomes, some people have gotten much longer periods. I've been happy with- extremely happy with my GP, my family and my haematologist. Participant 011ATR

Overall positive with the exception of one or two occasions

It's been a little bit mixed. My GP was really good. She didn't diagnose amyloidosis, but she's always been someone who, if it's five things, you get things tested. I've got a lot to be thankful to her for picking up the low blood albumin in the first place. The renal physician, I didn't feel a connection to really. He's a fairly elderly chap and he always struck me as being a little bit- what's the word? Treating you a bit like, not a child, but he wasn't really forthcoming with good science. It was, 'Oh yes, I've treated a lot of these people and the best thing to do is to just wait. We'll check every couple of months what's happening with your urine and your blood.' I just didn't feel confident in what he was saying to me, particularly as I was learning quite a bit at the time. My haematologist though has been great. He's always been really upfront about what's happening, what the risks are, what the different treatments were likely to do, like when I went on to the cyclophosphamide dexamethasone and thalidomide. Participant 002AL

90% of it's been very good, 10%, it's been a few GPs who didn't really know where they were at with it or they've never heard of it. A couple of them didn't believe, one still doesn't believe there's any such thing. Participant 002ALX

Mixed really, I would say. My GP since hasn't really had much information about it, hasn't had any brochures to give me or anything like that. NAME DOCTOR, I keep referring back to him, but he's been wonderful. Also, we have a couple of meetings, gatherings, discussion groups at the PA hospital which have been-- I think there's only one and then the second one had to be cancelled because of the Coronavirus. That was extremely helpful and very, very, very helpful, people there running it, extremely helpful and very welcoming and putting you at your ease. Participant 003ALX

Overall negative

It was a little irregular. That can be frustrating because of the lack of awareness. Then they go to a practitioner, lack of awareness from the public. There isn't enough literature, but you couldn't look without knowing what it is, to begin with. You could research weight loss or diarrhoea. Amyloidosis is a good imitator of other diseases. I think it doesn't help. I'm glad Australia has more, but I think general education to the medical profession can be- the number is quite-- The number of times I've been into the hospital, three different hospitals that I go to here and the doctors who see me will go, 'We heard about in med school there is really not one expert here. Participant 002ATR

Health professionals, amyloidosis and they'd almost say, 'Well, what's that? I learned about that in med school, but it wasn't something of great relevance because it was a because it's relatively rare condition'. They, in turn, have to re-educate themselves perhaps on their knowledge about this. From there, proper treatments have to be given by that relevant health professional, like the GP, the lung specialist, the hospice. They really have to brush up on their knowledge and to tailor the treatment that I'll receive. The heart has tube in it because amyloidosis affects the heart. They used to tailor the treatment to look after my heart. Lung specialist has to ensure that I don't get a food on the lungs, look after my lungs in that respect. They'd be most relevant to the healing but again tailor any treatment that might be necessary to my condition because, once again, it's a rare condition and the treatment as such becomes I think specific to the conditions. Participant 006AL

Terrible. Except for the people at the NAME HOSPITAL. No one else knows about it. Participant 009ATR

Holistic (Two way, supportive and comprehensive conversations)

Since we've moved up here and being with NAME CLINICIAN, you just can't fault the system. He's been so good. If we've asked any questions, he's taken the time and explained everything in plain English, which has been a breath of fresh air. NAME CLINICIAN, he is just awesome. Participant 003CA

If I have a problem about anything, I can ring up the NAME HOSPITAL, and I'll say-- I've got a problem at the moment, actually. I've got a cancer beside my ear, a lump beside my ear. I went to my GP. He had scans done, and I said, 'Look, can you send the results to the NAME HOSPITAL Amyloid Clinic?' Anyway, as soon as I got the results, they got it as well, and I rang them up the next day. She says, 'Yes, we know. Everything's being organized.' I cannot complain. I've got no complaints about the NAME HOSPITAL. Participant 005AL

Pretty good. Pretty good, yes. I go down to LOCATION METROPOLITAN every six months and I see my heart specialist every six months, they're both fully in charge of the heart part of it and the amyloid part. They're keeping as much as an eye on me as possibly I suppose. Either of those places I can ring up or get in touch with if I need certain answers and questions. I'd talk to the amyloid clinic in LOCATION METROPOLITAN to email reasonably often about if I've got any questions come up whether I want to know something about them. They'll then they'll find the answer for me and send it back, or get someone to email, usually email, with the information I want. Participant 008ATR

Limited in understanding

Health professionals, amyloidosis and they'd almost say, 'Well, what's that? I learned about that in med school, but it wasn't something of great relevance because it was a because it's relatively rare condition'. They, in turn, have to re-educate themselves perhaps on their knowledge about this. From there, proper treatments have to be given by that relevant health professional, like the GP, the lung specialist, the hospice. They really have to brush up on their knowledge and to tailor the treatment that I'll receive. Participant 006AL

It's been really good once I found my specialist. Initially, it wasn't great because I didn't have anyone to ask or talk to, but once I actually got through the gatekeepers of referrals and things and got in a room with a specialist, it's been excellent from that point forward. Participant 006ATR

Terrible. Except for the people at the NAME HOSPITAL. No one else knows about it. Participant 009ATR

Table 6.7: Healthcare professional communication

Health professional communication	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	12	33.33	4	22.22	8	32.00	6	60.00	2	25.00	6	27.27	6	42.86	2	22.22	10	37.04
Participant describes health professional communication as limited in relation to their understanding of the condition	11	30.56	5	27.78	6	24.00	3	30.00	3	37.50	6	27.27	5	35.71	2	22.22	9	33.33
Overall positive	15	41.67	10	55.56	13	52.00	4	40.00	1	12.50	12	54.55	3	21.43	4	44.44	11	40.74
Overall positive, with the exception of one or two occasions	11	30.56	4	22.22	6	24.00	4	40.00	3	37.50	5	22.73	6	42.86	2	22.22	9	33.33
Overall negative	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	3	13.64	2	14.29	2	22.22	3	11.11

Health professional communication	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	12	33.33	1	12.50	8	42.11	3	37.50	5	35.71	5	35.71	4	36.36	8	32.00
Participant describes health professional communication as limited in relation to their understanding of the condition	11	30.56	2	25.00	5	26.32	3	37.50	5	35.71	3	21.43	2	18.18	9	36.00
Overall positive	15	41.67	3	37.50	8	42.11	4	50.00	7	50.00	7	50.00	5	45.45	10	40.00
Overall positive, with the exception of one or two occasions	11	30.56	2	25.00	5	26.32	3	37.50	4	28.57	4	28.57	3	27.27	8	32.00
Overall negative	5	13.89	1	12.50	3	15.79	1	12.50	2	14.29	2	14.29	1	9.09	4	16.00

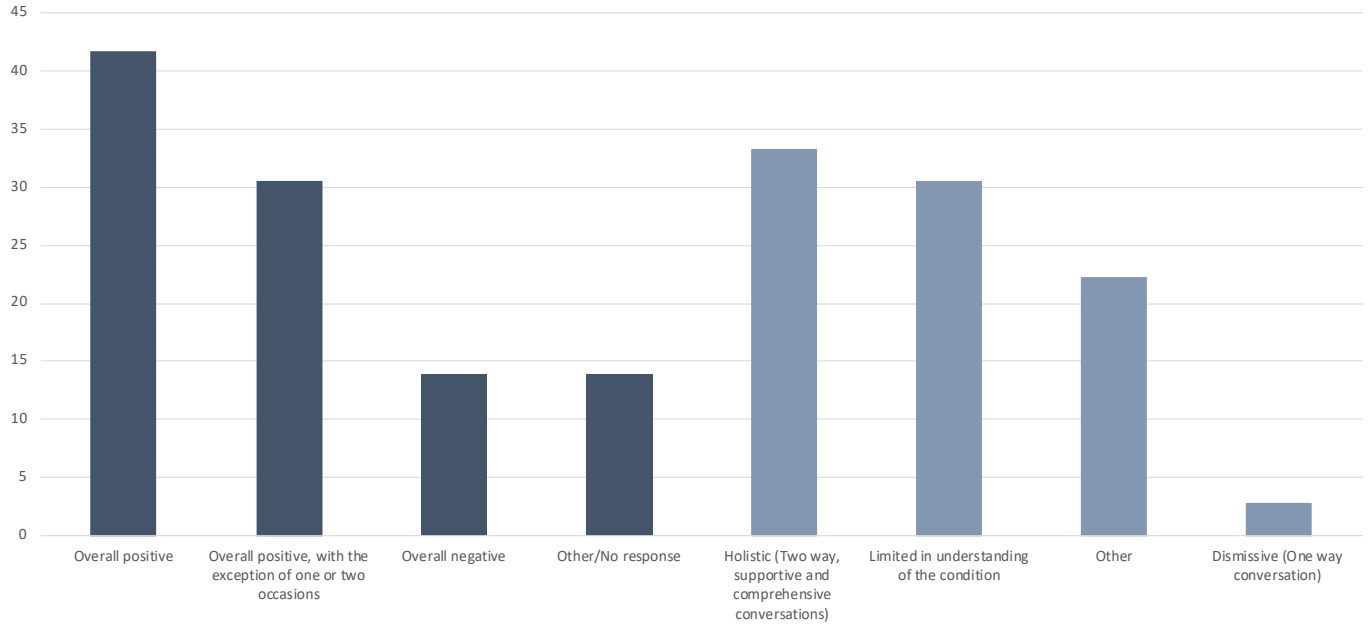

Figure 6.7: Healthcare professional communication

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, four 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 Table 6.8.

Overall, the participants in this PEEK study had an average score for **'Partners in health: knowledge'** (Median = 28.00, IQR = 4.25), **'Partners in health: recognition and management of symptoms'** (Mean = 20.68, SD = 2.47), **'Partners in health: adherence to treatment'** (Median = 16.00, IQR = 1.00), and **'Partners in health: total score'** (Mean = 81.04, SD = 8.66) were in the highest quintile indicating very good recognition and management of symptoms, and very good adherence to treatment.

The average scores for **'Partners in health: coping'** (Median = 18.50, IQR = 7.50), was in the second highest quintile indicating good knowledge, coping and overall knowledge and confidence for managing their own health.

Comparisons of Partners in health have been made based on **Participant type** (Figures 6.8 to 6.12, Table

6.9), **Gender** (Figures 6.13 to 6.17, Tables 6.10 to 6.11), **Location,** (Figures 6.18 to 6.22, Tables 6.12 to 6.13), **Age** (Figures 6.23 to 6.27, Tables 6.14 to 6.17), **Education** (Figures 6.28 to 6.32, Tables 6.18 to 6.19), and **SEIFA** (Figures 6.33 to 6.37, Tables 6.20 to 6.21).

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. Participants in this study had excellent 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). Participants in this study had very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

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. Participants in this study had excellent recognition and management of symptoms.

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. Participants in this study had an excellent ability to adhere to treatments and communicate with healthcare professionals.

The 'Partners in health: total score' measures the overall knowledge, coping and confidence for managing their own health. Participants in this study had excellent overall knowledge, coping and confidence for managing their own health.

Table 6.8: Partners in health summary statistics

Partners in health scale (n=28)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	27.36	3.53	28.00	4.25	0 to 32	5
Partners in health: coping	17.68	4.46	18.50	7.50	0 to 24	4
Partners in health: recognition and management of symptoms*	20.68	2.47	21.00	4.25	0 to 24	5
Partners in health: adherence to treatment	15.32	0.98	16.00	1.00	0 to 16	5
Partners in health: total score*	81.04	8.66	82.00	12.50	0 to 96	5

Comparisons of Partners in health scales by participant type

Participant type were grouped according to diagnosis; *ATTR-cardiac* group include participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

The assumptions for normality of residuals was not met for a one-way ANOVA, a Kruskal-Wallis test was used (Table 6.9).

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

Table 6.9: Partners in health by Participant type Kruskal-Wallis test and summary statistics

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	ATTR-cardiac	18	50.00	28.00	4.75	0.10	2	0.9520
	All-cardiac	25	69.44	28.00	4.00			
	AL amyloidosis	10	27.78	28.00	3.00			
Coping	ATTR-cardiac	18	50.00	18.00	7.50	0.48	2	0.7874
	All-cardiac	25	69.44	18.00	8.00			
	AL amyloidosis	10	27.78	20.00	6.00			
Recognition and management of symptoms	ATTR-cardiac	18	50.00	21.00	2.75	0.43	2	0.8058
	All-cardiac	25	69.44	21.00	3.00			
	AL amyloidosis	10	27.78	20.00	4.50			
Adherence to treatment	ATTR-cardiac	18	50.00	16.00	1.00	0.04	2	0.9803
	All-cardiac	25	69.44	16.00	1.00			
	AL amyloidosis	10	27.78	15.50	1.00			
Total score	ATTR-cardiac	18	50.00	82.00	11.50	0.06	2	0.9691
	All-cardiac	25	69.44	83.00	13.00			
	AL amyloidosis	10	27.78	83.00	12.00			

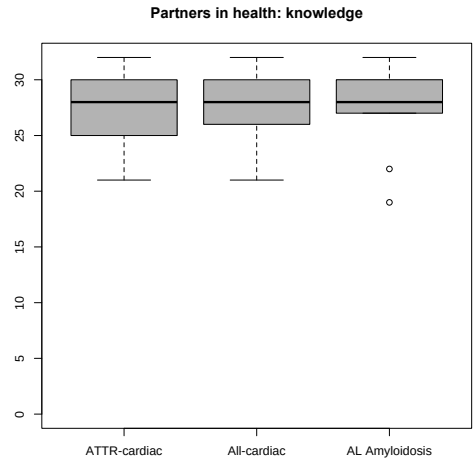

Figure 6.8: Boxplot of 'Partners in health: knowledge' by participant type

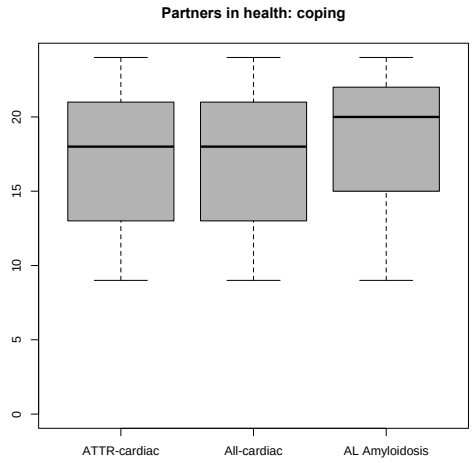

Figure 6.9: Boxplot of 'Partners in health: coping' by participant type

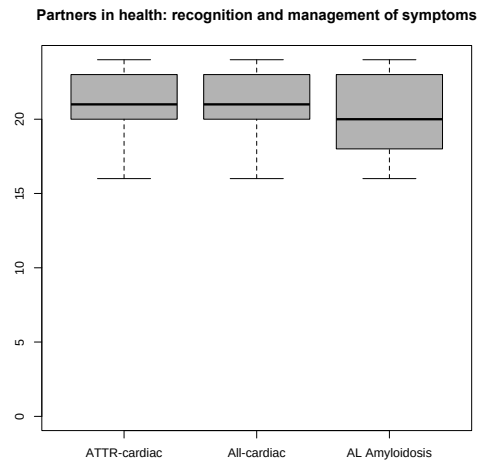

Figure 6.10: Boxplot of 'Partners in health: recognition and management of symptoms' by participant type

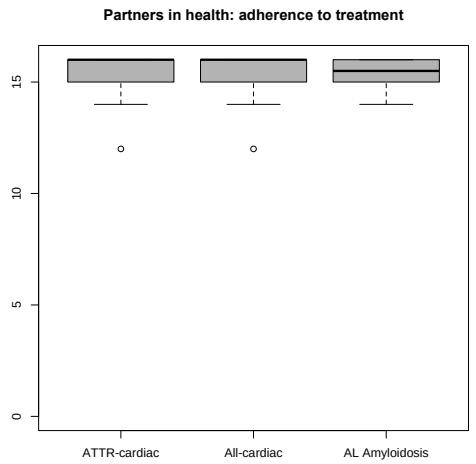

Figure 6.11: Boxplot of 'Partners in health: adherence to treatment' by participant type

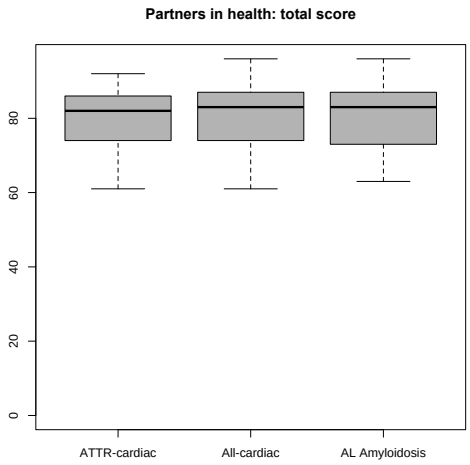

Figure 6.12: Boxplot of 'Partners in health Total score' by participant type

Comparisons of Partners in health scales by Gender

Comparisons were made by **Gender**, between males (n=21, 675.00) and females (n=7, 25.00%).

Boxplots of each Partners in health scale by **Gender** are displayed in Figures 6.13 to 6.17 summary statistics are displayed in Tables 6.10 and 6.11. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.11).

No significant differences were observed between male and female participants for any of the Partners in health scales.

Table 6.10: Partners in health by Gender summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Recognition and management of symptoms	Female	7	25.00	21	3	-0.04	26	0.9657
	Male	21	75.00	21	2			
Total score	Female	7	25.00	79	10	0.56	26	0.5805
	Male	21	75.00	82	8			

Table 6.11: Partners in health by Gender summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Female	7	25.00	25	6	106.00	0.0863
	Male	21	75.00	28	3		
Coping	Female	7	25.00	20	2	63.00	0.5932
	Male	21	75.00	18	9		
Adherence to treatment	Female	7	25.00	16	1	74.00	1.0000
	Male	21	75.00	16	1		

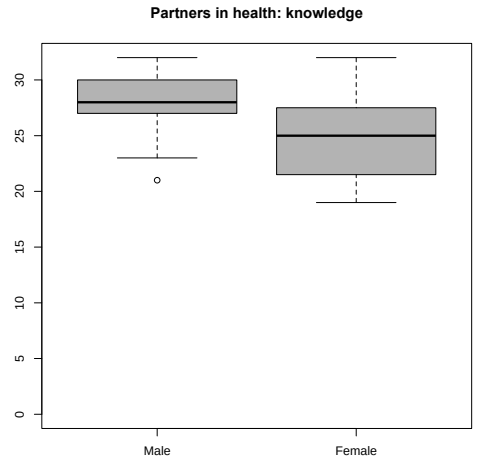

Figure 6.13: Boxplot of 'Partners in health: knowledge' by Gender

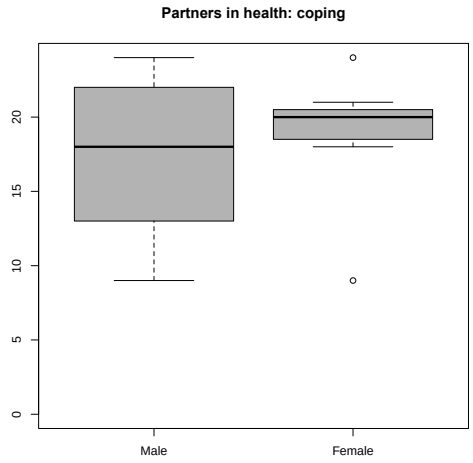

Figure 6.14: Boxplot of 'Partners in health: coping' by Gender

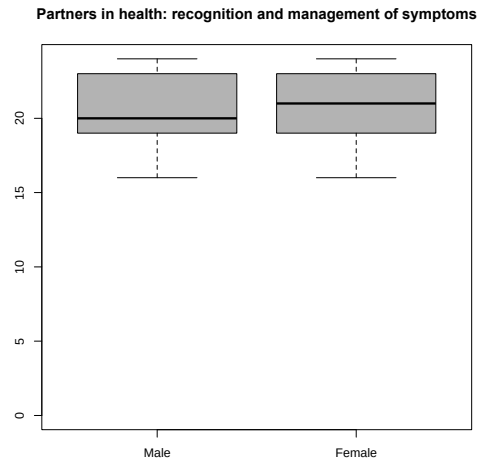

Figure 6.15: Boxplot of 'Partners in health: recognition and management of symptoms' by Gender

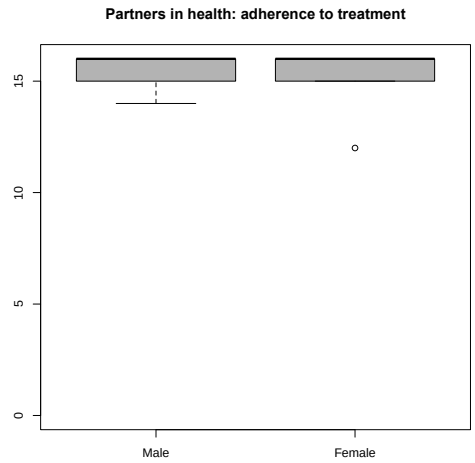

Figure 6.16: Boxplot of 'Partners in health: adherence to treatment' by Gender

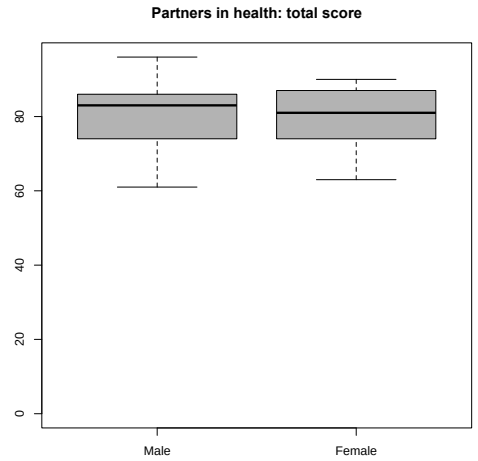

Figure 6.17: Boxplot of 'Partners in health Total score' by Gender

Comparisons of Partners in health scales 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 a major city, *Metropolitan* (n=22, 78.57%) were compared to those living in regional or rural areas, *Regional or remote* (n=6, 21.43%).

Boxplots of each Partners in health scale by **Location** are displayed in Figures 6.18 to 6.22, summary statistics are displayed in Tables 6.12 to 6.13. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.13).

No significant differences were observed between participants that lived in metropolitan areas compared to those that lived in regional or remote areas for any of the Partners in health scales.

Table 6.12: Partners in health by Location summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Coping	Regional or remote	6	21.43	19.00	4.20	0.81	26	0.4237
	Metropolitan	22	78.57	17.32	4.56			
Recognition and management of symptoms	Regional or remote	6	21.43	20.83	2.04	0.17	26	0.8661
	Metropolitan	22	78.57	20.64	2.61			
Total score	Regional or remote	6	21.43	83.00	9.67	0.62	26	0.5409
	Metropolitan	22	78.57	80.50	8.53			

Table 6.13: Partners in health by Location summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	6	21.43	29.00	3.50	77	0.5716
	Metropolitan	22	78.57	28.00	4.75		
Adherence to treatment	Regional or remote	6	21.43	15.00	1.50	45	0.1982
	Metropolitan	22	78.57	16.00	1.00		

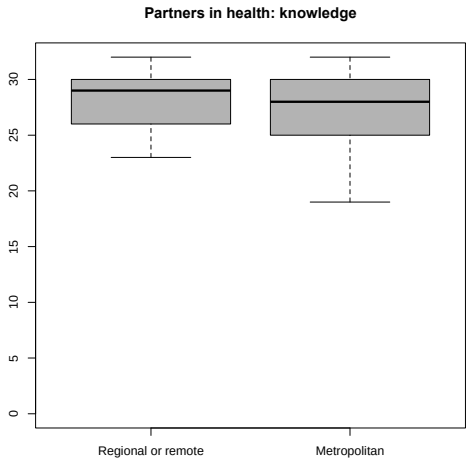

Figure 6.18: Boxplot of 'Partners in health: knowledge' by Location

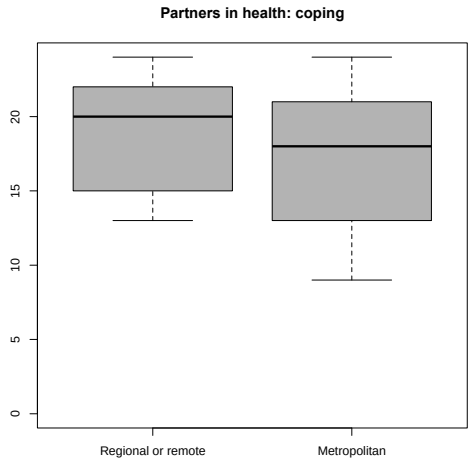

Figure 6.19: Boxplot of 'Partners in health: coping' by Location

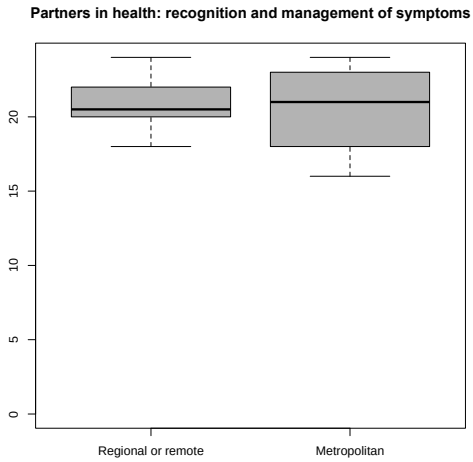

Figure 6.20: Boxplot of 'Partners in health: recognition and management of symptoms' by Location

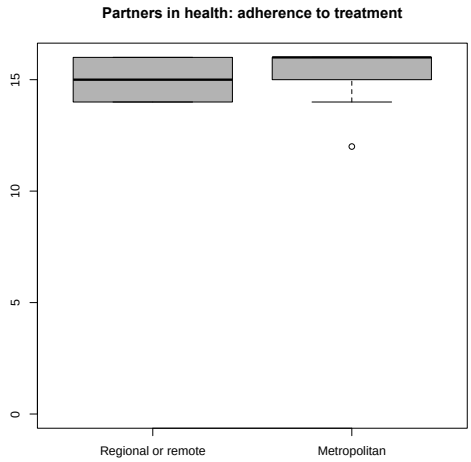

Figure 6.21: Boxplot of 'Partners in health: adherence to treatment' by Location

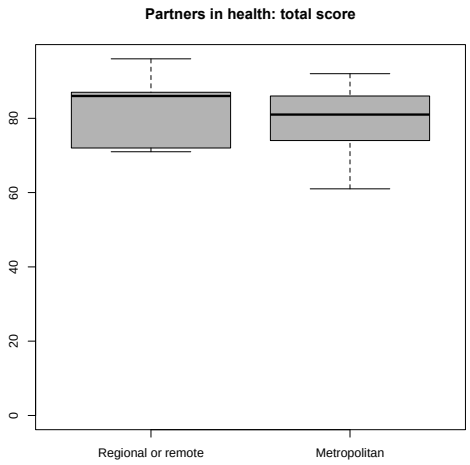

Figure 6.22: Boxplot of 'Partners in health Total score' by Location

Comparisons of Partners in health scales by Age

Participants were groups according to **Age,** with comparisons made between participants *Aged 55 to 64* (n=6, 22.22%), *Aged 65 to 74* (n=13, 48.15%), and *Aged 75 or older* (n=8, 29.63%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each Partners in health scale by **Age** are displayed in Figures 6.23 to 6.27, summary statistics are displayed in Tables 6.14 and 6.16.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.14). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 6.15).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.16). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal-Wallis test (Table 6.17).

A one way ANOVA test indicated a statistically significant difference in the **'Partners in health scale'** scale between groups, [$F(2, 26) = 5.92$, $p = 0.0082$] (Table 6.17). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Aged 65 to 74* subgroup (Mean = 85.08, SD = 7.20) was significantly higher compared to participants in the *Aged 55 to 64* subgroup (Mean = 72.50, SD = 8.96, p = 0.0059).

A Kruskal-Wallis test indicated a statistically significant difference in the **'Partners in health scale'** scale between groups, [$\chi^2(2) = 7.15$, $p = 0.0280$]. Wilcoxon rank sum tests between groups indicated that participants in the *Aged 65 to 74* subgroup (Median = 54.29, IQR = 15.00), scored significantly higher than participants in the *Aged 55 to 64* subgroup (Median = 22.86, IQR = 15.00, p = 0.0230).

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 *Aged 65 to 74* subgroup scored higher than participants in the *Aged 55 to 64* subgroup. This indicates that participants in the *Aged 65 to 74* subgroup, had an excellent ability to manage the effects of their health condition, compared to a moderate ability to manage for participants in the *Aged 55 to 64* subgroup.

The 'Partners in health: total score' measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the *Aged 65 to 74* subgroup scored higher than participants in the *Aged 55 to 64* subgroup. This indicates that participants in the *Aged 65 to 74* subgroup, had excellent overall knowledge, coping and confidence for managing their own health, compared to very good overall knowledge, coping and confidence for participants in the *Aged 55 to 64* subgroup.

Table 6.14: Partners in health by Age ANOVA test and summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Knowledge	Aged 55 to 64	6	22.22	25.00	3.74	Between groups	68.10	2	34.05	3.067	0.0651
	Aged 65 to 74	13	48.15	28.92	2.25	Within groups	266.40	24	11.1		
	Aged 75 and older	8	29.63	26.75	4.40	Total	334.50	26			
Recognition and management of symptoms	Aged 55 to 64	6	22.22	19.33	2.34	Between groups	24.69	2	12.345	2.245	0.1280
	Aged 65 to 74	13	48.15	21.69	2.14	Within groups	131.98	24	5.499		
	Aged 75 and older	8	29.63	20.38	2.67	Total	156.67	26			
Total score	Aged 55 to 64	6	22.22	72.50	8.96	Between groups	651.70	2	325.90	5.92	0.0082*
	Aged 65 to 74	13	48.15	85.08	7.20	Within groups	1321.90	24	55.10		
	Aged 75 and older	8	29.63	81.75	6.52	Total	1973.60	26			

Table 6.15: Partners in health by Age post hoc Tukey HSD test

Partners in health scale	Group	Difference	Upper	Lower	p adjusted
Total score	Aged 65 to 74 - Aged 55 to 64	12.58	3.43	21.72	0.0059*
	Aged 75 and older - Aged 55 to 64	9.25	-0.76	19.26	0.0739
	Aged 75 and older - Aged 65 to 74	-3.33	-11.66	5.00	0.5855

Table 6.16: Partners in health by Age Kruskal-Wallis test and summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	c^2	dF	p-value
Knowledge	Aged 55 to 64	6	22.22	22.86	13.50	7.15	2	0.0280*
	Aged 65 to 74	13	48.15	54.29	20.00			
	Aged 75 and older	8	29.63	22.86	21.00			
Adherence to treatment	Aged 55 to 64	6	22.22	22.86	15.00	5.23	2	0.0731
	Aged 65 to 74	13	48.15	54.29	15.00			
	Aged 75 and older	8	29.63	22.86	16.00			

Table 6.17: Partners in health by Age post hoc pairwise Wilcoxon rank sum test

Partners in health scale	Group	Aged 55 to 64	Aged 65 to 74
Knowledge	Aged 65 to 74	0.0230*	-
	Aged 75 and older	0.089	0.826

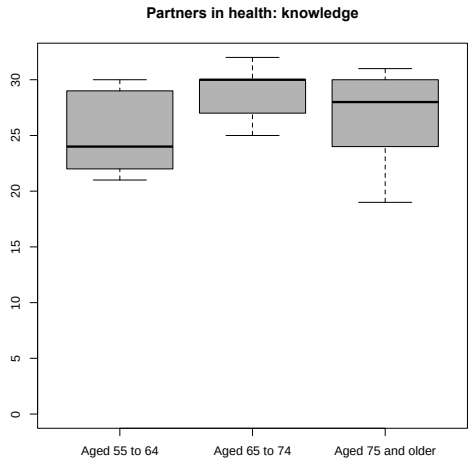

Figure 6.23: Boxplot of 'Partners in health: knowledge' by age

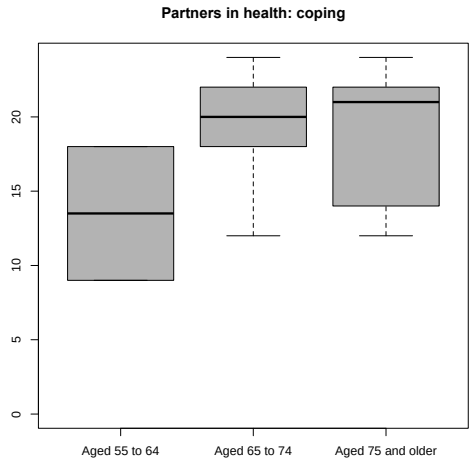

Figure 6.24: Boxplot of 'Partners in health: coping' by age

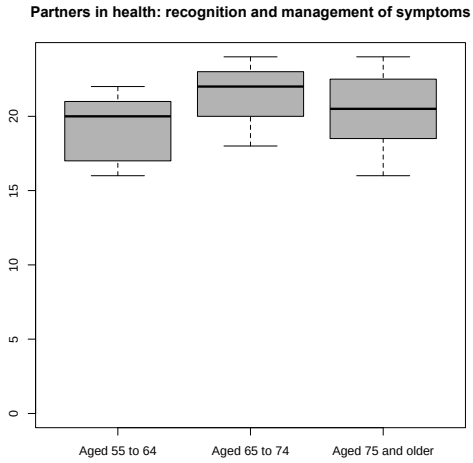

Figure 6.25: Boxplot of 'Partners in health: recognition and management of symptoms' by age

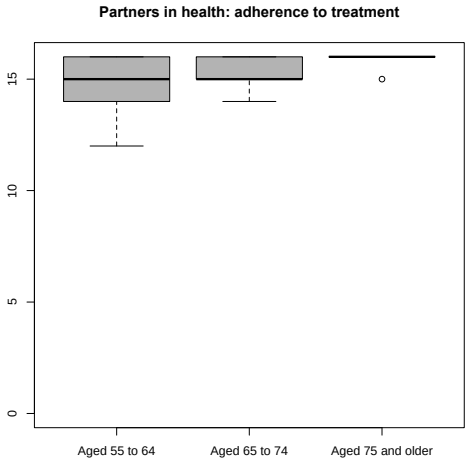

Figure 6.26: Boxplot of 'Partners in health: adherence to treatment' by age

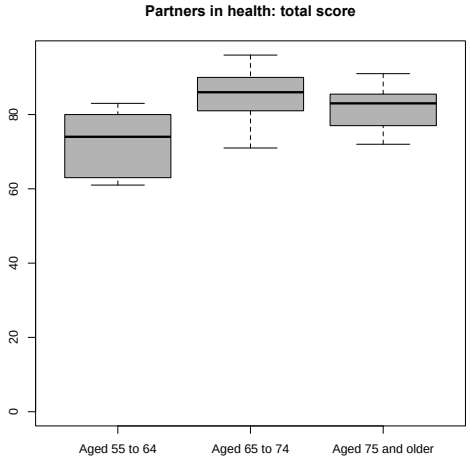

Figure 6.27: Boxplot of 'Partners in health Total score' by age

Comparisons of Partners in health scales by Education

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **Education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Boxplots of each Partners in health scale by **Education** are displayed in Figures 6.28 to 6.32, summary statistics are displayed in Tables 6.18 to 6.19. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

No significant differences were observed between participants in the *Trade or high school* subgroup compared to those in the *University* subgroup for any of the Partners in health scales.

Table 6.18: Partners in health by Education summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Knowledge	Trade or high school	14	50.00	26.79	4.04	-0.85	26	0.4019
	University	14	50.00	27.93	2.97			
Recognition and management of symptoms	Trade or high school	14	50.00	20.07	2.67	-1.32	26	0.1980
	University	14	50.00	21.29	2.16			
Total score	Trade or high school	14	50.00	80.43	8.92	-0.36	26	0.7181
	University	14	50.00	81.64	8.68			

Table 6.19: Partners in health by Education summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Coping	Trade or high school	14	50.00	20.00	7.50	114.00	0.4734
	University	14	50.00	18.00	5.75		
Adherence to treatment	Trade or high school	14	50.00	16.00	1.00	96.50	0.9589
	University	14	50.00	16.00	1.00		

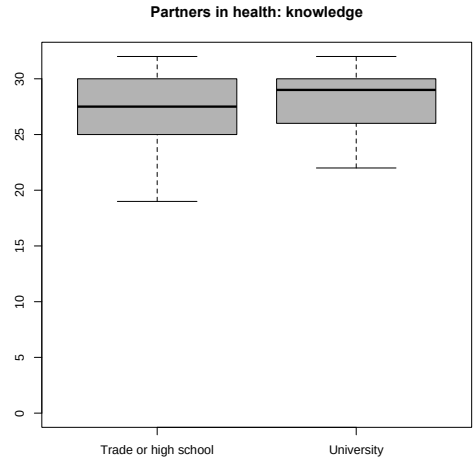

Figure 6.28: Boxplot of 'Partners in health: knowledge' by education

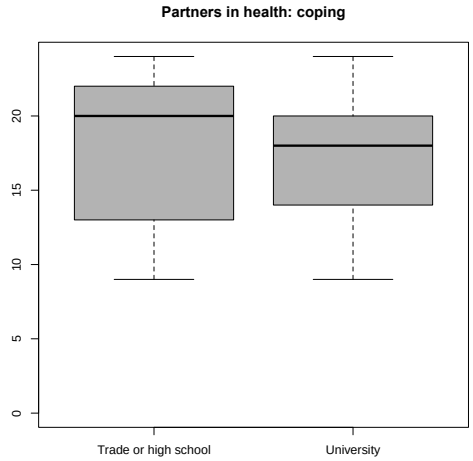

Figure 6.29: Boxplot of 'Partners in health: coping' by education

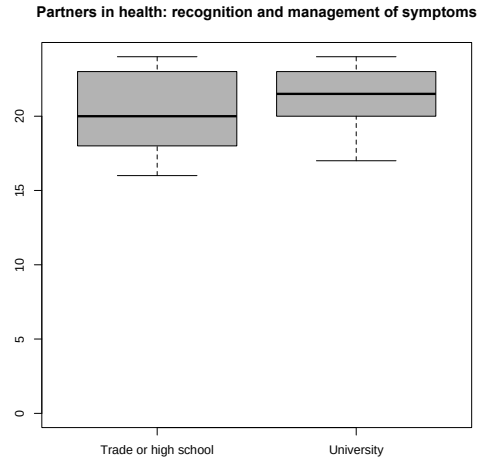

Figure 6.30: Boxplot of 'Partners in health: recognition and management of symptoms' by education

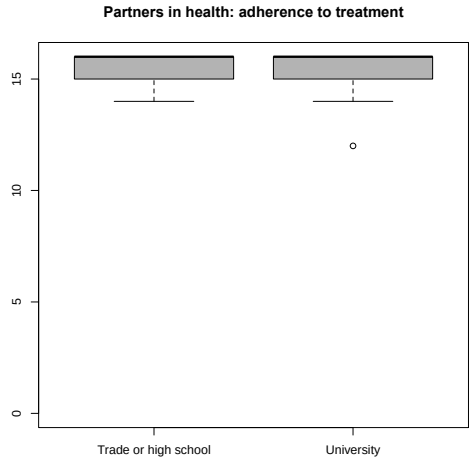

Figure 6.31: Boxplot of 'Partners in health: adherence to treatment' by education

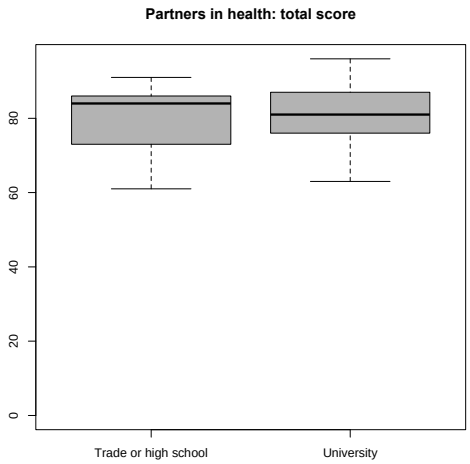

Figure 6.32: Boxplot of 'Partners in health Total score' by education

Comparisons of Partners in health scales by SEIFA

Comparisons were made by 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 higher SEIFA score of 7-10, *Higher SEIFA* (n=20, 71.43%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=8, 28.57%).

Boxplots of each Partners in health scale by **SEIFA** are displayed in Figures 6.33 to 6.37, summary statistics are displayed in Tables 6.20 to 6.21. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants in the *Mid to low SEIFA* subgroup compared to those in the *Higher SEIFA* subgroup for any of the Partners in health scales.

Table 6.20: Partners in health by SEIFA summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Coping	Mid to low SEIFA	8	28.57	18.88	3.31	0.89	26	0.3798
	Higher SEIFA	20	71.43	17.20	4.84			
Total score	Mid to low SEIFA	8	28.57	83.00	7.48	0.75	26	0.4582
	Higher SEIFA	20	71.43	80.25	9.15			

Table 6.21: Partners in health by SEIFA summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low SEIFA	8	28.57	28.50	3.50	94.00	0.4879
	Higher SEIFA	20	71.43	28.00	5.00		
Recognition and management of symptoms	Mid to low SEIFA	8	28.57	20.50	1.50	77.50	0.9183
	Higher SEIFA	20	71.43	21.50	5.00		
Adherence to treatment	Mid to low SEIFA	8	28.57	15.50	2.00	65.50	0.4248
	Higher SEIFA	20	71.43	16.00	1.00		

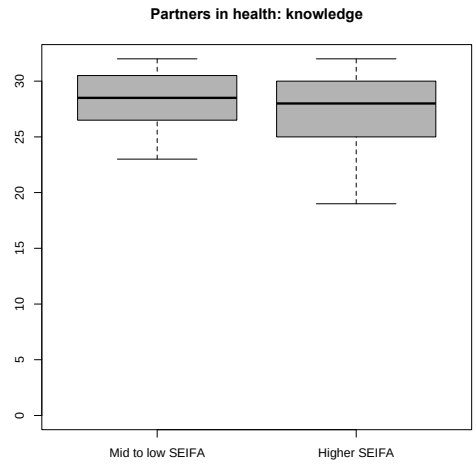

Figure 6.33: Boxplot of 'Partners in health: knowledge' by SEIFA

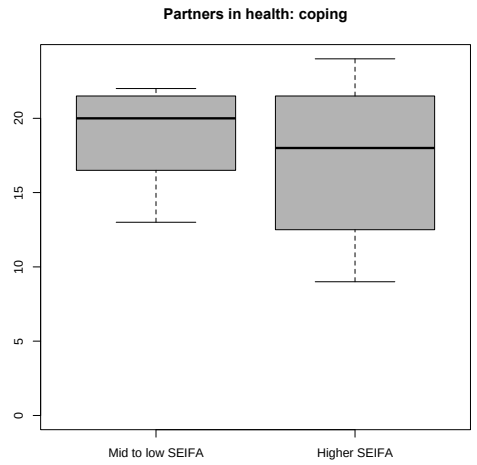

Figure 6.34: Boxplot of 'Partners in health: coping' by SEIFA

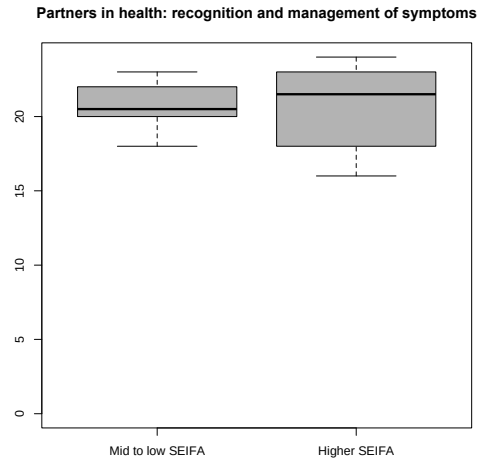

Figure 6.35: Boxplot of 'Partners in health: recognition and management of symptoms' by SEIFA

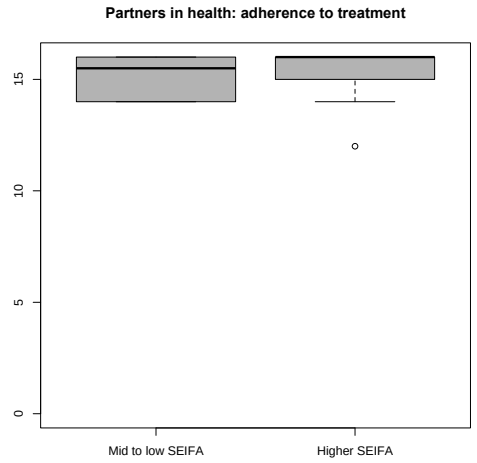

Figure 6.36: Boxplot of 'Partners in health: adherence to treatment' by SEIFA

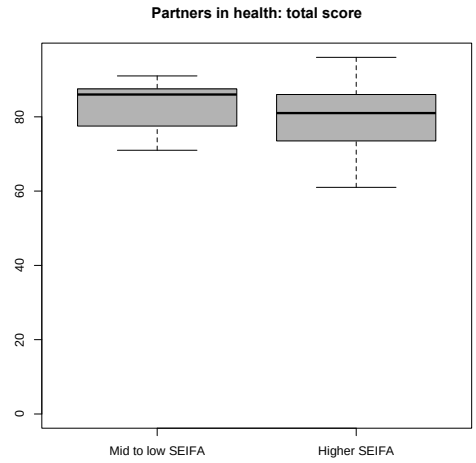

Figure 6.37: Boxplot of 'Partners in health Total score' by SEIFA

Ability to take medicine as prescribed

Participants were asked in general how good they were at taking medicine as prescribed and sticking to it.

The majority of participants responded that they took medicine as prescribed all the time (n=23, 82.14%)

Table 6.22: Ability to take medicine as prescribed

Ability to take medicine as prescribed	Number (n=28)	Percent
Never	0	0.00
Rarely	0	0.00
Sometimes	1	3.57
Most of the time	4	14.29
All of the time	23	82.14

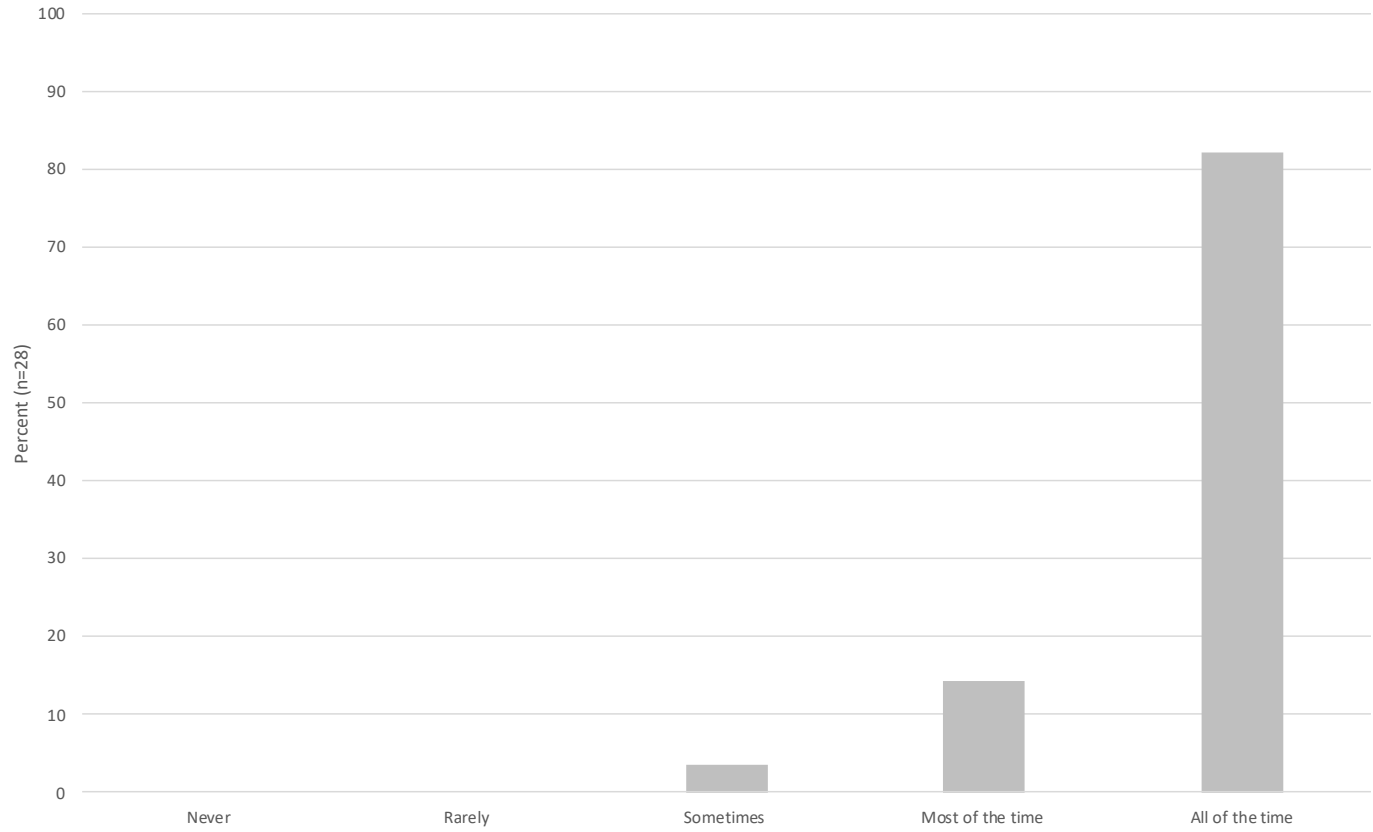

Figure 6.38: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=27, 75.00%), disease management (n=26, 72.22%), and disease cause (n=22, 61.11%) were most frequently given to participants by healthcare professionals, and information about psychological or social support (n=8, 22.22%), and complementary therapies (n=4, 11.11%) were given least often (Table 6.23, Figure 6.39).

In relation to subgroup variations, participants in the *University* subgroup (71.43%) were given for information about disease cause more often than the general population (61.11%).

Participants in the *Male* (86.36%), *Metropolitan* (88.89%), and *University* (100.00%) subgroups were given for information about treatment options more often than the general population (75.00%), while *Female* (57.14%), *Trade or high school* (57.14%), and *University* (57.14%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (90.00%), and *University* (92.86%) subgroups were given for information about disease management more often than the general population (72.22%), while participants in the *ATTR-cardiac* (61.11%), *Trade or high school (*50.00%). subgroups were given this information less often.

Participants in the *ATTR-cardiac* (72.22%), *All cardiac* (64.00%), *Male* (63.64%), *Aged 65 to 74* (63.16%) and *University* (64.29%) subgroups were given for information about clinical trials more often than the general population (52.78%), while participants in the *AL amyloidosis* (40.00%), *Female* (35.71%) and *Metropolitan* (33.33%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (60.00%) and *Higher SEIFA* (48.00%) subgroups were given information about dietary information more often than the general population (36.11%), while participants in *ATTR-cardiac* (16.67%), *Metropolitan* (11.11%), *Mid to low SEIFA* (9.09%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (60.00%), *Aged 65 to 74* (57.89%) and *University* (64.29%) subgroups were given for information about physical activity more often than the general population (41.67%), while participants in the *Metropolitan* (22.22%), *Trade or high school* (28.57%), and *Mid to low SEIFA* subgroups were given this information less often.

Participants in the *Metropolitan* (44.44%) subgroup were given for information about hereditary considerations more often than the general population (27.78%).

Table 6.23: Information given by health professionals

Information topic	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Metropolitan		Regional or remote	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=27	%	n=9	%
Disease Cause	22	61.11	12	66.67	16	64.00	6	60.00	4	50.00	14	63.64	8	57.14	6	66.67	16	59.26
Treatment options	27	75.00	14	77.78	20	80.00	8	80.00	5	62.50	19	86.36	8	57.14	8	88.89	19	70.37
Disease management	26	72.22	11	61.11	17	68.00	9	90.00	6	75.00	16	72.73	10	71.43	7	77.78	19	70.37
Complementary therapies	4	11.11	1	5.56	2	8.00	2	20.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41
How to interpret test results	9	25.00	6	33.33	8	32.00	3	30.00	0	0.00	7	31.82	2	14.29	0	0.00	9	33.33
Clinical trials	19	52.78	13	72.22	16	64.00	4	40.00	2	25.00	14	63.64	5	35.71	3	33.33	16	59.26
Dietary information	13	36.11	3	16.67	7	28.00	6	60.00	4	50.00	7	31.82	6	42.86	1	11.11	12	44.44
Physical activity	15	41.67	7	38.89	12	48.00	6	60.00	2	25.00	10	45.45	5	35.71	2	22.22	13	48.15
Psychological/social support	8	22.22	4	22.22	4	16.00	2	20.00	2	25.00	5	22.73	3	21.43	1	11.11	7	25.93
Hereditary considerations	10	27.78	6	33.33	9	36.00	3	30.00	1	12.50	6	27.27	4	28.57	4	44.44	6	22.22

Information topic	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Disease Cause	22	61.11	5	62.50	13	68.42	3	37.50	8	57.14	10	71.43	7	63.64	15	60.00
Treatment options	27	75.00	7	87.50	14	73.68	5	62.50	8	57.14	14	100.00	8	72.73	19	76.00
Disease management	26	72.22	4	50.00	15	78.95	6	75.00	7	50.00	13	92.86	8	72.73	18	72.00
Complementary therapies	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	2	14.29	2	18.18	2	8.00
How to interpret test results	9	25.00	2	25.00	5	26.32	2	25.00	6	42.86	3	21.43	3	27.27	6	24.00
Clinical trials	19	52.78	3	37.50	12	63.16	3	37.50	8	57.14	9	64.29	6	54.55	13	52.00
Dietary information	13	36.11	2	25.00	8	42.11	3	37.50	4	28.57	5	35.71	1	9.09	12	48.00
Physical activity	15	41.67	1	12.50	11	57.89	2	25.00	4	28.57	9	64.29	3	27.27	12	48.00
Psychological/social support	8	22.22	2	25.00	4	21.05	1	12.50	1	7.14	5	35.71	1	9.09	7	28.00
Hereditary considerations	10	27.78	3	37.50	5	26.32	2	25.00	5	35.71	4	28.57	4	36.36	6	24.00

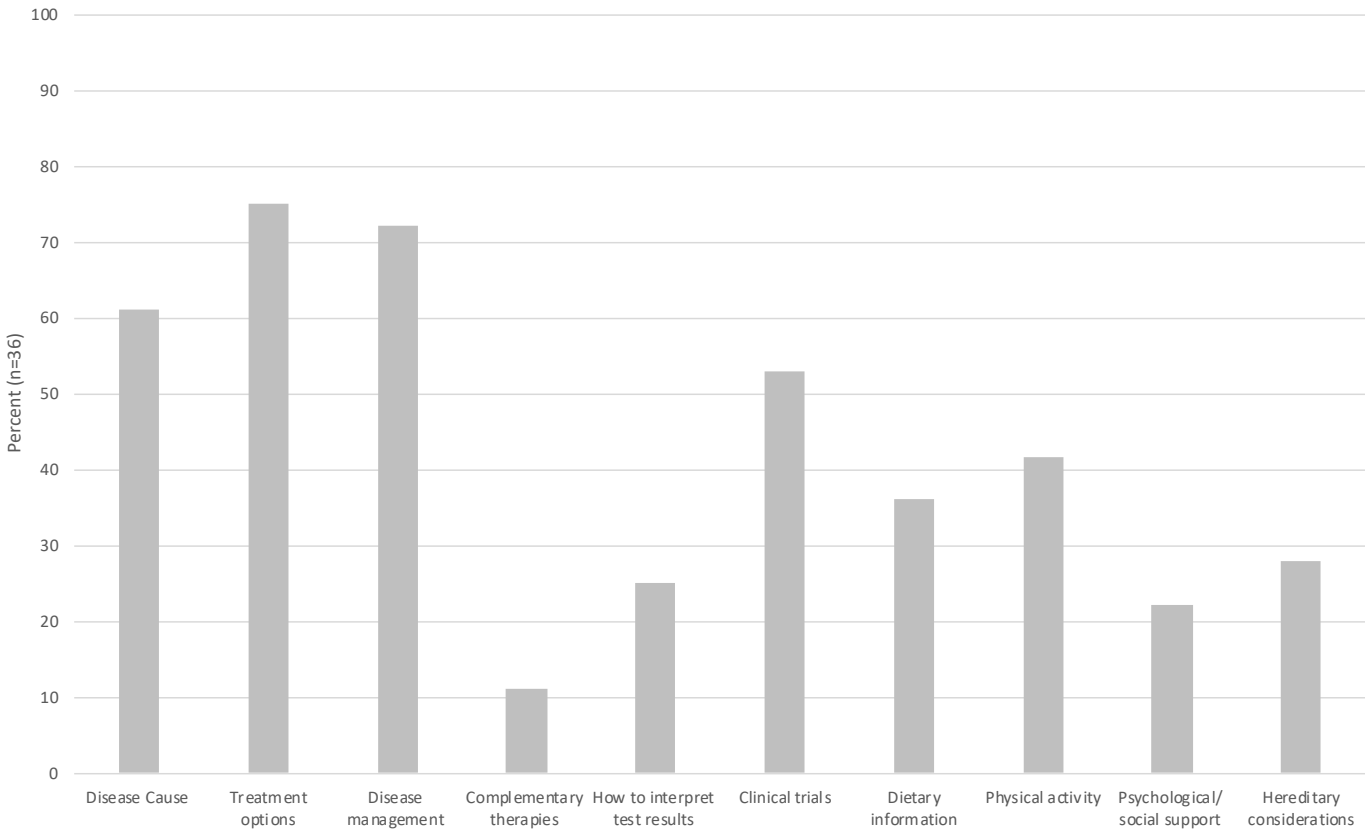

Figure 6.39: Information given by health professionals

Information searched independently

Participants were then asked, after receiving information from healthcare professionals, what information did they need to search for independently? Information about disease management (58.33%), disease cause (55.56%), and treatment options (55.56%) were most often searched for independently by participants. Psychological and social support (27.78%), and hereditary considerations (30.56%) were least searched for (Table 6.24, Figure 6.40).

In relation to subgroup variations, participants in the *ATTR-cardiac* (66.67%), *Metropolitan* (66.67%) and *Mid to low SEIFA* (72.73%) subgroups (71.43%) were searched for information about disease cause more often than the general population (55.56%), while participants in the *AL amyloidosis* (20.00%) subgroup searched for this information less often.

Female (71.43%) participants searched for information about treatment options more often than the general population (55.56%), while participants in the *AL amyloidosis* (30.00%), *Male* (45.45%), *Metropolitan* (44.44%) and *Trade or high school* (42.86%) subgroups searched for this information less often.

Participants in the *Aged 65 to 74* (47.37%), *Trade or high school* (42.86%) subgroups searched for information about Disease management less often than the general population (58.33%).

Participants in the *Female* (57.14%), *Mid to low SEIFA (54.55%)* subgroups searched for information about Complementary therapies more often than the general population (41.67%), while participants in the *AL amyloidosis* (20.00%*), Aged 65 to 74* (31.58%), *Trade or high school (*28.57%) searched for this information less often.

Participants in the *ATTR-cardiac* (61.11%), *Mid to low SEIFA* (72.73%) subgroups searched for information about clinical trials more often than the general population (50.00%), while *Female* participants (35.71%), searched for this information less often.

Participants in the *Mid to low SEIFA* (54.55%) subgroup searched for information about dietary information more often than the general population (38.89%).

Participants in the *Amyloidosis* (20.00%) subgroup searched for information about physical *activity* less often than the general population (36.11%).

Participants in the *Metropolitan* (44.44%) subgroup searched for information about psychological/social support more often than the general population (27.78%), while participants in the *ATTR-cardiac* (16.67%), *All cardiac* (16.00%), *AL amyloidosis* (10.00%) and *University* (7.14%) subgroups searched for this information less often.

Participants in the *Metropolitan* (44.44%), *Mid to low SEIFA* (54.55%) subgroups searched for information about hereditary considerations more often than the general population (30.56%), while participants in the *Higher SEIFA* (20.00%) subgroup, searched for this information less often.

Table 6.24: Information searched for independently

Information topic	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Metropolitan		Regional or remote	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=27	%	n=9	%
Disease Cause	20	55.56	12	66.67	14	56.00	2	20.00	6	75.00	11	50.00	9	64.29	6	66.67	14	51.85
Treatment options	20	55.56	10	55.56	13	52.00	3	30.00	7	87.50	10	45.45	10	71.43	4	44.44	16	59.26
Disease management	21	58.33	11	61.11	15	60.00	5	50.00	5	62.50	12	54.55	9	64.29	6	66.67	15	55.56
Complementary therapies	15	41.67	8	44.44	10	40.00	2	20.00	5	62.50	7	31.82	8	57.14	4	44.44	11	40.74
How to interpret test results	15	41.67	8	44.44	11	44.00	4	40.00	3	37.50	9	40.91	6	42.86	3	33.33	12	44.44
Clinical trials	18	50.00	11	61.11	14	56.00	4	40.00	3	37.50	13	59.09	5	35.71	5	55.56	13	48.15
Dietary information	14	38.89	6	33.33	9	36.00	4	40.00	4	50.00	9	40.91	5	35.71	4	44.44	10	37.04
Physical activity	13	36.11	7	38.89	9	36.00	2	20.00	4	50.00	8	36.36	5	35.71	3	33.33	10	37.04
Psychological/social support	10	27.78	3	16.67	4	16.00	1	10.00	6	75.00	5	22.73	5	35.71	4	44.44	6	22.22
Hereditary considerations	11	30.56	5	27.78	8	32.00	3	30.00	3	37.50	6	27.27	5	35.71	4	44.44	7	25.93

Information topic	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Disease Cause	20	55.56	8	100.00	10	52.63	2	25.00	7	50.00	7	50.00	8	72.73	12	48.00
Treatment options	20	55.56	6	75.00	11	57.89	2	25.00	6	42.86	7	50.00	7	63.64	13	52.00
Disease management	21	58.33	7	87.50	9	47.37	4	50.00	6	42.86	10	71.43	7	63.64	14	56.00
Complementary therapies	15	41.67	6	75.00	6	31.58	2	25.00	4	28.57	6	42.86	6	54.55	9	36.00
How to interpret test results	15	41.67	4	50.00	8	42.11	3	37.50	7	50.00	5	35.71	4	36.36	11	44.00
Clinical trials	18	50.00	6	75.00	8	42.11	3	37.50	8	57.14	7	50.00	8	72.73	10	40.00
Dietary information	14	38.89	5	62.50	8	42.11	0	0.00	5	35.71	5	35.71	6	54.55	8	32.00
Physical activity	13	36.11	4	50.00	6	31.58	2	25.00	4	28.57	5	35.71	5	45.45	8	32.00
Psychological/social support	10	27.78	2	25.00	7	36.84	1	12.50	3	21.43	1	7.14	3	27.27	7	28.00
Hereditary considerations	11	30.56	5	62.50	6	31.58	0	0.00	4	28.57	4	28.57	6	54.55	5	20.00

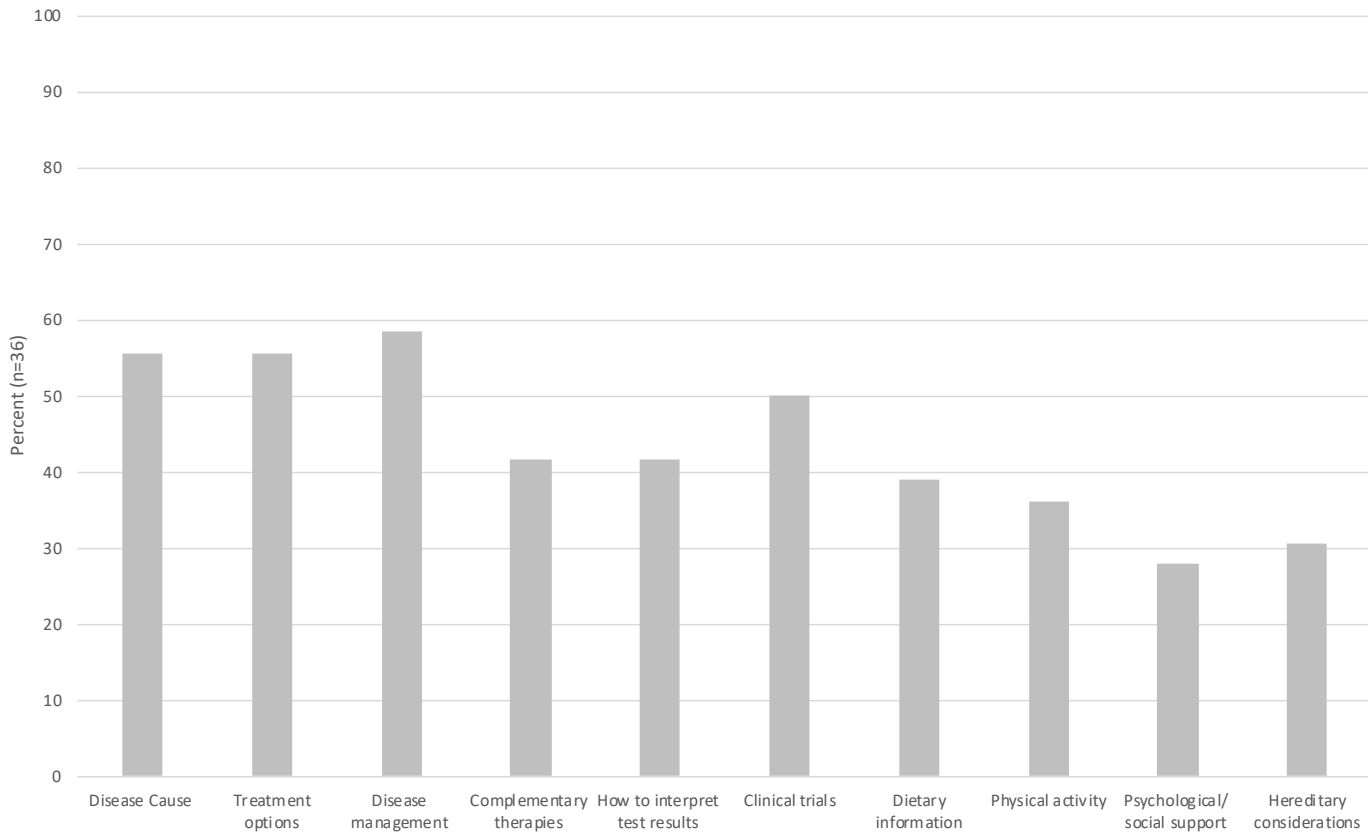

Figure 6.40: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for psychological/social support (n=21, 58.33%), hereditary considerations genes or genomic biomarker information (n=21, 58.33%), and complementary therapies (n=20, 55.56%).

Participants were given most information either from healthcare professionals or independently for disease management (n=16, 44.44%), and treatment options (n=15, 41.67%). The topic that was most searched for independently following no information from health professionals was complementary therapies (n=12, 33.33%) (Table 6.25, Figure 6.41).

Table 6.25: 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=36	%	n=36	%	n=36	%	n=36	%
Disease cause	4	11.11	12	33.33	10	27.78	10	27.78
Treatment options	4	11.11	12	33.33	15	41.67	5	13.89
Disease management	5	13.89	10	27.78	16	44.44	5	13.89
Complementary therapies	20	55.56	1	2.78	3	8.33	12	33.33
How to interpret test results	17	47.22	4	11.11	5	13.89	10	27.78
Clinical trials	9	25.00	9	25.00	10	27.78	8	22.22
Dietary information	14	38.89	8	22.22	5	13.89	9	25.00
Physical activity	15	41.67	8	22.22	7	19.44	6	16.67
Psychological/social support	21	58.33	5	13.89	3	8.33	7	19.44
Hereditary considerations	21	58.33	4	11.11	6	16.67	5	13.89

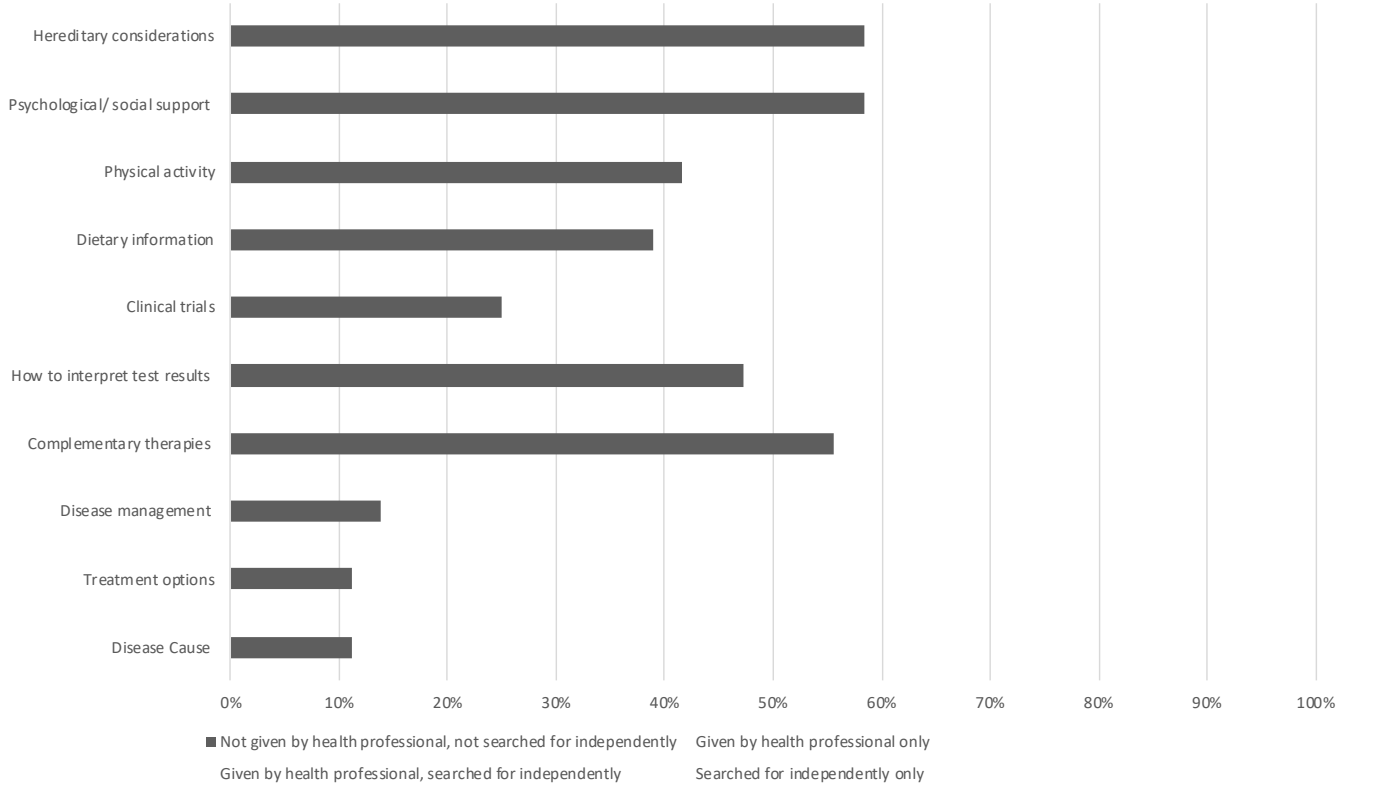

Figure 6.41: Information gaps

Accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.26 and Figure 6.42. With a weighted ranking, the higher the score, the more trusted the source of information to the participant.

Across all participants, information from the hospital or clinic where treated was most accessed, followed by information from non-profit or charities or patient organisations.

Table 6.26: Most accessed information

Information source	Weighted average (n=28)
Non-profit organisations, charity or patient organisations	3.14
Government	2.43
Pharmaceutical companies	2.89
Hospital or clinic I am being treated in	3.79
Medical journals	2.75

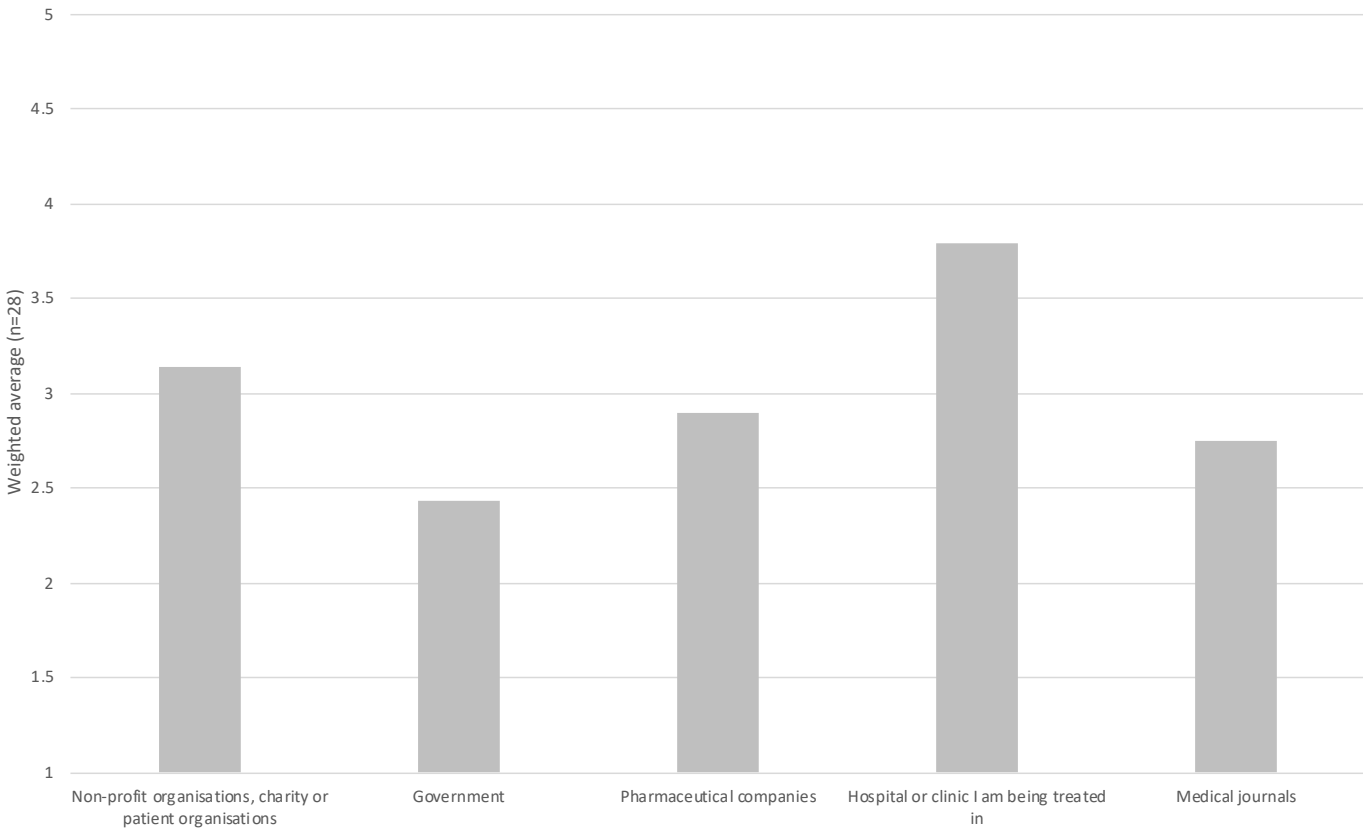

Figure 6.42: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were eleven participants (39.29%) that had accessed 'My Health Record', while 15 (53.57%) had not, two participants did not know what it is (7.14%), and four participants (4.00%) were not sure.

Of those that had accessed 'My Health Record', five participants (45.45%) found it good or acceptable, six participants (54.54%) found it poor, or very poor.

Table 6.27: Accessed 'My Health Record'

Accessed "My health record"	Number (n=28)	Percent
Yes	11	39.29
No	15	53.57
I am not sure	2	7.14

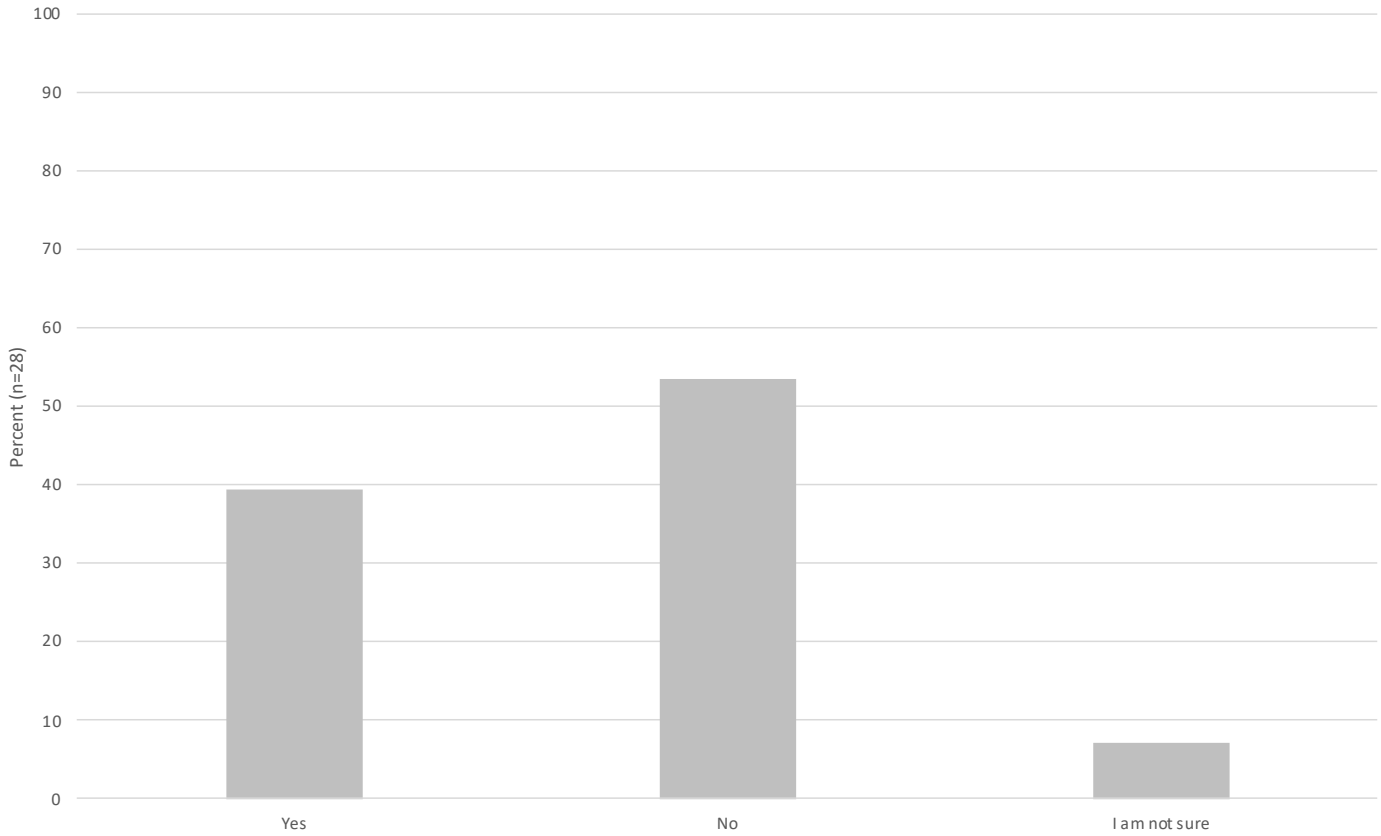

Figure 6.43: Accessed 'My Health Record'

Table 6.28: How useful was 'My Health Record'

How useful was "My health record"	Number (n=11)	Percent
Very poor	2	18.18
Poor	4	36.36
Acceptable	4	36.36
Good	1	9.09
Very good	0	0.00

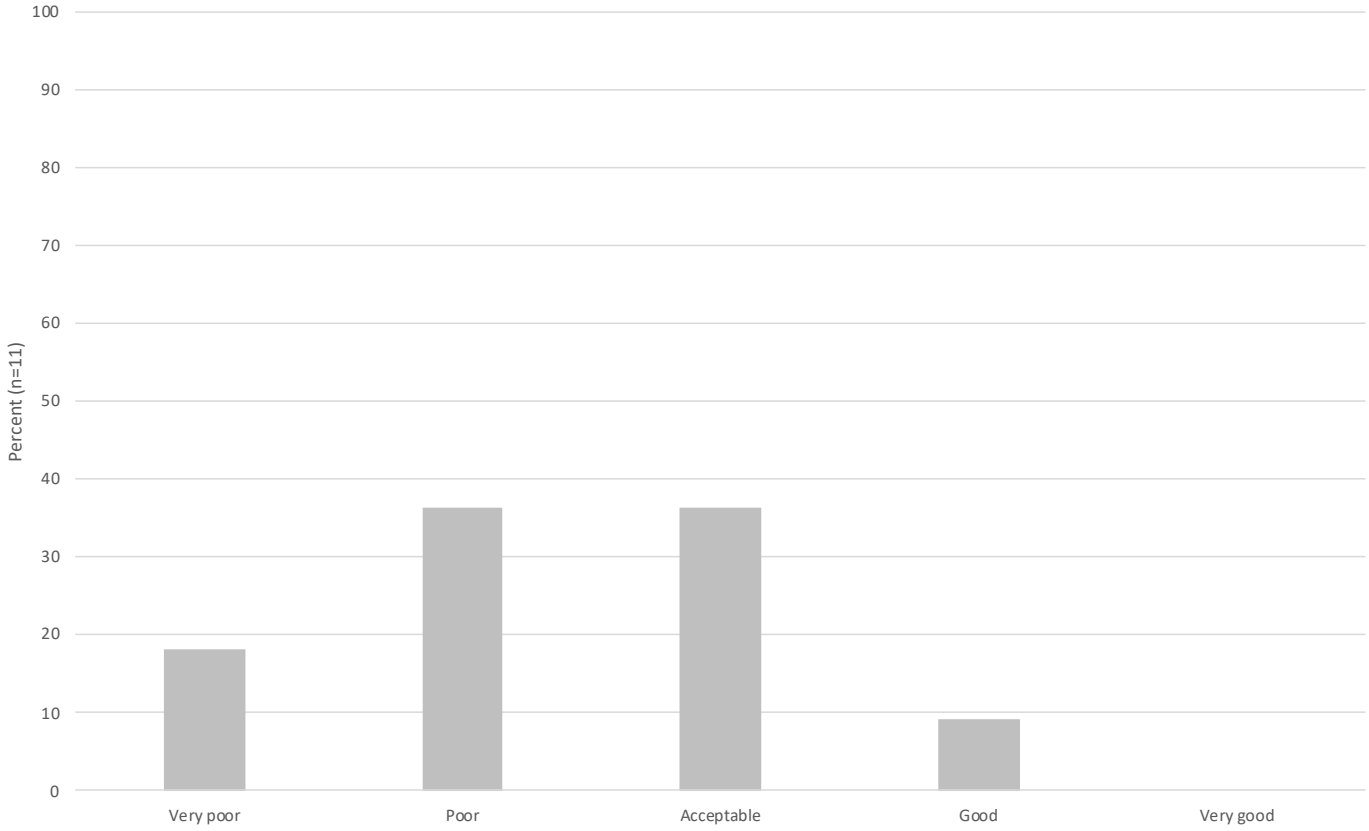

Figure 6.44: How useful was 'My Health Record'