Section 9

Expectations and messages to decision-makers

Section 9 Summary: Expectations and messages to decision-makers

Expectations of future treatments

- In the structured interview, participants were asked what their expectations of future treatments are. The most common theme was participants expected treatments to be more affordable (n=18, 50.00%), followed by the expectation that future treatments would be more effective (n=8, 22.22%). There were six participants (16.67%) that recommended future treatments should have fewer or less intense side effects and four participants (11.11%) that called for future treatments to be less invasive.

Expectations of future information

- Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was participants having no recommendations or feeling satisfied with the information currently available (n=7, 19.44%), and this was followed by the expectation that future information would be easier to understand (n=6, 16.67%). There were five participants (13.89%) that recommended more information to inform the community and decision-makers about the condition. There were also four participants (11.11%) who suggested future information provide more details about new treatments and trials and four participants (11.11%) that called for more details about the specific classification of their condition.

Expectations of future communication with healthcare professionals

- Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will involve health professionals having a better knowledge of the condition (n=13, 36.11%), and this was followed by no recommendations or participants feeling they had experienced good communication (n=10, 27.78%).

Expectations of future care and support

- Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was more access to support services in future (n=8, 22.22%), and this was followed by participants having no recommendations or being satisfied with the care they have received (n=6, 16.67%). There were four participants (11.11%) that recommended future care and support involving more peer support such as support groups and four participants (11.11%) that called for care and support to include more long-term condition management or care planning.

What participants are grateful for in the health system

- Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was participants expressing feeling grateful for the entire healthcare system (n=13, 36.11%). This was followed by those who were grateful for healthcare staff (n=10, 27.78%), low cost or free medical care through the government (n=10, 27.78%), timely access to treatment (n=5, 13.89%) and access to private healthcare/insurance (n=4, 11.11%).

Symptoms and aspects of quality of life

- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported for participants with ATTR-cardiac were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and arm and leg symptoms (e.g. numbing, tingling, weakness, pain).

- The most important aspects reported for participants with AL amyloidosis were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs).

Values for decision-making

- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were ‘How safe the medication is and weighing up the risks and benefits’, and ‘The severity of the side effects’. The least important were ‘The financial costs to me and my family’.

Values for decision-makers

- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

- Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. The majority of participants (n=19, 67.86%) would use a treatment for more than ten years for a good quality of life, even if it didn’t offer a cure.

Message to decision-makers

- Participants were asked, ‘If you were standing in front of the health minister, what would your message be in relation to your condition?’. The most common message was that treatments need to be affordable (n=10, 27.78%). This was followed by the message that there should be more clinical trials and/or new treatments (n=8, 22.22%), that there should be improved access to support and care (n=6, 16.67%), the need to take the condition seriously (n=5, 13.89%), the need to invest in professional development so that clinicians better understand the condition (n=5, 13.89%) and finally, to invest in research, including the effort to find new treatments (n=4, 11.11%).

Expectations of future treatments

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was participants expected treatments to be more affordable (n=18, 50.00%), followed by the expectation that future treatments would be more effective (n=8, 22.22%). There were six participants (16.67%) that recommended future treatments should have fewer or less intense side effects and four participants (11.11%) that called for future treatments to be less invasive.

In relation to subgroup variations, participants in the *Aged 75 or older* (37.50%) subgroup described the expectation that future treatments would be more affordable less frequently than the general population (50.00%), while those in the *Carer* (62.50%), *Aged 55 to 64* (62.50%), and *Female* (64.29%) subgroups described this more frequently.

Participants in the *Carer* (0.00%), *Female* (0.00%), and *Regional or remote* (11.11%) subgroups described the expectation that future treatments would be more effective less frequently than the general population (22.22%), while those in the *ATTR-cardiac* (33.33%), and *Male* (36.36%) subgroups described this more frequently.

Participants in the the general population (16.67%). described the expectation that future treatments would have fewer or less intense side effects, however no participants described this in the *Aged 75 or older* (0.00%) subgroup.

Participants in the *Aged 55 to 64* (25.00%), and *Female* (21.43%) subgroups described the expectation that future treatments would be less invasive more frequently than the general population (11.11%), while those in *Regional or remote* (0.00%), and *Mid to low SEIFA* (0.00) subgroups did not describe this at all.

More affordable

Well, obviously, the main would be costs to be brought down for those ones…I know it costs time to develop with these things, but those prices seem pretty high. Participant 001ALX

I think a lot of the cost, for example, some of the marker ones, not on the PBS though, I'm being charged the full amount for those, $89 a pop. Participant 003AL

Well, obviously the cost. If it ever gets to the point where some of them are paid for, that would be fantastic. Participant 012ATR

More effective

Well, the aim that I'd really love to have is some treatment that works for other types that actually gets in and effectively eats away this disease. I mean, that is a long, long, long, long way and it'll never be in my lifetime of course. To me, that would be the ideal, so that when people are diagnosed with my problem, they can go onto this treatment and say, 'Well, in two or three years if you keep taking this drug, you'll just have a normal heart instead of having a heart that only works at 30% of the average person.' To me, that would be the ideal situation. Participant 003ATR

If they could find something to dissolve amyloid in your system, and even not permanently, but just to give people a better quality of life with amyloid-free in their kidneys or heart or liver or wherever they have it. Participant 005AL

Just the cost for me and effectiveness. For somebody that has to pay for these treatments and the effectiveness, people like guarantees of course but they like best of all assurances that the benefit is going to be worth the cost. A lot of people cannot afford new treatments. Those two things together would be relevant to most people. Participant 006AL

Fewer or less intense side effects

Side effects, for me, I would like them to be known about. So, we know what's going to possibly going to happen and we can be aware of it. Participant 015ATR

It also does give you the chance to go away even if you just go for a weekend away or something like that. Yes, the least possible side effects if something was to give him really worse side effects than he has now and without any particular benefits. Participant 002CA

Well, everyone if there's new treatment there I suppose everyone expects it to not to have any side effects and to make it better as soon as possible. Participant 008ATR

Less invasive

Yes, so treatment-- a tablet is OK, I mean you just put it in the mouth. There are times that I have had to use injection, once I know-- you might look at and one's you might not. An IV drip because that would be really--The choices would be I think, for the future to see right now treatment is only for pre-transplant on the-- I know that there is post-transplant, that will be the trialled in Sweden, but they need three patients to do that. Participant 002ATR

What I would most like to see? I suppose the way it is administered. It depends if it's going to be an injection I suppose or tablets to ingest. If there was a discussion about preference for that and any side effects and I had a choice that would be something I would want to know about and have a choice in the administration of the treatment. Even if it was ongoing like a meeting with a health professional and discussion sort of thing that would be fine. I would be happy to do that. Participant 003ALX

In delivery, that is something that I would rather it be either an in-home where like taking medication, things like that. I don't like the idea of outpatients having to go into a hospital on a regular basis, because that's basically totally messing with your day and while you are trying to work, that's not good. So least invasive possible. Participant 015ATR

Table 9.1: Expectations of future treatments

Expectations of future treatments	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 the expectation that future treatment will be more affordable	18	50.00	8	44.44	11	44.00	5	50.00	5	62.50	9	40.91	9	64.29	4	44.44	14	51.85
Participant describes the expectation that future treatment will be more effective	8	22.22	6	33.33	8	32.00	2	20.00	0	0.00	8	36.36	0	0.00	1	11.11	7	25.93
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	16.67	3	16.67	4	16.00	1	10.00	2	25.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes the expectation that future treatment will be less invasive	4	11.11	2	11.11	2	8.00	1	10.00	1	12.50	1	4.55	3	21.43	0	0.00	4	14.81

Expectations of future treatments	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 the expectation that future treatment will be more affordable	18	50.00	5	62.50	10	52.63	3	37.50	7	50.00	6	42.86	5	45.45	13	52.00
Participant describes the expectation that future treatment will be more effective	8	22.22	1	12.50	4	21.05	2	25.00	4	28.57	4	28.57	2	18.18	6	24.00
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	16.67	1	12.50	5	26.32	0	0.00	2	14.29	2	14.29	1	9.09	5	20.00
Participant describes the expectation that future treatment will be less invasive	4	11.11	2	25.00	1	5.26	1	12.50	1	7.14	2	14.29	0	0.00	4	16.00

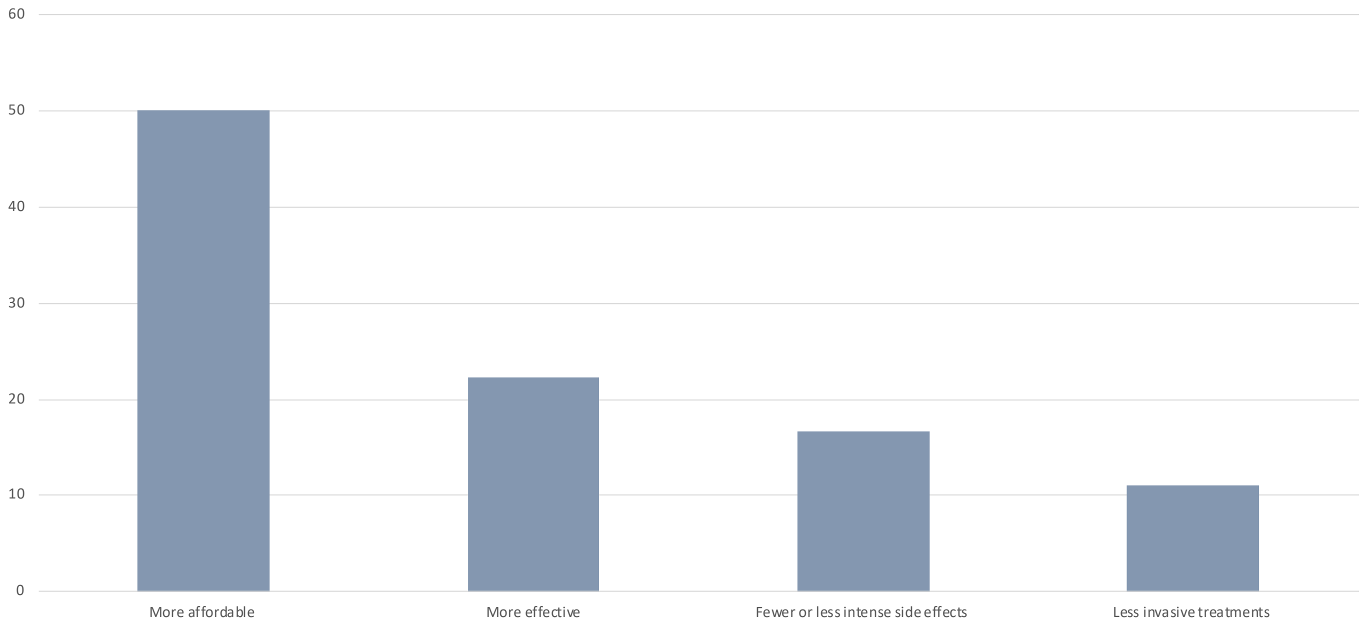

Figure 9.1: Expectations of future treatments

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was participants having no recommendations or feeling satisfied with the information currently available (n=7, 19.44%), and this was followed by the expectation that future information would be easier to understand (n=6, 16.67%). There were five participants (13.89%) that recommended more information to inform the community and decision-makers about the condition. There were also four participants (11.11%) who suggested future information provide more details about new treatments and trials and four participants (11.11%) that called for more details about the specific classification of their condition.

In relation to subgroup variations, participants in the *Regional or remote* (33.33%) subgroup described being satisfied with information or having no recommendations more frequently than the general population (19.44%).

Participants in the *AL amyloidosis* (30.00%), *Regional or remote* (33.33%), and *Mid to low SEIFA* (27.27%) subgroups described expectations that future information would be easier to understand more frequently than the general population (16.67%), while those in the *ATTR-cardiac* described this less frequently (5.56%).

Participants in the *Aged 75 or older* (25.00%) subgroup described the expectation that future information will help to inform the community and decision-makers about their condition more frequently than the general population (13.89%), whereas those in the *Regional or remote* (0.00%) subgroup did not describe this at all.

No participants in the *Carer* (0.00%), *Female* (0.00%), or *Trade or high school* (0.00%) subgroups described the expectation that future information about provide more details about new treatments and trials. Participants in the *University* (28.57%), and *Regional or remote* (22.22%) described this more frequently than the general population (11.11%).

Participants in the general population(11.11%) described expecting future information to provide more details about the specific classification of their condition, while no participants described this in the *AL amyloidosis* (0.00%) subgroup.

No recommendations/satisfied with existing information

No, I think what I have accessed is adequate information for me, personally. Participant 001ATR

I didn't find researching information difficult and if something didn't answer my question, I was comfortable with finding another source…I was comfortable with the amount of information that was out there definitely. Participant 001CA

The pamphlets they gave me when I first got diagnosed were comprehensive. They weren't full of jargon, so they were good. The information I'm getting from my doctor it's been pretty accurate... there's not much more they could say or do. Participant 004ATR

Easier to understand

I've tried reading some of the reports that are put out about the end results of the trials, et cetera, but they get too wordy and technical for us. If they're able to be summarised, maybe they are in layman's terms, et cetera. It's one or two pages. Participant 001ALX

I suppose just a very basic layman's term of description would help me a bit more. There's a little thing here I'm reading, the free light chains that fold into amyloid fibrils. That sort of thing, I guess I could-- You shouldn't Google these sorts of things, but yes, more information, more basic information as far as I'm concerned, it would be for my situation. Participant 003ALX

For one, I'm not a medical person, and two, I don't want to get it wrong. It really needs to be explained in layman's terms. 'If you have this type of amyloidosis, this is the type of medication you need. Participant 005CA

Inform the community (raise awareness)

I think more information has to be given by just normal doctors. I don't think that enough people know about Amyloidosis. I don't think education-- People need to be aware of it. The education level, whether that goes to doctors so that when someone's there, when a patient comes in and they have something that could be Amyloidosis, the *doctor needs to know that that may be Amyloidosis rather than sitting and waiting like we did for 12 weeks to find out what he had. Participant 004CA*

I think more available information and more learning, I suppose. I still reckon a lot of people have never heard of the word, amyloidosis, me included, actually. Have never heard, and then I knew that a lot of people still say like, 'There's no treatment for that.' I say, 'You don't really give a damn, that is true.' It might have but and that's as far as your treatment, but available the information and for the promotion or awareness, I suppose, of information. Participant 006ATR

For me, I'm happy with it that I'm going to get back on that blinking high horse of mine, the GPs need to be informed. They really do. They've got a lot to do, it's a rare disease. Even if there is just a little something on top of their minds that says, 'Going down these lines carpal tunnel, both wrists, could be amyloids.' I want other people to get the information, not me. Participant 015ATR

New treatments and trials

The information, as I've mentioned before, comes from a variety of sources. What would interest me or what I would look for is new information. New, and that means- I'm again repeating what I've said before- is any new drugs or any trials. I think we've got to that point which I can't go. Going back, I think I'm sufficiently informed. Going forward, of course, I'll be interested in looking at anything. Participant 001AL

Interesting what the potential future developments, nearness of new drugs, or the clinical trials for new drugs that there might be. Participant 004AL

Now that the websites up, I think, the topics I'd like to see covered at would be the status of new drugs and trials, and secondly what are the tell-tale signs of worsening condition and what you should and shouldn't do. Participant 011ATR

Specific classification of condition

There are so many different amyloidosis. I don't know the diseases. Possibly a clear classification on them. Just that there is different things. You know? Simple, not too difficult, just outlining the major aspect that there is available. What could be done. Participant 005ATR

You can't go and talk to another patient that's got this, because we haven't found anyone that's got this. There's different ones around with hereditary type but it's different from mine. Participant 009ATR

Yes, I would like to see more information on actually in the eye. As I said I did a Zoom here recently which was interesting, but it didn't relate to anything of mine. There were three doctors talking. It would have related to some people and they probably would've found it wonderful but as I said, it didn't relate to me. Participant 010ATR

Table 9.2: Expectations of future information

Expectations of future 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 has no recommendations/is satisfied with the information currently available	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	4	18.18	3	21.43	3	33.33	4	14.81
Participant describes the expectation that future information will be easier to understand	6	16.67	1	5.56	2	8.00	3	30.00	2	25.00	3	13.64	3	21.43	3	33.33	3	11.11
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	4	18.18	1	7.14	0	0.00	5	18.52
Participant describes the expectation that future information will provide more details about new treatments and trials	4	11.11	2	11.11	4	16.00	2	20.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41
Participant describes the expectation that future information will provide more details on specific classifications of their condition	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	2	9.09	2	14.29	1	11.11	3	11.11

Expectations of future 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 has no recommendations/is satisfied with the information currently available	7	19.44	1	12.50	4	21.05	2	25.00	3	21.43	3	21.43	2	18.18	5	20.00
Participant describes the expectation that future information will be easier to understand	6	16.67	2	25.00	3	15.79	1	12.50	2	14.29	2	14.29	3	27.27	3	12.00
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	5	13.89	1	12.50	1	5.26	2	25.00	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes the expectation that future information will provide more details about new treatments and trials	4	11.11	1	12.50	2	10.53	1	12.50	0	0.00	4	28.57	1	9.09	3	12.00
Participant describes the expectation that future information will provide more details on specific classifications of their condition	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	1	7.14	1	9.09	3	12.00

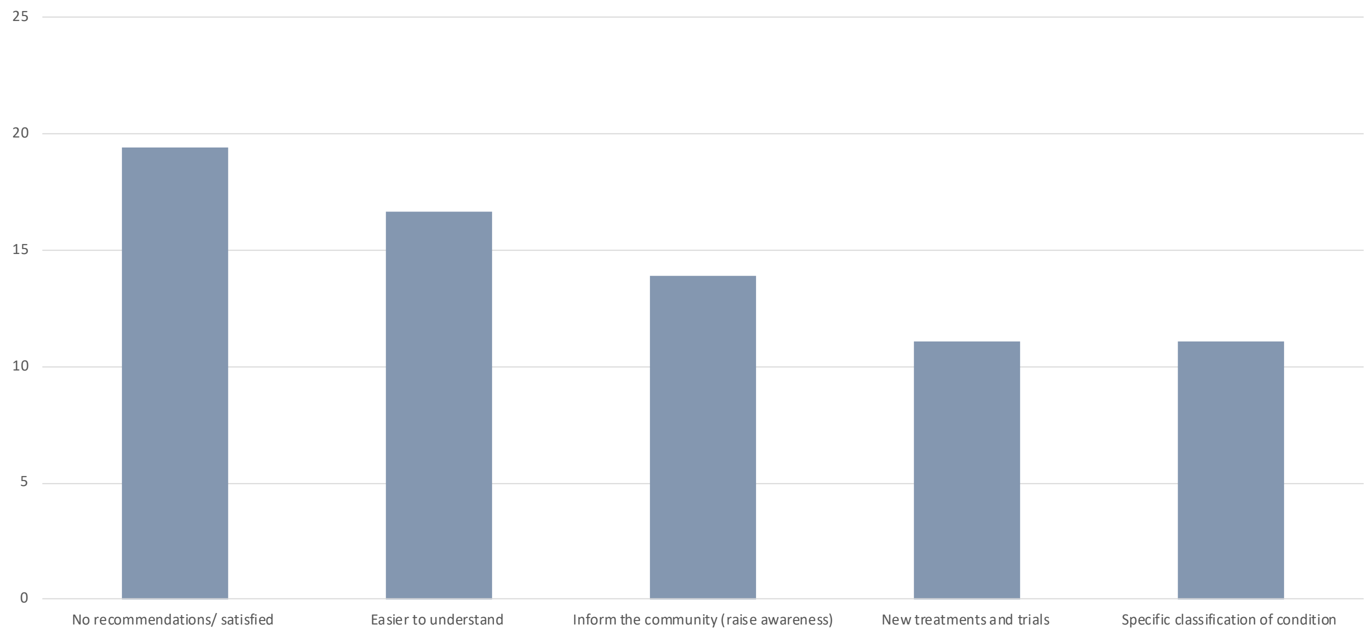

Figure 9.2: Expectations of future information

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will involve health professionals having a better knowledge of the condition (n=13, 36.11%), and this was followed by no recommendations or participants feeling they had experienced good communication (n=10, 27.78%).

In relation to subgroup variations, participants in the *Carer* (25.00%), and *Aged 75 or older* (25.00%) subgroups described wanting health professionals to have a better knowledge of their condition less frequently than the general population (36.11%).

Participants in the *Carer* (12.50%), *Aged 55 to 64* (12.50%), and *Female* (14.29%) subgroups described having experienced good communication or having no recommendations less frequently than the general population (27.78%), while those in the *AL amyloidosis* (50.00%), *Aged 75 or older* (62.50%), *University* (47.86%), and *Regional or remote* (44.44%) subgroups described this more frequently.

Better knowledge of condition

I think health professionals should be honest when they don't know about amyloidosis and that they do reach out to keep the patients informed...I think that there needs to be more education and training for them. Participant 002ATR

The only thing in relation to health professionals is that there needs to be more education at the general practice level to be looking for this as a potential diagnosis, because I haven't met one person who hasn't been on 12 months' worth of looking and trying to find out why they were going downhill. It's more about education. Participant 002CA

I think health professionals need more knowledge about the disease itself. A lot of them don't know

about it. They've never heard of it. We've come across a couple of doctors now that- even our own neurosurgeon or neuro guy didn't know. He said, 'I've never heard of it'. Participant 009ATR

No recommendations/good communication

No. I think I'm pretty lucky that I've got good health professionals. I let my GP know what's going on. I'm trying to think. I don't recall saying, 'We should do this' or 'we should do that'. No, nothing in my case I can think of. Participant 001ALX

No. My experience is such that I wouldn't really change the people I've dealt with. It's hard to believe that I haven't run into somebody that had caused me any hustles at all. I'm big enough, I'm ugly enough to stand up for myself, and NAME wanted to do a heart biopsy, I told him he had to wait to autopsy. Participant 002ALX

No, I don't think so. I thought the way that they had NAME there that was so open 24 hours a day, practically, who have a vast knowledge of amyloidosis, that was just fantastic to know that you could pick up a phone and talk to her, and she would actually get you through to a cardiac specialist, whoever you wanted, very easily. I'd hate to see that go away, because she's a voluntary worker. As a patient, it was fantastic to know she was there. It was really good. Participant 017ATR

Table 9.3: Expectations of future healthcare professional communication

Expectations of future 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 the expectation that future communication will have health professionals with a better knowledge of the condition	13	36.11	8	44.44	10	40.00	3	30.00	2	25.00	7	31.82	6	42.86	3	33.33	10	37.04
Participant has no recommendations/experienced good communication	10	27.78	4	22.22	7	28.00	5	50.00	1	12.50	8	36.36	2	14.29	4	44.44	6	22.22

Expectations of future 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 the expectation that future communication will have health professionals with a better knowledge of the condition	13	36.11	3	37.50	8	42.11	2	25.00	6	42.86	5	35.71	4	36.36	9	36.00
Participant has no recommendations/experienced good communication	10	27.78	1	12.50	4	21.05	5	62.50	3	21.43	6	42.86	2	18.18	8	32.00

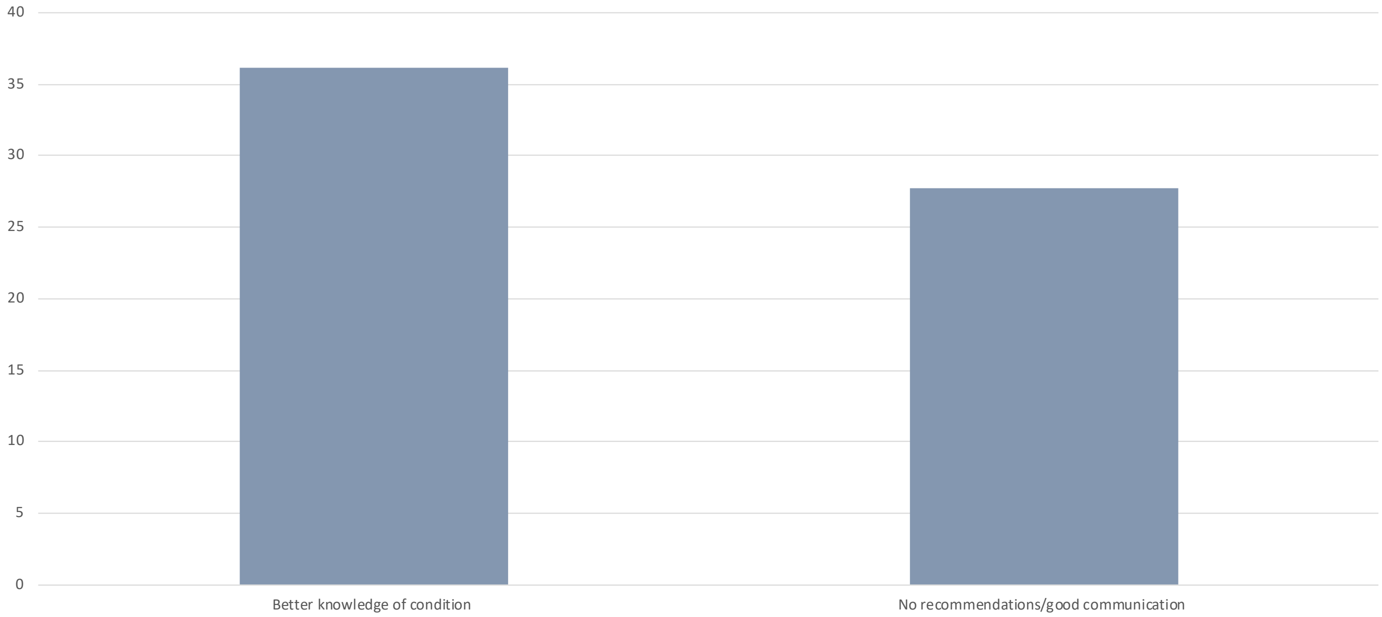

Figure 9.3: Expectations of future healthcare professional communication

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was more access to support services in future (n=8, 22.22%), and this was followed by participants having no recommendations or being satisfied with the care they have received (n=6, 16.67%). There were four participants (11.11%) that recommended future care and support involving more peer support such as support groups and four participants (11.11%) that called for care and support to include more long-term condition management or care planning.

In relation to subgroup variations, participants in the *AL amyloidosis* (10.00%), and *University* (7.14%) subgroups described wanting better access to support services in the future less frequently than the general population (22.22%), while those in the *Carer* (50.00%), *Aged 65 to 74* (36.84%), *Female* (35.71%), *Regional or remote* (44.44%) and *Mid to low SEIFA* (36.36%) subgroups described this more frequently. There were no participants in the *Aged 75 or older* (0.00%) subgroup that described this.

Participants in the *AL amyloidosis* (30.00%), and *Trade or high school* (28.57%) subgroups described having no recommendations or being satisfied with the care they have received more frequently than the general population (16.67%), while those in the *Carer* (0.00%) subgroup did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%), *Regional or remote* (0.00%) or *Mid to low SEIFA* (0.00%) subgroups described wanting future care and support to include more peer support. Those in the *Aged 75 or older* (25.00%) subgroup described this more frequently than the general population (11.11%).

Those in the *Aged 55 to 64* (25.00%), and *Regional or remote* (22.22%) subgroups described wanting future support and care to include more long-term condition management more frequently than the general population (11.11%), while participants in the *AL amyloidosis* (0.00%), and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

Access to support services

There are people out there miles out in the country that have Amyloidosis and have to come into the hospitals. I believe that there should be accommodation for these people...I feel that there should be people that can pick them up from the airport, take them to places. Participant 004CA

I don't know what other charities there would be, but I would think probably, maybe for a lot of people, it's having someone to talk to, especially in those early days, about it, to find you to get to the right path and know what's available and how to help them would be really helpful. Participant 012ATR

Well, I think I'm pretty all right, but then a person by themselves would probably need a bit of support, someone to talk to or keep an eye on them. As it gets worse, you probably become incapacitated and you'll need probably pretty intensive care. Participant 014ATR

No recommendations

Let me think, what I would need help with? Sorry. I can't think of anything. Let me see. I get the support that NAME CLINIC they ran some services on exercises and that sort of thing and eating, and what to eat. That was good. No, I can't think of anything, sorry. Participant 001ALX

I haven't needed a lot of help. I know that it might sound big headed. To be perfectly honest, no. If it can be improved, but I don't think if there's necessarily anything not available or not at least missing to me as we're managing the disease. I think as a result of the questions you asked me, I may well ask some additional questions next time I meet NAME CLINICIAN, but no, I'm pretty comfortable with the care and the information and the like, that's been provided. Participant 004AL

No, I don't think so. I'm lucky to have a fantastic wife who cared for me fantastically. We didn't need any outside support. She might, but I didn't. Participant 017ATR

Peer support

I know recently we had to do one. We had two sessions, we had a support group meeting and an education meeting, and I think more people got on board that then-- Maybe sometimes people can't get to a local, actual physical meet up group, so maybe some more online stuff is a good idea. Participant 002AL

I think support groups are probably a big help, but again because in this case, in my case because the numbers are so small, obviously the support group is very small and it's all like people live in different areas, you've got to travel sometimes and again sometimes you can't. Meetings will be held or support groups will be held but that's not as if you can just drive 15 minutes and you're meeting a group of people, you have to drive an hour and half or whatever, but I think support groups will do. Participant 003ATR

I think I've a couple of group or, what they call it, the chat group or something in LOCATION REGIONAL where everyone can meet once a month and have a talk about their problems. Compare problems. That sort of thing, it would probably be good I reckon. It's just sort of-- I think you got to be-- If someone in the right position, they might know that and get that going. I've had three or four names. Participant 008ATR

Care planning

I think the answer is that there is almost more that could be done to assist us. Just to provide better assistance. Because life always has to explain to different aspects in the situation and everybody also is different will be affected in different ways. Just a matter, again, to discover what is going on inside and also doctor patients may we require further assistance. Understanding the feeling and what it can create, but then those patients can be as a group and also as individuals because of their own systems. Participant 005ATR

I think I would've liked more one-on-one, not one-on-one really, more feedback on the ATTR, rather than just a pamphlet, because when we searched, it's pretty tricky to get that non-medical, so we educated ourselves, me more so, because NAME HUSBAND became so overwhelmed sometimes… The thing is, if anything happens, I'll have to explain to every medical person what was used in his medicine. Especially emergency, because they're not going to just contact a cardiologist come up from LOCATION METROPOLITAN hurrying. The support team, I think has to be through the medical system, but they don't communicate, NAME HOSPITAL 1 don't communicate with the NAME HOSPITAL 2. Even with travel, they don't communicate. Participant 005CA

It's not dementia, it's not Parkinson's, so you can't treat it in the same way. That, to me, would be-- that level of care, but specifically tailored to the-- At the end of the day, so the very last day, my dad's mind was as clear as a bell, it wasn't a problem. Treat him like he's got dementia, no way, he would have thrown things at you if you could have picked him up. That's what I mean, it needs to be condition-specific care because, otherwise, if you treated me like I have dementia, I'd pick up a bowl and throw it at you because that's not what I am. That needs to be recognised when they're planning their care. Participant 014ATR

Table 9.4: Expectations of future care and support

Expectations of future care and support	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 the expectation that future care and support will include more access to support services	8	22.22	3	16.67	4	16.00	1	10.00	4	50.00	3	13.64	5	35.71	4	44.44	4	14.81
Participant has no recommendations/is satisfied with care received	6	16.67	3	16.67	5	20.00	3	30.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	11.11	2	11.11	4	16.00	2	20.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41

Expectations of future care and support	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 the expectation that future care and support will include more access to support services	8	22.22	1	12.50	7	36.84	0	0.00	3	21.43	1	7.14	4	36.36	4	16.00
Participant has no recommendations/is satisfied with care received	6	16.67	1	12.50	3	15.79	2	25.00	4	28.57	2	14.29	1	9.09	5	20.00
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	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 the expectation that future care and support will include more long-term condition management (care planning)	4	11.11	2	25.00	2	10.53	0	0.00	1	7.14	2	14.29	2	18.18	2	8.00

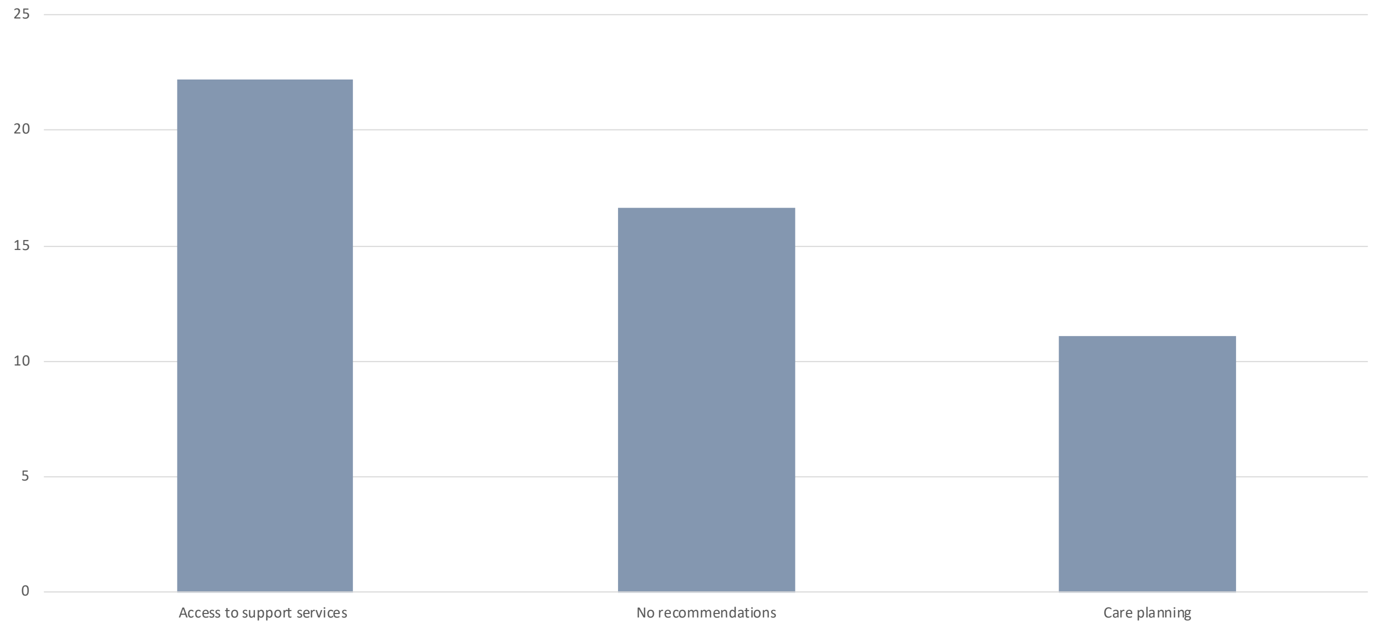

Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was participants expressing feeling grateful for the entire healthcare system (n=13, 36.11%). This was followed by those who were grateful for healthcare staff (n=10, 27.78%), low cost or free medical care through the government (n=10, 27.78%), timely access to treatment (n=5, 13.89%) and access to private healthcare/insurance (n=4, 11.11%).

In relation to subgroup variations, participants in the *Carer* (12.50%), *Aged 55 to 64* (12.50%), and *University* (21.43%) subgroups described being grateful for the entire health system less frequently than the general population (36.11%), while those in the *AL amyloidosis* (60.00%), *Aged 75 or older* (50.00%), and *Trade or high school* (64.29%) subgroups described this more frequently.

Participants in the *Aged 65 to 74* (10.53%), and *Trade or high school* (14.29%) subgroups described being grateful for healthcare staff less frequently than the general population (27.78%), while those in the *Aged 55 to 64* (50.00%) subgroup described this more frequently.

No participants in the *Trade or high school* (0.00%), and *Mid to low SEIFA* (0.00%) subgroups described bring grateful for timely access to treatment. Participants in the *Carer* (25.00%), and *Aged 55 to 64* (25.00%) subgroup described this more frequently than the general population (13.89%).

Participants in the *AL amyloidosis* (30.00%), and *Regional or remote* (22.22%) subgroups described being thankful for access to private healthcare or insurance more frequently than the general population (11.11%), while those in *ATTR-cardiac* (0.00%) subgroup did not describe this at all.

Entire health system

Just for living in the health system that we live in basically. Thank God our taxes go to some good. Participant 001ATR

Yes, I agree with you, we've got a brilliant health system. I think people who complain about the public system in particular need a good boot up the backside because it's probably the best public health system in the world. Participant 002ALX

The Australian health system is second to none. Trust me. I'm just ever so grateful for the assistance that we've had. Participant 003CA

Healthcare staff

I think I'm particularly grateful for the quality of his oncologist and haematologist. We've always had, I think it's important to have a great trust in the person who's managing your health, especially when it's a life-threatening health condition. We have always had that, there's never been any time

we moved out of NAME CLINICIAN. We always felt he was very well connected with renal specialists and heart specialists. They actually were a team, so NAME HUSBAND felt that he was not going from one to another without communication. So, they've always been informed with NAME HUSBAND'S blood tests and progress. That's been very important to have those professionals who are helping to manage your condition, communicating, and connected to one another. Participant 001CA

The ambulance took me straight through NAME HOSPITAL and honestly, the care there was just amazing. The same at the NAME HOSPITAL, the care is just wonderful, the people doing the tests on me, the urine test, the blood tests, all the nurses, whatever, even the people at the reception, I think they chose them especially for it because they're so caring and so positive. Participant 003ALX

Now, I've just been there, I've been thankful for every time I've been in hospital or wherever that I've never come across a cranky nurse, doctor or anything like that. They've always been understanding and obliging, and we've heard some horrible misadventures in the hospital, but they've always been there, they've never been--they largely never been put down or belittled in any way like that. Participant 003ATR

Low cost/free medical care

The availability of the doctors under the PBS and the public health system, so I don't have too many expenses. For a while there, I was visiting my haematologist as a private patient, that was costing me. The day we had a meeting, it turned out not to be convenient, so I asked to be moved. I realised he also had whatever, they're called consulting rooms at NAME HOSPITAL. I asked to move to there…The cost is the biggest benefit. Participant 001ALX

Well, the amyloidosis clinic at NAME HOSPITAL because when we go there if we have any sort of a test, an echocardiogram or any sort of test, it's all covered by the health system, which means that if you weren't in the position of being able to afford specialist doctors who're running private practices, that you still have access to that kind of care, the same level of care. Participant 002CA

Heck, yes. I'm grateful to going and having a scan, and not paying for it under Medicare. I can't believe that such a sophisticated thing and people interpreting it is all under. Yes. When I look at what's happened in a place like LOCATION OVERSEAS, when I look at Australia, oh, gee-whiz! No, I'm very grateful for Medicare in Australia. Participant 007ATR

Timely access to treatment

I am extraordinarily grateful for the availability of pharmaceuticals. It was a little bit of a shock when we thought carfilzomib might be the answer to NAME HUSBAND's condition, and it wasn't going to be available. NAME HUSBAND said to NAME DOCTOR, 'we'll buy it, you just get it'. But NAME DOCTOR said it wasn't quite like that. You couldn't just go and buy it off the shelf. We were very grateful when he pleaded the case to PBS, and it did become available to NAME HUSBAND. Participant 001CA

The Australian health system is second to none. Trust me. I'm just ever so grateful for the assistance that we've had. I think being a rare thing, I think the one time we had to go over to HOSPITAL METROPOLITAN in an emergency and the minute they knew that NAME HUSBAND had been on thalidomide and had amyloid, they just picked him up and took him straight in. Participant 003CA

The thing that has always pleased and surprised me in comparison to living over in the UK with the NHS, is the speed at which things are done. I'm not talking about whether you're under a private healthcare scheme or anything like that, just going straight into the health system, the speed at which things are done is great and I am very appreciative of that, again, on a daily basis. I have heard them say on the television, 'It takes two days before somebody gets seen and has treatment for something.' Yes, and in the UK, it's three years, shut up and smile. I am always pleased for that. Participant 015ATR

Access to private healthcare/private insurance

I would agree that the health system is very good. Also, carrying private insurance, which we do. I have access pretty much immediately. Participant 001AL

We have insurance, and even meant for chronic conditions like the management for, you can go on a care plan, which we have done over the course of 2015 to now. We've gone through care plan for nutrition through our local GP, nutrition,

counselling, physios and now physio again, we haven't done it every year, but I think it's handy in that you can have the first 10 at a rebate. That has been so beneficial. Not only a GP, we didn't know that so the GP have been great in terms of, 'I think you need to go on a care plan, and this is what it will look like'. Then you can pay those components. Participant 005CA

I can look at it from both sides because I could look at the health system and be thankful that we do have a really good health system. Further, I can be very thankful that I'm a NAME INSURER client because that does cover all the costs. I'm doubly grateful. Participant 006AL

Table 9.5: What participants are grateful for in the health system

Aspects of the health system that people are grateful for	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 is grateful for the entire health system	13	36.11	6	33.33	10	40.00	6	60.00	1	12.50	8	36.36	5	35.71	3	33.33	10	37.04
Participant is grateful for healthcare staff	10	27.78	5	27.78	5	20.00	2	20.00	3	37.50	6	27.27	4	28.57	3	33.33	7	25.93
Participant is grateful for low cost/free medical care through the government	10	27.78	5	27.78	6	24.00	2	20.00	3	37.50	6	27.27	4	28.57	2	22.22	8	29.63
Participant is grateful for timely access to treatment	5	13.89	1	5.56	3	12.00	2	20.00	2	25.00	3	13.64	2	14.29	2	22.22	3	11.11
Participant is grateful for access to private healthcare/private insurance	4	11.11	0	0.00	3	12.00	3	30.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41

Aspects of the health system that people are grateful for	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 is grateful for the entire health system	13	36.11	1	12.50	8	42.11	4	50.00	9	64.29	3	21.43	4	36.36	9	36.00
Participant is grateful for healthcare staff	10	27.78	4	50.00	2	10.53	3	37.50	2	14.29	5	35.71	2	18.18	8	32.00
Participant is grateful for low cost/free medical care through the government	10	27.78	3	37.50	4	21.05	2	25.00	3	21.43	4	28.57	3	27.27	7	28.00
Participant is grateful for timely access to treatment	5	13.89	2	25.00	2	10.53	1	12.50	0	0.00	3	21.43	0	0.00	5	20.00
Participant is grateful for access to private healthcare/private insurance	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	2	14.29	1	9.09	3	12.00

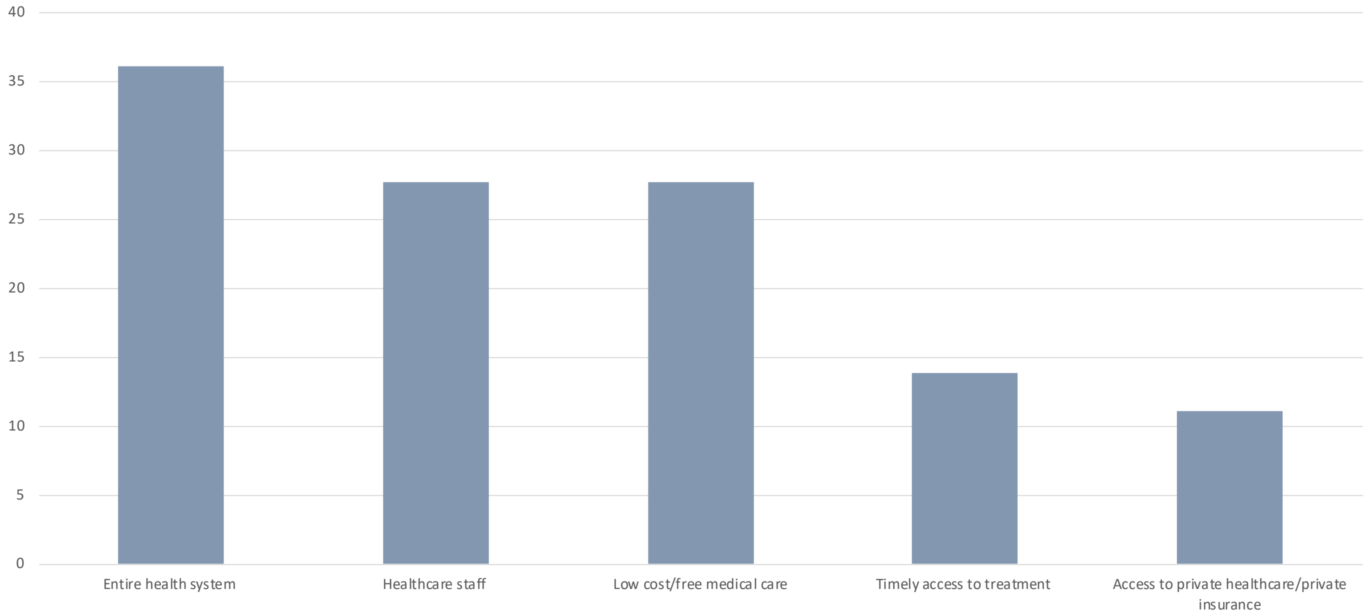

Figure 9.5: What participants are grateful for in the health system

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 9 is the least important. A weighted average is presented in Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported for participants with ATTR-cardiac were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and arm and leg symptoms (e.g. numbing, tingling, weakness, pain).

The most important aspects reported for participants with AL amyloidosis were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs).

Table 9.6: Symptoms and aspects of quality of life ATTR-cardiac

Symptom	Weighted average (n=18)
Heart and lung symptoms (e.g. short of breath, palpitations, chest pain)	4.11
Fatigue	2.78
Arm and leg symptoms (e.g. numbing, tingling, weakness, pain)	2.94
Head and neck symptoms (e.g. light-headedness, dizziness, eye floaters)	2.33
Stomach symptoms (e.g. appetite, bloating, diarrhoea, nausea, weight loss)	2.83

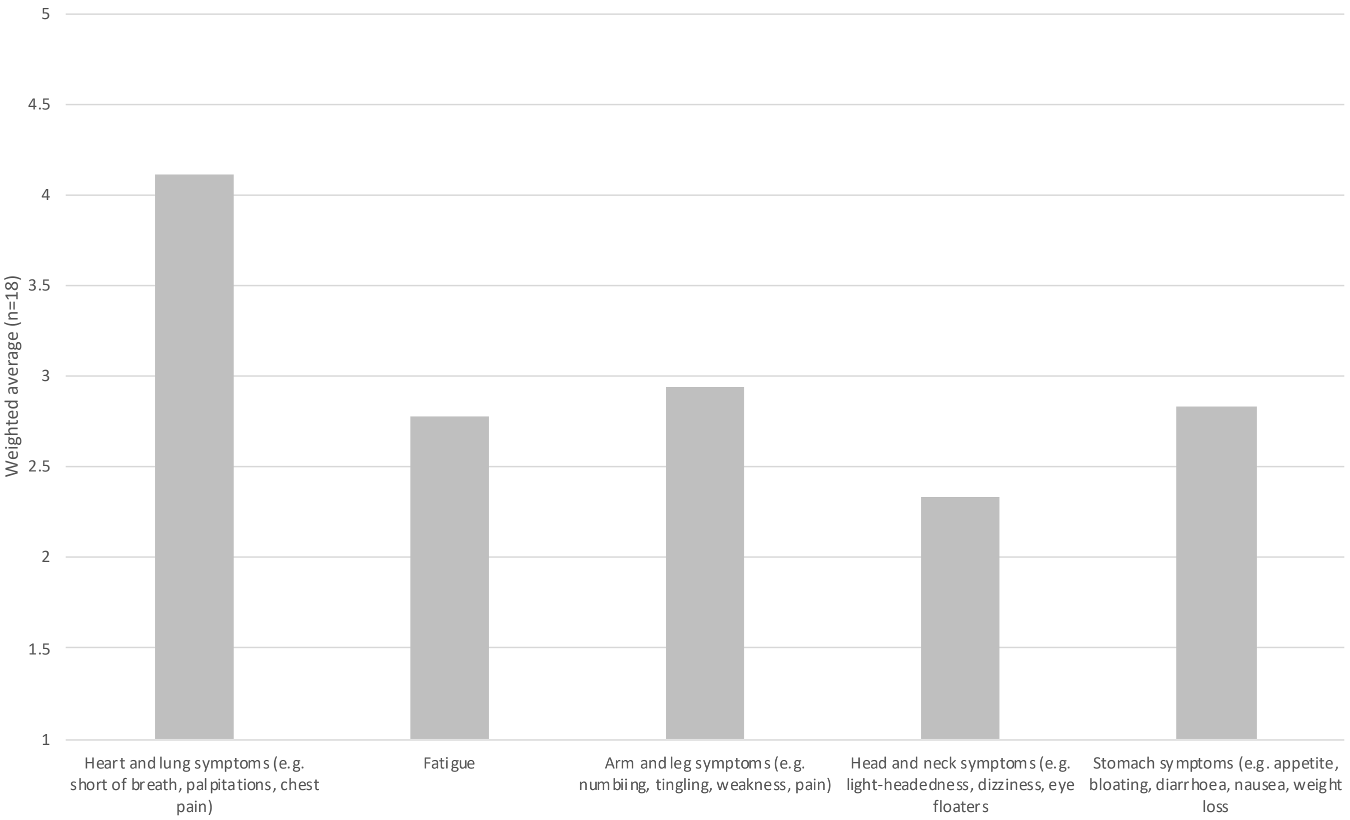

Figure 9.6: Symptoms and aspects of quality of life ATTR-cardiac

Table 9.7: Symptoms and aspects of quality of life AL amyloidosis

Symptom	Weighted average (n=10)
Heart and lung symptoms (e.g. short of breath, palpitations, chest pain)	5.33
Kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs)	4.22
Fatigue	3.80
Arm and leg symptoms (e.g. numbing, tingling, weakness, pain)	3.00
Head and neck symptoms (e.g. light-headedness, dizziness, eye floaters)	2.70
Stomach symptoms (e.g. appetite, bloating, diarrhoea, nausea, weight loss)	2.44

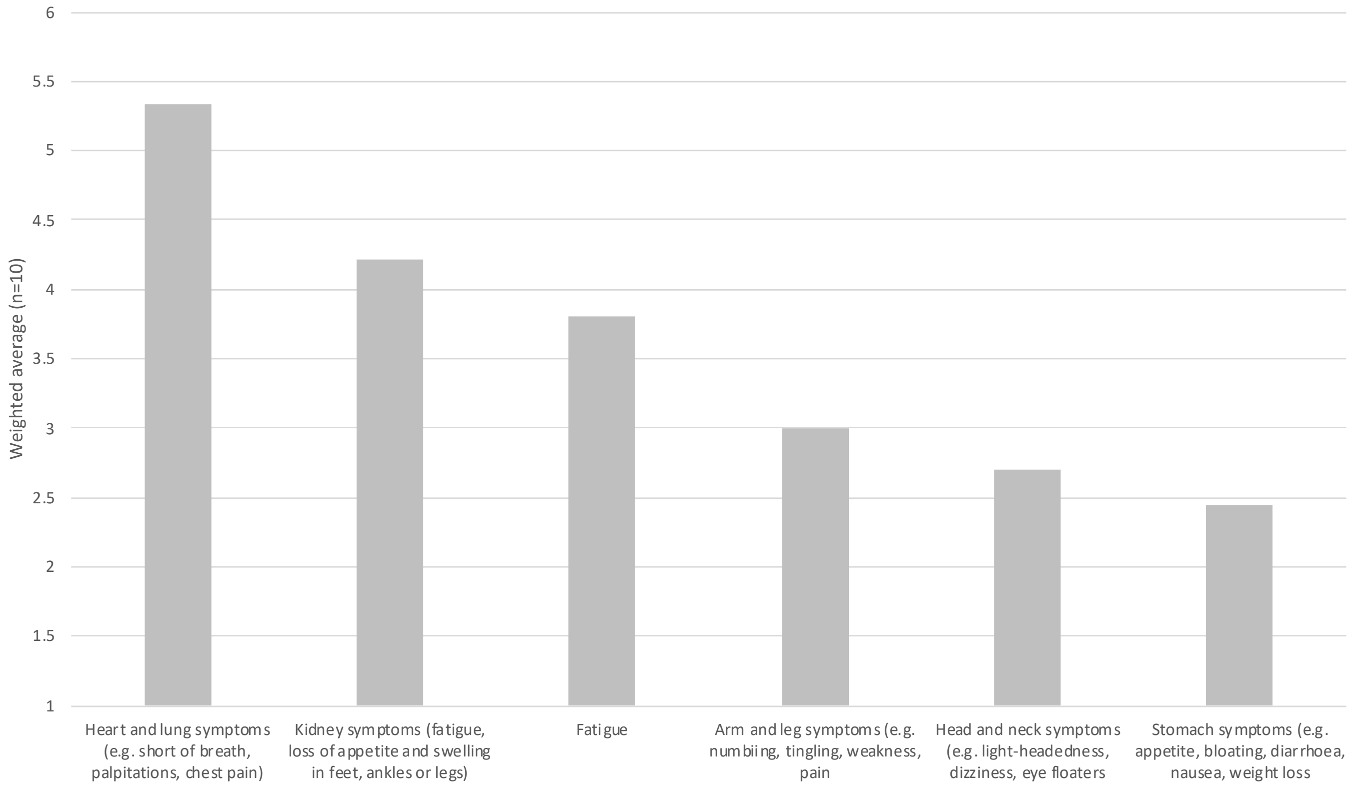

Figure 9.7: Symptoms and aspects of quality of life AL amyloidosis

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.8.

With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects were ‘How safe the medication is and weighing up the risks and benefits’, and ‘The severity of the side effects’. The least important were ‘The financial costs to me and my family’.

Table 9.8: Values in making decisions

Symptom	Weighted average (n=36)
How safe the medication is and weighing up the risks and benefits	7.06
The severity of the side effects	6.36
Time impact of the treatment on my quality of life	4.97
How the treatment is administered	4.19
How personalised the treatment is for me	4.50
The ability to include my family in making treatment decisions	3.67
My ability to follow and stick to a treatment regime	2.78
The financial costs to me and my family	2.47

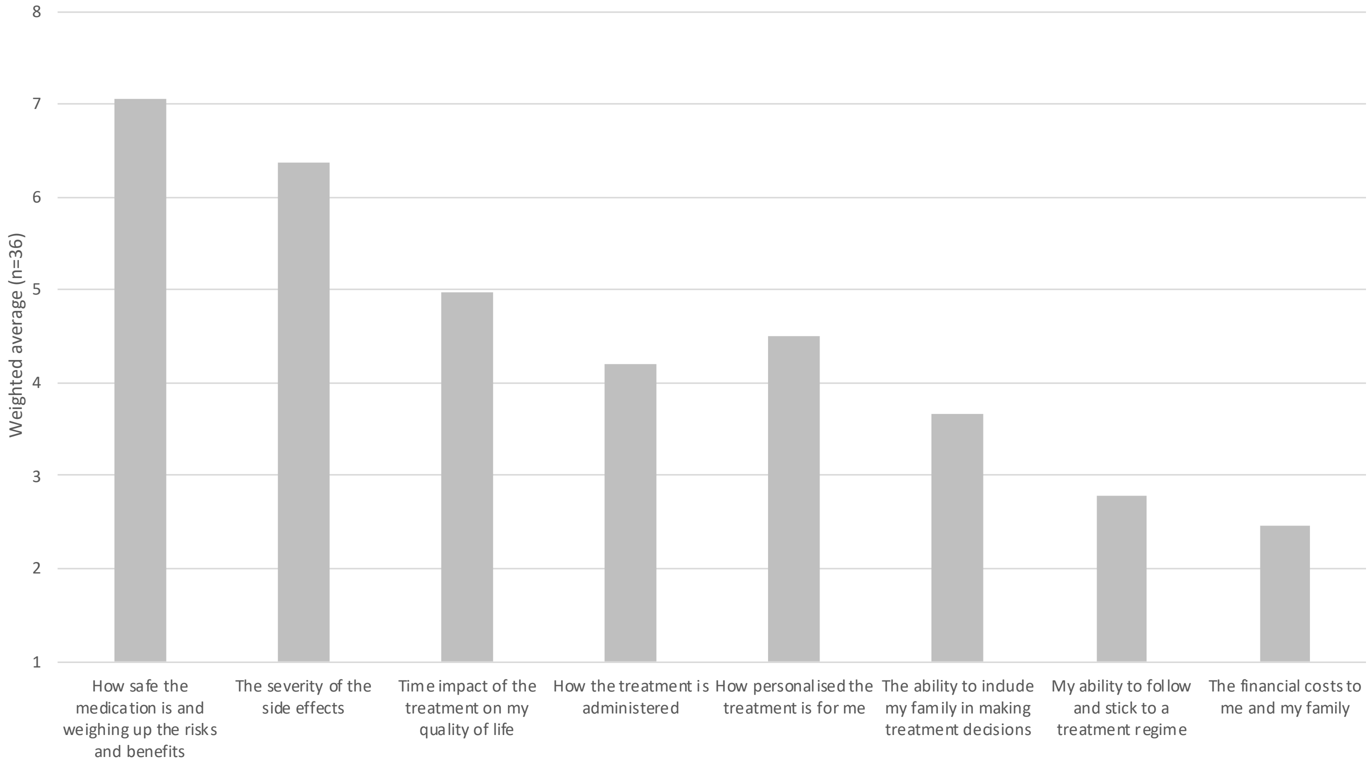

Figure 9.8: Values in making decisions

Values for decision-makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.9. With a weighted ranking, the higher the score, the greater value it is to participants. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government.

Table 9.9: Values for decision-makers

Symptom	Weighted average (n=36)
Economic value to government and tax payers	1.25
Economic value to patients and their families	2.53
Quality of life for patients	4.39
Compassion	2.92
All patients being able to access all available treatments and services	3.92

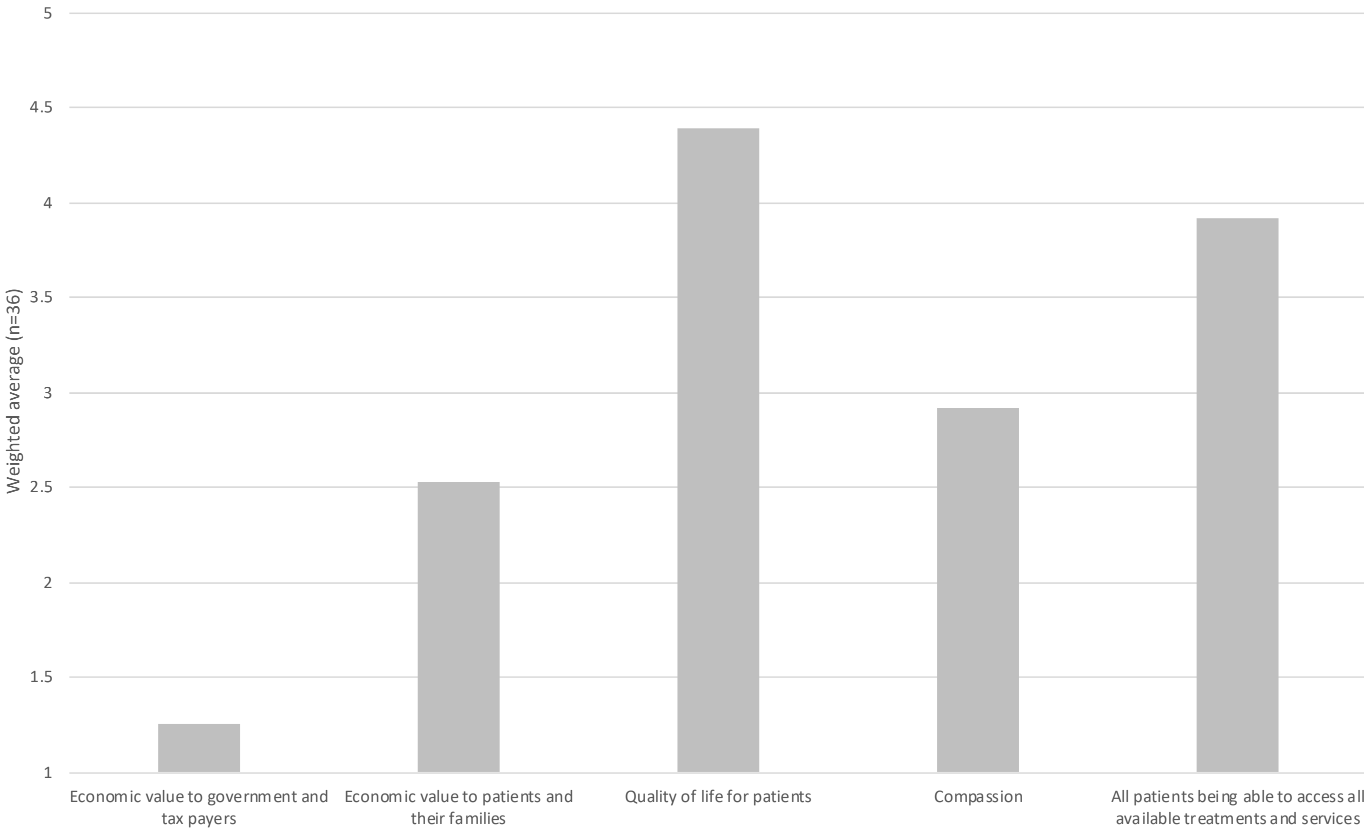

Figure 9.9: Values for decision-makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=19, 67.86%) would use a treatment for more than ten years for a good quality of life, even if it didn't offer a cure.

Table 9.10: Time taking medication to improve quality of life

Time	Number (n=28)	Percent
1 to 2 years	3	10.71
3 to 4 years	2	7.14
5 to 10 years	4	14.29
More than 10 years	19	67.86

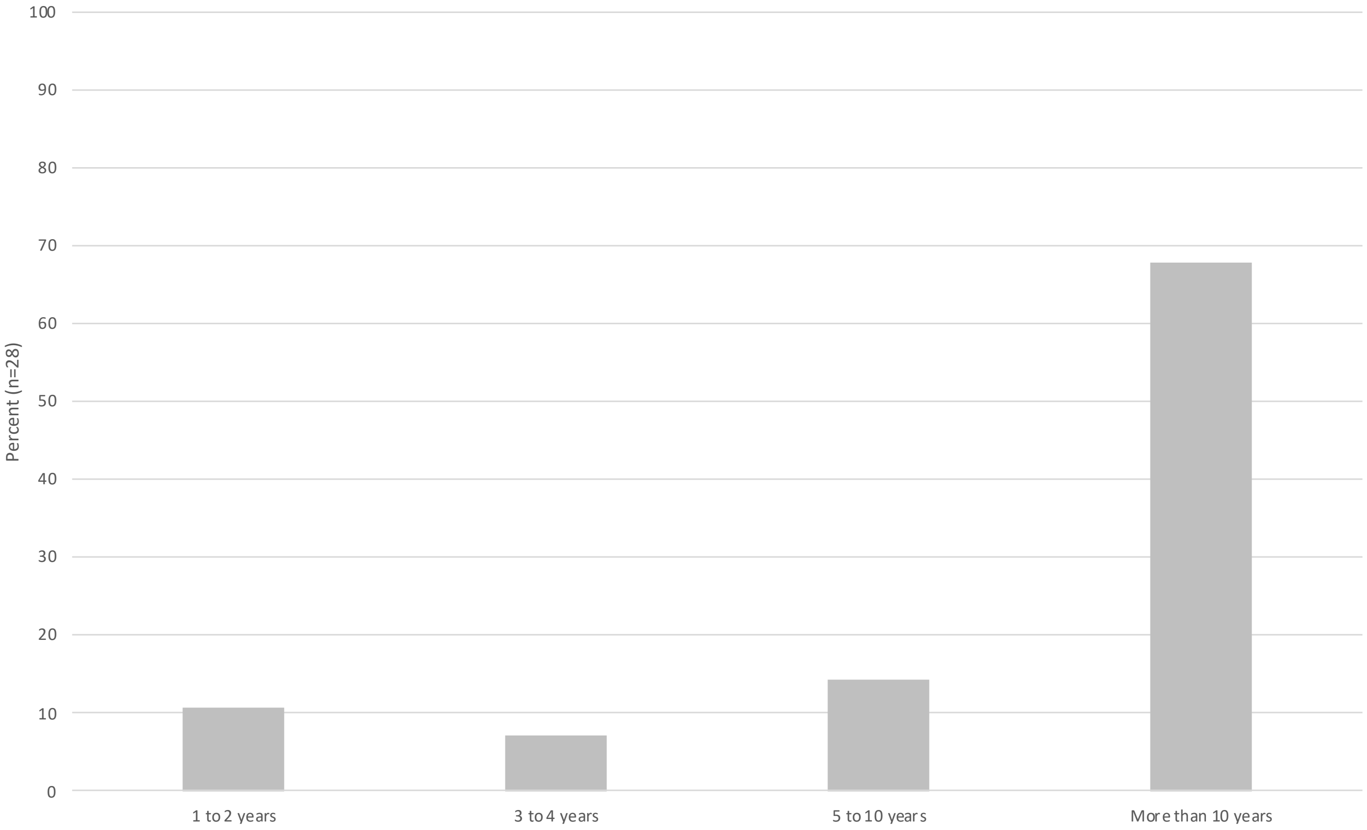

Figure 9.10: Time taking medication to improve quality of life

Messages to decision-makers

Participants were asked, 'If you were standing in front of the health minister, what would your message be in relation to your condition?' The most common message was that treatments need to be affordable (n=10, 27.78%). This was followed by the message that there should be more clinical trials and/or new treatments (n=8, 22.22%), that there should be improved access to support and care (n=6, 16.67%), the need to take the condition seriously (n=5, 13.89%), the need to invest in professional development so that clinicians better understand the condition (n=5, 13.89%) and finally, to invest in research, including the effort to find new treatments (n=4, 11.11%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (50.00%), and *Regional or remote* (55.56%) subgroups described wanting treatments to be more affordable more frequently than the general population (27.78%), while those *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *AL Amyloidosis* (10.00%) subgroup described the message that there should be more clinical trials and/or new treatments less frequently than the general population (22.22%), while those in *Regional or remote* (44.44%), and *Mid to low SEIFA* (36.36%) subgroups described this more frequently. Participants in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Those in the *ATTR-cardiac* (27.78%), *Aged 75 or older* (35.50%), and *Trade or high school* (35.71%) subgroups described the message to improve access to support and care more frequently than the general population (16.67%), while the participants in the in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Regional or remote* (0.00%) subgroups did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%), *Female* (0.00%), *Regional or remote* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups described the message that decision-makers should take the condition more seriously. Participants in the *Aged 75 or older* (37.50%) subgroup described this more frequently than the general population (13.89%).

Those in the *Aged 55 to 64* (25.00%) subgroup described the message that there should be more investment in professional development so that clinicians better understand the condition more frequently than the general population (13.89%), while participants in the *Carer* (0.00%) and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Regional or remote* (0.00%) subgroups described wanting to see more investment in research (including new treatments). Those in the *AL amyloidosis* (30.00%), *Aged 75 or older* (25.00%), and *Trade or high school* (21.43%) described this more frequently than the general population (11.11%).

Affordable treatments

I would say to him that medication that has been shown to be efficacious overseas, and there's plenty of data for that, that medication should be put on the PBS as soon as possible…That should be covered by PBS and that makes it affordable for everybody. Participant 003AL

Probably the big one is the cost of some of the drugs...Supporting those rare diseases is so incredibly important and the sheer cost involved of being sick. We were very fortunate to be close by really good doctors and hospitals and all of that sort of thing, but the people that have got to travel for care that is in then a huge impact on them financially. Participant 003CA

All drug treatments for all cancer patients should be free. Get rid of this, 'It costs too much' bullshit. Just give the people the drugs they need to treat what they've got. Participant 004ATR

More clinical trials and/or new treatments

I would say to him that medication that has been shown to be efficacious overseas, and there's plenty of data for that, that medication should be put on the PBS as soon as possible so that it can be utilised by people that that medication is appropriate to. Because sometimes a particular medication isn't appropriate for everybody. That should be covered by PBS and that makes it affordable for everybody. Participant 003AL

I would stand in front of the health minister and I would say, you really need to do something about getting the trials into Australia. We need to basically be able to have the same opportunities as what people do overseas. We need to be able to cut through all of the red tape and look at people's lives rather than sitting and thinking, 'oh, this is going to take this long.' People are dying. People around us are dying. Yet people overseas are having the benefits of these drugs that we never get. Please, look at it, have a look at it. Participant 008ATR

Well, I would be preaching on-- while people, I'm probably one of them, are waiting for all these drugs to be approved. You won't be here to take advantage of them and how they take too long to get things. If they have been in other countries, why can't this happen in Australia? Probably you have enough guinea pigs elsewhere that show that it does work and it's beneficial. Then they got to do it all again over here. If it was available, probably a lot of us wouldn't be able to afford it anyway. Participant 014ATR

Improve access to support and care

I would probably suggest to put some more funding available to an amyloid centre in each capital city…Because the waiting list when I was first got an appointment- and I really pushed NAME CLINICIAN to get an appointment at NAME HOSPITAL and I was I like after, and I find out this number which I was told to do. I said- went back in and I said I'd be bloody dead by the time I get an appointment at this hospital. They asked me for my Centrelink card to have available my Medicare card and my Centrelink card, and I'm thinking, 'What sort of hospital am I dealing with?'. Participant 001ATR

Access for people in regional and remote areas would be a big thing to alert the health minister to. They miss out on a lot. I have to travel a long way from LOCATION REGIONAL where I've got a lot of relations, having to drive because flying is too expensive all the way to LOCATION REGIONAL or LOCATION REGIONAL for treatment or even to LOCATION METROPOLITAN. That sort of thing would be really helpful. Regional assistance, regional specialists to visit on a regular basis. Participant 003ALX

No. I think it's Sydney, Melbourne and Brisbane that have got the centres. It must be awful for people in places like that. You're still a long way away to accessing the part from the internet and things I guess-- and dedicated, like you said, with a nurse or someone you could speak to when you can't get to your doctor, but I guess they've got to be associated with the doctors. They cannot be generalised in another state when they don't know your case or anything. They'd have to work with the doctors. The funding for that would be helpful. Participant 012ATR

Take the condition seriously

I understand that there are lots of conditions, diseases, cancers, and whatever that affects a whole lot more people than amyloidosis. The rare diseases area-- I think there are some groups and associations now which are looking at rare diseases, not only amyloidosis. The restriction I feel that we're always under is that because amyloidosis is a rare condition, the actual research, trials, funding, et cetera, would rank low priority. The clinic at NAME HOSPITAL, as a say, which seems to be the headquarters of these things, often says to me, 'Well, look, we're trying to get more funding. We're trying to get more information, but we don't rank high on the list of priorities'. Participant 001AL

Regardless, if you're affected with a cancer or a terminal disease, it is extremely important to you and your family and shouldn't be put aside and say, 'Well, of course, there's only 1 in 100,000, we won't worry too much about that.' I think that's not a very good attitude. Participant 003ATR

I reckon there's a lot more people that are affected by this than they have any idea about. I think genuinely there's probably a lot more people suffering from it than they've ever heard about what it is. It's a bigger issue than people realise. It's still incredibly-- I know it's hard because there's only so much funding to go around. I think overall, it's a pretty underfunded thing. Participant 006ATR

Invest in professional development

Well, it's not up to him really, any administrative, but I think that it comes from grassroots, it comes from the universities, it comes from some teaching within the hospital. It doesn't come from the Health Minister. He can't enforce the education towards the medical students. Participant 001ATR

The other thing I would say, again, is doctors, specialists, GPs, they lack information, they need to have it there. I don't mean this in a nasty way, even down to the chemist, the pharmacist, whatever it is, they should be able to have the alarm bell ringing. Like I said, carpal tunnel, 'Okay, we'll just double check that it isn't a problem down the line with that as well.' I can only talk about my particular version, but that's what I see. It's the education and being-- If you're given the education, then will allow you to be aware of it. Participant 015ATR

I think, first of all, there needs to be a greater awareness among specialists. There is an argument for GPs to have a better understanding of it. I know with my GP, as soon as I mention I've got this or that or whatever, he's quite quick at saying, look, 'I'll refer you to this specialist.' It is something significant-- Do you know what I mean. Participant 016ATR

Invest in research (including new treatments)

I'd thank him for it, and then suggest that it may be a little bit more for some Australian research would be appreciated. The health system itself, well, as I say, I think is the best in the world. I've looked at the health systems in a few countries around the world. Participant 002ALX

More funding for research. Amyloidosis is one of those low-- because people haven't heard about it-- the NAME HOSPITAL estimates that there's probably 10,000 people in Australia walking around undiagnosed. That's the biggest thing about amyloidosis, getting the diagnosis. They mimic so many other things. A patient goes to the doctor and says, 'I just feel lethargic. I don't know why. I'm tired all of the time.' That could be any number of things. Participant 005AL

That they need to increase the funding to try to find more things that can help with remission and stuff like that. Research, they need the money for research, I guess, because that's the way they're going to be able to help a lot more. Participant 012ATR

Table 9.11: Messages to decision-makers

Message to decision-makers	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's message is that treatments need to be affordable	10	27.78	5	27.78	7	28.00	3	30.00	2	25.00	7	31.82	3	21.43	5	55.56	5	18.52
Participant's message is that there should be more clinical trials and/or new treatments	8	22.22	5	27.78	6	24.00	1	10.00	2	25.00	6	27.27	2	14.29	4	44.44	4	14.81
Participant's message is to improve access to support and care	6	16.67	5	27.78	5	20.00	1	10.00	0	0.00	3	13.64	3	21.43	0	0.00	6	22.22
Participant's message is to take the condition seriously	5	13.89	3	16.67	5	20.00	2	20.00	0	0.00	5	22.73	0	0.00	0	0.00	5	18.52
Participant's message is to invest in professional development so that clinicians understand the condition	5	13.89	3	16.67	4	16.00	2	20.00	0	0.00	4	18.18	1	7.14	1	11.11	4	14.81
Participant's message is to invest in research (including to find new treatments)	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81

Message to decision-makers	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's message is that treatments need to be affordable	10	27.78	4	50.00	6	31.58	0	0.00	4	28.57	4	28.57	4	36.36	6	24.00
Participant's message is that there should be more clinical trials and/or new treatments	8	22.22	2	25.00	6	31.58	0	0.00	3	21.43	3	21.43	4	36.36	4	16.00
Participant's message is to improve access to support and care	6	16.67	0	0.00	3	15.79	3	37.50	5	35.71	1	7.14	2	18.18	4	16.00
Participant's message is to take the condition seriously	5	13.89	0	0.00	1	5.26	3	37.50	2	14.29	3	21.43	0	0.00	5	20.00
Participant's message is to invest in professional development so that clinicians understand the condition	5	13.89	2	25.00	3	15.79	0	0.00	2	14.29	3	21.43	2	18.18	3	12.00
Participant's message is to invest in research (including to find new treatments)	4	11.11	0	0.00	2	10.53	2	25.00	3	21.43	1	7.14	2	18.18	2	8.00

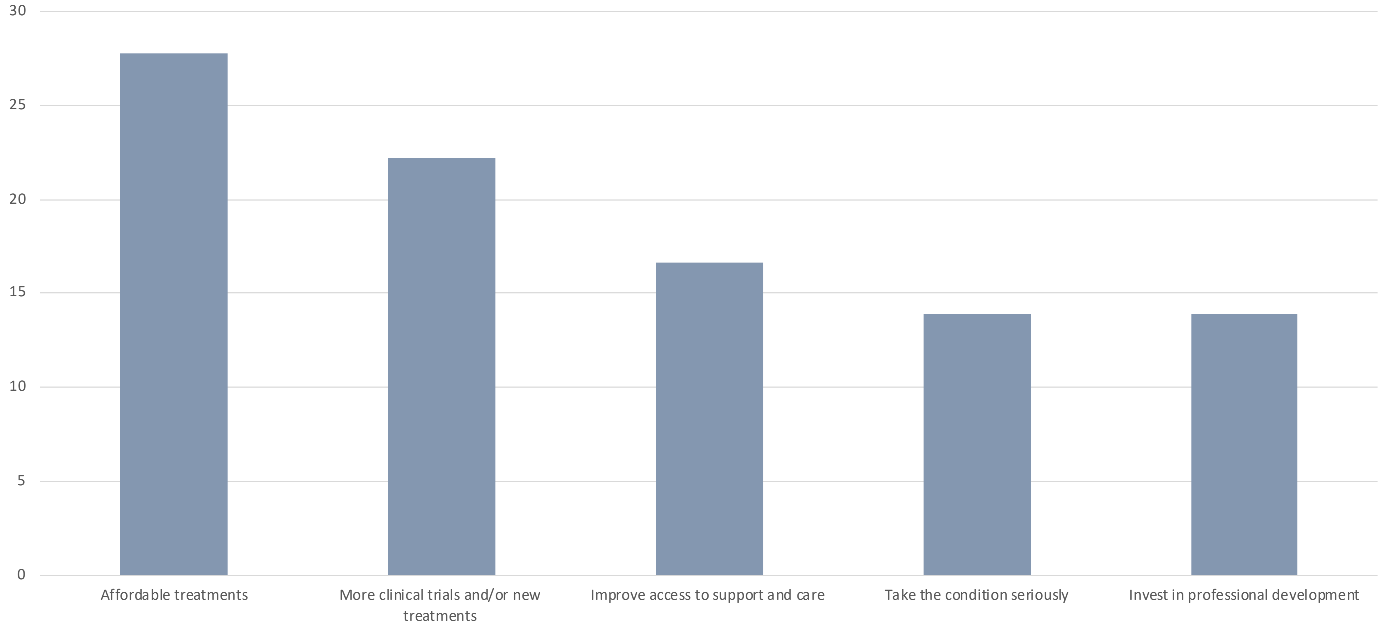

Figure 9.11: Messages to decision-makers