Section 3

Symptoms and diagnosis

Section 3 Summary: Symptoms and diagnosis

Symptoms

- Participants had between zero and 13 symptoms (median = 5.00, IQR = 3.00), most commonly three to four symptoms (n=6, 21.43%) (Table 3.1). The most common symptoms for all participants were fatigue (n=18, 64.29%), being short of breath (n=16, 57.14%), limb weakness (n=16, 57.14%), and light-headedness (n=16, 57.14%).

- The median quality of life was between 1.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was average" range. Median quality of life for the most common symptoms (fatigue, short of breath, light-headedness, and limb weakness) was between 3.00 and 4.00, in the life was a little distressing.

Symptoms leading to diagnosis

- In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was excessive weight loss (n=8, 22.22%). There were seven participants (19.44%) who described experiencing breathlessness and four participants (11.11%) who described having tiredness. A final four participants (11.11%) identified a specific physical sensation, such as numbness or tingling in their fingers or toes, which led to their diagnosis.

- When discussing symptoms leading to their diagnosis, participants described how soon after experiencing symptoms they sought medical attention. There were five participants (13.89%) that described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. An additional three participants (8.33%) also mentioned having symptoms and not seeking medical attention initially, but they provided no reason for this.

- Overall, 18 participants (50.00%) described having symptoms and seeking medical attention relatively soon. There were eight participants (22.22%) that described having symptoms and not seeking medical attention initially, and a final five participants (13.89%) that described having no symptoms or not noticing them prior to diagnosis.

- There were nine participants (25.00%) that described a diagnostic pathway that required appointments with a general practitioner and two or more specialists. There were also nine participants (25.00%) who described receiving a diagnosis following referral from their general practitioner to a specialist. A final six participants (16.67%) described receiving diagnosis following a specialist ordering tests. They made no mention of a GP referral.

- When discussing symptoms, overall participants had either a strong recollection of symptoms (69.44%) or describes not experiencing any symptoms prior to diagnosis (11.11%).

Diagnostic tests

- Participants had between one and 11 diagnostic tests, most commonly five to six tests (n=11, 39.29%) (Median = 6.5, IQR = 3.25) (Table 3.5, Figure 3.5). The most common diagnostic tests were blood tests (n=23, 82.14%), electrocardiogram (n=18, 64.29%), and echocardiogram (n=16, 57.14%).

Time from symptoms to diagnosis

- Participants most commonly had more than a year between noticing symptoms and being diagnosed (n=11, 42.31%), followed by between 6 months and a year (n=7, 26.92%). There were five participants (19.23%)

that had noticed symptoms between one and six months before getting diagnosed, and three participants (11.54%) that had less than one month.

Time from diagnostic tests to diagnosis

- The majority of participants waited between 2 and 3 weeks (n=8, 28.57%) or more than 4 weeks (n=8, 28.57%).

Diagnosis provider and location

- The diagnosis was given most commonly by the haematologist (n=9, 32.14%), followed by a cardiologist (n=7, 25.00%). The diagnosis was most commonly given at a specialist clinic (n=28, 67.86%).

Understanding of disease at diagnosis

- Participants were asked in the structured interview how much they knew about their condition at diagnosis and the reason for their level of knowledge. There were 15 participants (41.67%) that gave no specific reason for their level of knowledge. There were eight participants (22.22%) who said they came to understand their condition more over time and through lived experience, and four participants (11.11%) described knowing very little about their condition at diagnosis, but that they were aware of family history with the condition.

- Overall, there were 27 participants (75.00%) that described knowing nothing or very little at diagnosis and these were the most common themes. There were three participants (8.33%) who noted that they knew good amount about the condition at diagnosis.

Emotional support at diagnosis

- Almost half of participants (including carers) had enough support (n=17, 47.22%), 6 participants (16.67%) had no support, and 13 participants (36.11%) had some support but it wasn't enough.

Information provided at diagnosis

- The majority of participants had enough information (n=20, 71.43%) at diagnosis. There were eight participants (28.57%) that had some information but not enough, and there were no participants that had no information at all at diagnosis.

Costs at diagnosis

- There were 12 participants (42.86%) who could recall the out of pocket expenses at diagnosis. There were eight participants who had no out of pocket expenses at diagnosis (28.57%), two that spent between $100 and $500 (7.14%), four who spent between $500 and $1000 (14.29%), and two who spent more than $1000 (7.14%) in out of pocket expenses

- In the follow-up question about the burden of costs at diagnosis, for 12 participants (60.00%) the cost was either slightly significant or not significant at all. For 5 participants (25.00%) the out of pocket expenses were somewhat significant, and for 3 participants (15.00%), the burden of out of pocket expenses were moderately significant.

Genetic tests and biomarkers

- The majority of participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=17, 60.71%). There were three participants who brought up the topic with their doctor (10.71%), and eight whose doctor brought up the topic (28.57%).

- Over half of the participants (not including carers) have not had any testing but would like to (n=15, 53.57%). There were a total of 10 participants that had the test, either paying for it themselves (n=5, 17.86%), or not paying out of pocket (n=5, 17.86%). Three participants did not have the test and had no interest in having one (10.71%).

- The majority of participants were not sure if they had specific biomarkers (n=15, 53.57%), there were five that stated they had no biomarkers (17.86%), and eight that were able to name specific markers that they had.

Understanding of prognosis

- Participants were asked in the structured interview to describe what their current understanding of their prognosis was. There were 15 participants (41.67%) that described that they had a discussion about prognosis, and there were 14 participants (38.89%) did not mention having discussions about prognosis.

- Overall, 18 participants (50.00%) described having a clear understanding of their prognosis and 11 described having an unclear understanding (30.56%).

- There were two main themes that were equally reported, including participants describing their prognosis in relation to the specific medical interventions they need to manage their condition (n=9, 25.00%) and relating their prognosis to a specific timeframe that they are expected to live (n=9, 25.00%). There were eight participants (22.22%) that described their prognosis in relation to poor outcomes or as a terminal condition and five participants (13.89%) that understood their prognosis as positive and their condition as manageable.

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis. They could choose from a set lit of symptoms and could then specify other symptoms not listed.

Participants had between zero and 13 symptoms (Median = 5.00, IQR = 3.00), most commonly three to four symptoms (n=6, 21.43%) (Table 3.1). The most common symptoms for all participants were fatigue (n=18, 64.29%), being short of breath (n=17, 60.71%), limb weakness (n=16, 57.14%), and light-headedness (n=16, 57.14%). These symptoms were the most common regardless of diagnosis (Table 3.2).

Participants were asked a follow-up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from 1 to 7, where 1 is "Life was very distressing" and 7 is "Life was great" (Table 3.3, Figure 3.3). The median quality of life was between 1.00 and 4.00 for all of the symptoms listed in the questionnaire. This is in the "Life was very distressing" to "Life was average" range. Median quality of life for the most common symptoms (fatigue, short of breath, light-headedness, and limb weakness) was between 3.00 and 4.00, in the life was a little distressing to average range.

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
No symptoms	2	7.14	0	0.00	1	4.00	2	20.00
1 to 2	3	10.71	3	16.67	3	12.00	0	0.00
3 to 4	6	21.43	4	22.22	5	20.00	2	20.00
5 to 6	3	10.71	1	5.56	2	8.00	2	20.00
7 to 8	5	17.86	3	16.67	5	20.00	2	20.00
9 to 10	5	17.86	4	22.22	5	20.00	1	10.00
11 or more	4	14.29	3	16.67	4	16.00	1	10.00

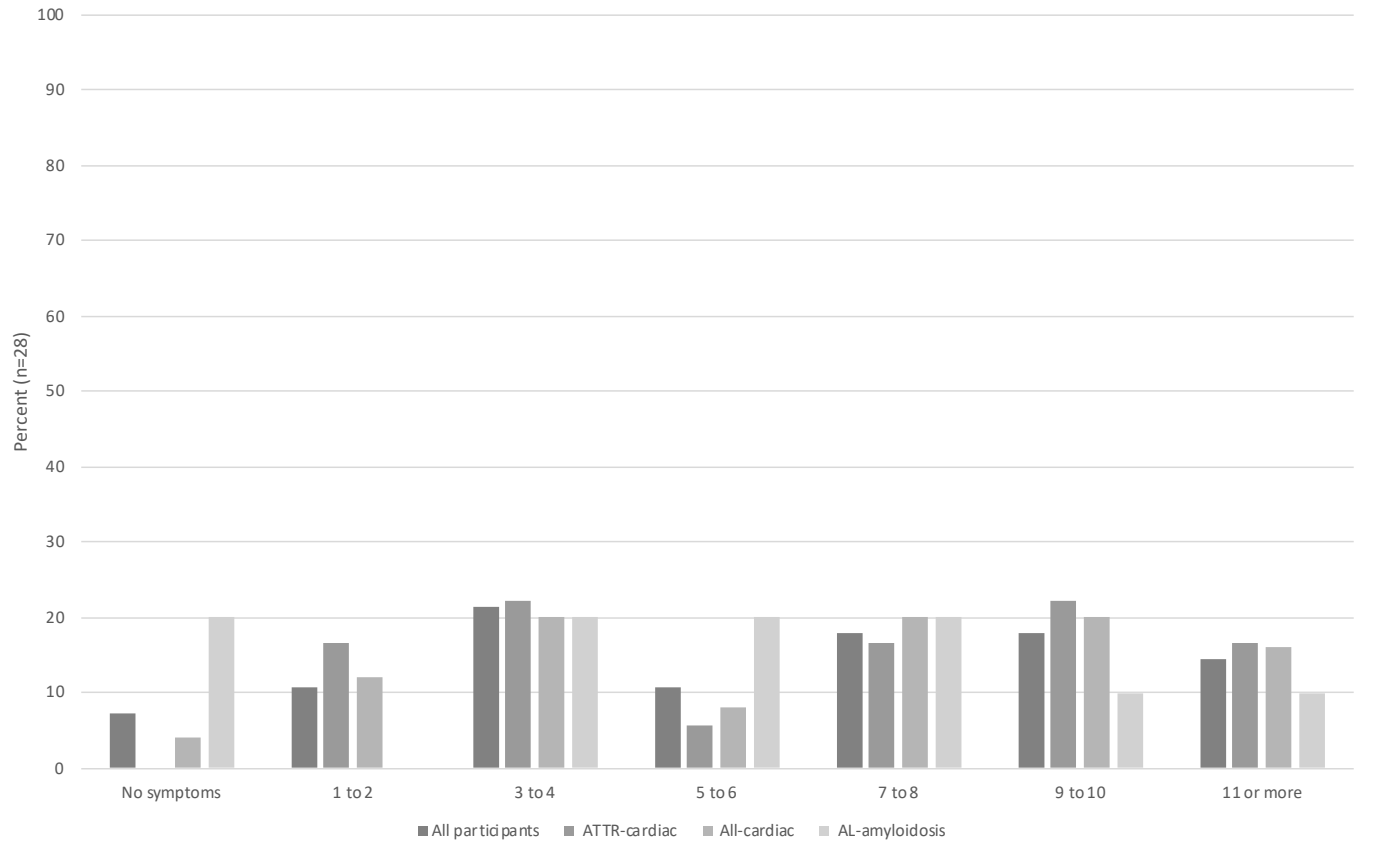
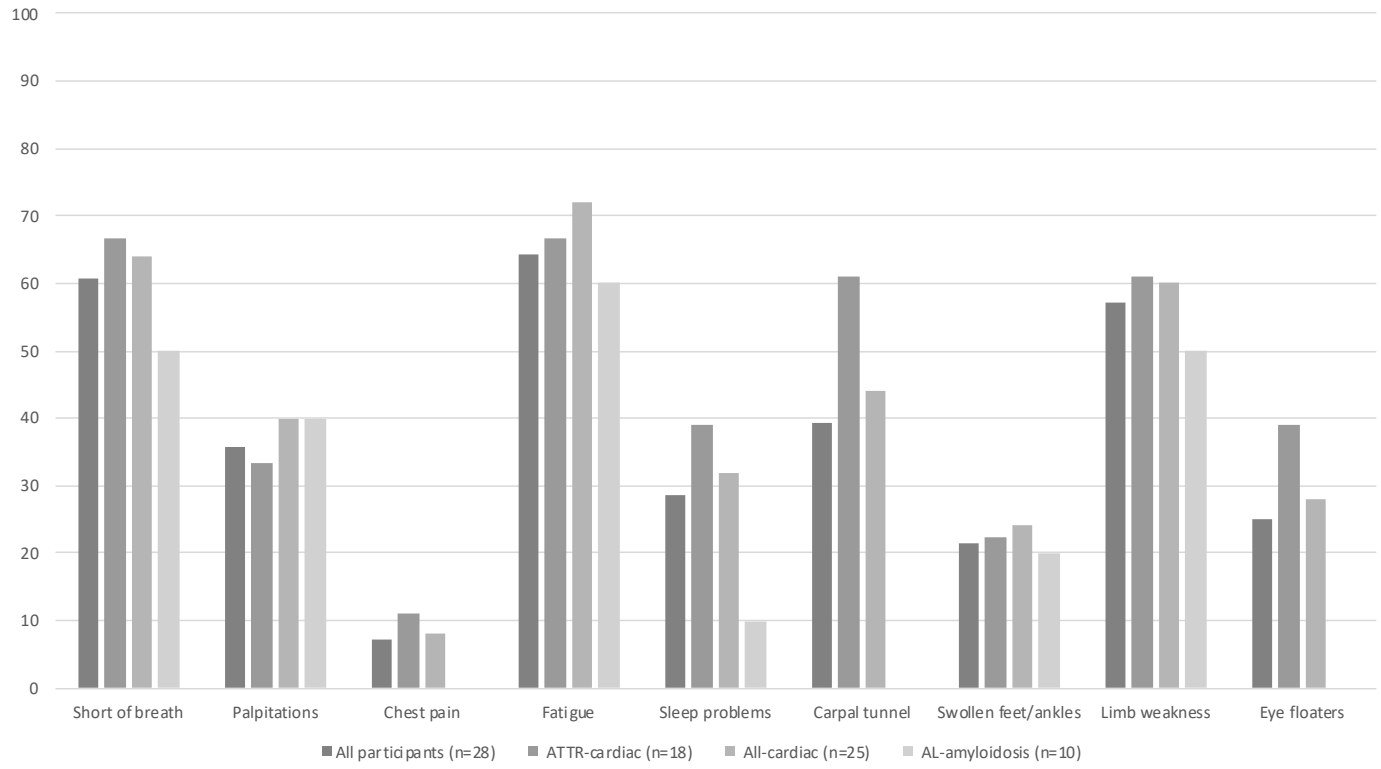


Figure 3.1: Number of symptoms per participant

Table 3.2: Symptoms

Symptom	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
Short of breath	17	60.71	12	66.67	16	64.00	5	50.00
Palpitations	10	35.71	6	33.33	10	40.00	4	40.00
Chest pain	2	7.14	2	11.11	2	8.00	0	0.00
Fatigue	18	64.29	12	66.67	18	72.00	6	60.00
Sleep problems	8	28.57	7	38.89	8	32.00	1	10.00
Carpal tunnel	11	39.29	11	61.11	11	44.00	0	0.00
Swollen feet/ankles	6	21.43	4	22.22	6	24.00	2	20.00
Limb weakness	16	57.14	11	61.11	15	60.00	5	50.00
Eye floaters	7	25.00	7	38.89	7	28.00	0	0.00
Lightheaded	16	57.14	11	61.11	14	56.00	5	50.00
Decrease appetite	10	35.71	8	44.44	10	40.00	2	20.00
Bloating	7	25.00	6	33.33	7	28.00	1	10.00
Diarrhea/constipation	11	39.29	6	33.33	9	36.00	5	50.00
Nausea	2	7.14	2	11.11	2	8.00	0	0.00
Weight loss	13	46.43	8	44.44	12	48.00	5	50.00
Swollen tongue	3	10.71	1	5.56	3	12.00	2	20.00
Skin changes	5	17.86	0	0.00	5	20.00	5	50.00
Other	10	35.71	4	22.22	9	36.00	6	60.00



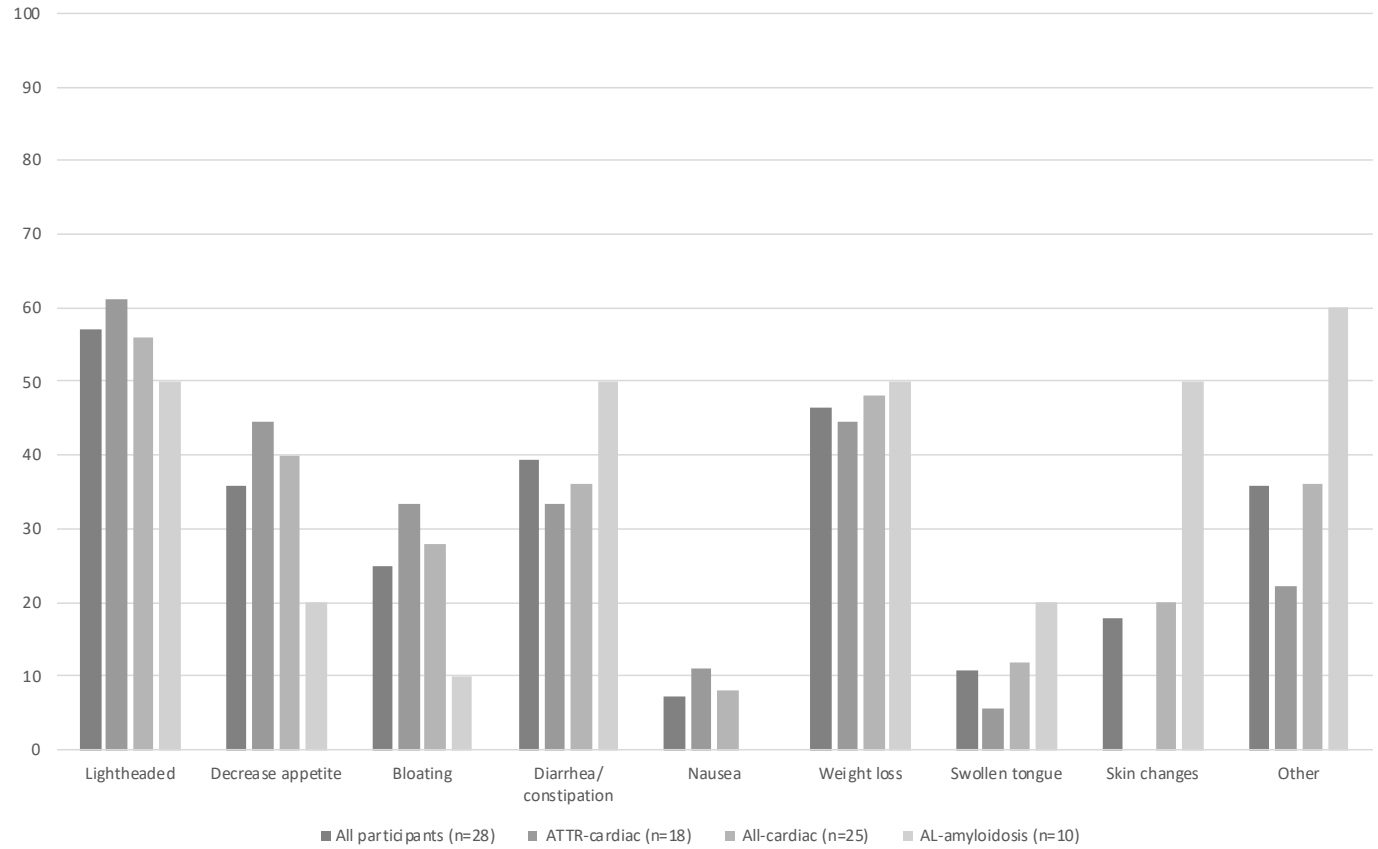


Figure 3.2: Symptoms

Table 3.3: Quality of life from symptoms

Symptom	Number (n=28)	Percent	Quality of life			
			Mean	SD	Median	IQR
Short of breath	17	60.71	4.00	1.70	4.00	2.00
Palpitations	10	35.71	3.63	1.51	3.00	2.25
Chest pain	2	7.14	1.00	0.00	1.00	0.00
Fatigue	18	64.29	3.33	1.33	3.00	1.75
Sleep problems	8	28.57	2.63	1.19	3.00	1.50
Carpal tunnel	11	39.29	3.82	1.47	4.00	2.00
Swollen feet/ankles	6	21.43	2.33	1.03	2.00	0.75
Limb weakness	16	57.14	3.25	1.44	3.00	3.00
Eye floaters	7	25.00	3.43	1.72	3.00	2.00
Lightheaded	16	57.14	3.70	1.46	4.00	2.00
Decrease appetite	10	35.71	2.90	1.10	3.00	0.75
Bloating	7	25.00	3.14	1.46	3.00	1.50
Diarrhea/constipation	11	39.29	3.45	1.69	3.00	2.50
Nausea	2	7.14	2.00	1.41	2.00	1.00
Weight loss	13	46.43	3.08	1.38	3.00	2.00
Swollen tongue	3	10.71	2.00	0.00	2.00	0.00
Skin changes	5	17.86	2.50	0.58	2.50	1.00

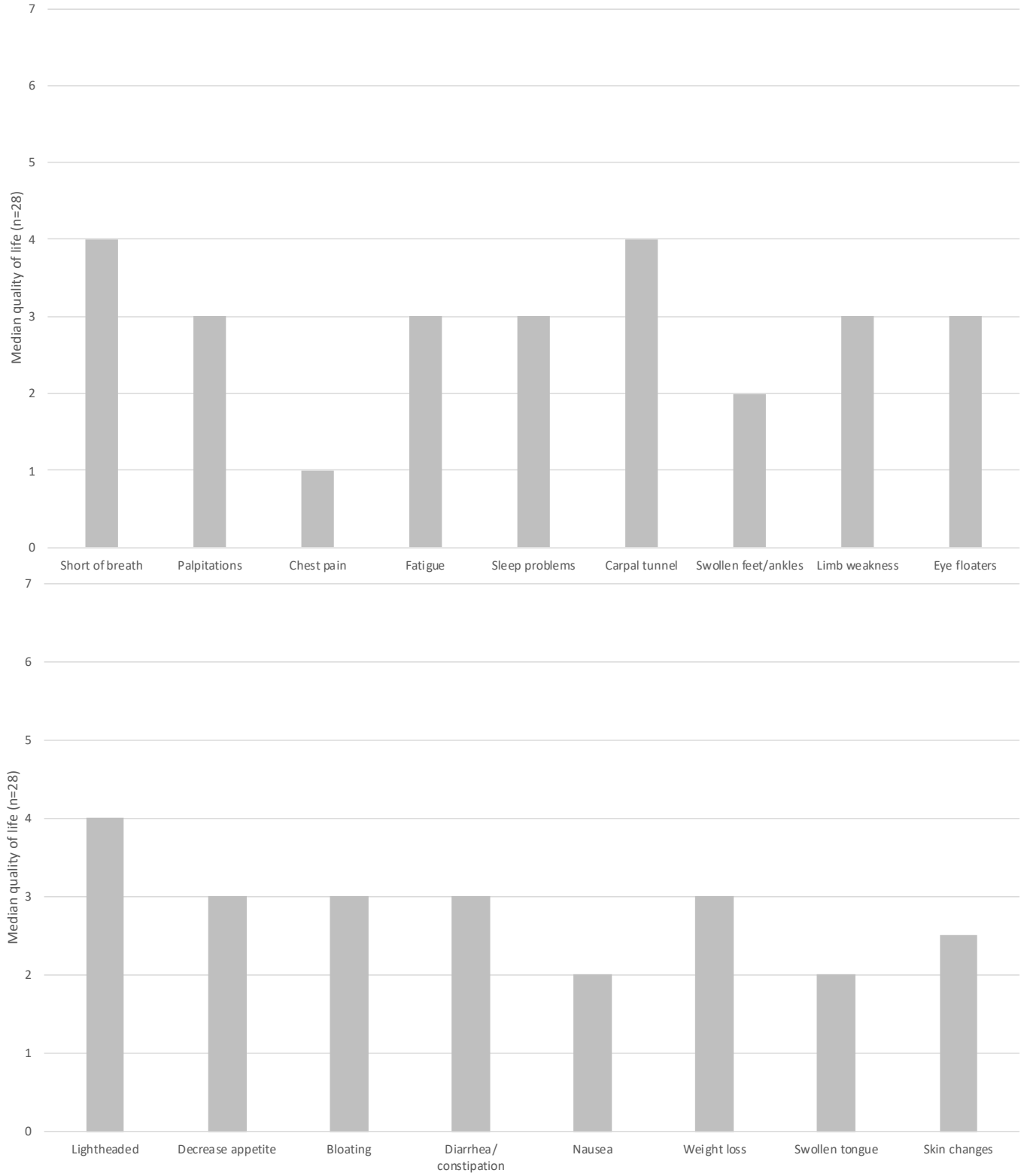


Figure 3.3: Quality of life from symptoms

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was excessive weight loss (n=8, 22.22%). There were seven participants (19.44%) who described experiencing breathlessness and four participants (11.11%) who described experiencing tiredness. A final four participants (11.11%) identified a specific physical sensation, such as numbness or tingling in their fingers or toes, which led to their diagnosis.

When discussing symptoms leading to their diagnosis, participants described how soon after experiencing symptoms they sought medical attention. There were five participants (13.89%) that described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. An additional three participants (8.33%) also mentioned having symptoms and not seeking medical attention initially, but they provided no reason for this.

Overall, 18 participants (50.00%) described having symptoms and seeking medical attention relatively soon. There were eight participants (22.22%) that described having symptoms and not seeking medical attention initially, and a final five participants (13.89%) that described having no symptoms or not noticing them prior to diagnosis.

There were nine participants (25.00%) that described a diagnostic pathway that required appointments with a general practitioner and two or more specialists. There were also nine participants (25.00%) who described receiving a diagnosis following referral from their general practitioner to a specialist. A final six participants (16.67%) described receiving diagnosis following a specialist ordering tests. They made no mention of a GP referral.

When discussing their symptoms, twenty-five participants had a strong recollection of symptoms (69.44%) and four had not experienced any symptoms prior to diagnosis (11.11%).

In relation to subgroup variations, participants in the *Regional or remote* (11.11%) and *Mid to low SEIFA* (9.09%) subgroups experienced excessive weight loss less frequently than the general population (22.22%), while those in the *Female* subgroup described this more frequently (35.71%).

Participants in the *Aged 65 to 74* (31.58%) subgroup described breathlessness more frequently than the general population (19.44%), while those in the *University* (7.14%), and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

No participants in the *AL amyloidosis*, *Aged 75 or older*, or *University* subgroups described a specific physical sensation such as numbness or tingling fingers as a symptom (0.00%). Whereas participants in the *Female* (21.43%), *Regional or remote* (22.22%), and *Mid to low SEIFA* (27.27%) subgroups described this more frequently than the general population (11.11%).

Participants in the general population (13.89%) described having symptoms and not seeking medical attention initially but recognising their importance in hindsight, while none of the participants in the *Regional or remote* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups described this at all.

Participants in the *Regional or remote* subgroup also describe having symptoms and not seeking medical attention without describing their reasons more frequently (22.22%) than the general population (8.33%).

Participants in the *Carer* (25.00%), *Aged 55 to 64* (25.00%), and *Regional or remote* (33.33%) subgroups described having symptoms and seeking medical attention relatively soon less frequently than the general population (50.00%). Participant in the *AL amyloidosis* (70.00%), *Aged 75 or older* (75.00%), and *Trade or high school* (64.29%) subgroups describe this more frequently.

Participants in the *Mid to low SEIFA* subgroup describe having symptoms and not seeking medical attention initially less frequently (9.09%) than the general population (22.22%). Participants in the *AL amyloidosis* (10.00%) subgroup described this more frequently.

Finally, no participants in the *Aged 75 or older* (0.00%) or *Trade or high school* (0.00%) subgroups described experiencing no symptoms prior to diagnosis. Participants in the *Aged 55 to 64* (37.50%), *University* (28.57%) and *Regional or remote* (33.33%) subgroups described this more frequently than the general population (13.89%).

Symptoms leading to diagnosis: Excessive weight loss

Loss of weight, about 20 kilos and have regained about four kilos of that over the treatment time, et cetera. It's a net loss of 15 kilos to date. Participant 001AL

Then I started to have weight loss. Unexplained weight loss. I was eating but I was just-- I wasn't exercising any more than what I would normally. In fact, I'd cut back because I was feeling fatigued and I'd lost interest. Participant 001ATR

Then in 2008, in about eight or nine months I lost about 30, 35 kilos. After a series of blood tests, my GP looked at me one day and said, 'Oh, I think you better go and see a haematologist.'
Participant 002ALX

Symptoms leading to diagnosis: Breathlessness

The principal symptom was just shortness of breath and sort of a gripping thirst the whole way up for the first sort of ten, fifteen minutes. Very unusual. I consulted my GP here in LOCATION REGIONAL and he says, 'Oh, you might have diabetes or some other renal condition' and sent me for a bunch of tests, but anyway no diabetes. Participant 004AL

First time I started to notice something wasn't right was in August 2017, when I was getting out of breath. As a result of that, everyone thought I was having a heart attack, so they sent me to a cardiologist. Participant 004ATR

I first noticed it when I started to get a little bit out of breath. I am usually been fairly fit. I'm retired now. I'm 71 years old, then I retired. Before that, I was pretty fit. I noticed we went away on holidays about six months after I retired over to LOCATION. I noticed that I was getting a bit out of breath carrying luggage and stuff around. Where I shouldn't normally have been. Participant 008ATR

Symptoms leading to diagnosis: Tiredness

Yes. Well, he was feeling particularly tired and not a lot of energy. He wasn't able to do some of the things he'd always done very comfortably...Then we went on a family hike and our daughter was with us and she said afterwards that he really struggled walking up the mountain and that was not typical of NAME HUSBAND. We live on three acres of land, which is a sloped property and we garden intensively. On that note, I think she might have coerced NAME HUSBAND into seeking some further advice, but it was really breathlessness, not having stamina and tiredness. Participant 001CA

I was very fatigued. Kidney function was dropping fairly rapidly. I had no energy at all. I was having a lot of, well, daily slight nosebleeds, which I'd never had in my life. That was about it. It was mainly the fatigue and just getting up every morning and not wanting to do anything. Participant 017ATR

Symptoms leading to diagnosis: Specific physical sensation

I don't know how long ago now, maybe three years ago. Two, three years ago. I've got generalised osteoarthritis, so I go to a rheumatologist. I went back for a follow up appointment six months after first seeing her. I said to her, "Look, I've got this cotton wool between my toes. I just feel like I've got cotton wool- started off this fluffiness between my toes. Now I feel like I've got pebbles sitting on the soles of my feet sort of thing." Hadn't really thought about peripheral neuropathy. Participant 001ATR

The next symptom that he had was neuropathy, finding it very hard walking on his feet and also tiredness which probably would have been also from the heart, but very, very tired and very, very, very sore feet which we call the neuropathy through the legs. Participant 004CA

He did have the tingling in the middle finger. He immediately went to a doctor and I told him about 23andMe, and the doctor asked him, 'Do you wake up in the morning with your arms asleep?' He did for several nights, but he thought it was just aging. Participant 005CA

Seeking medical attention: Did not seek medical attention initially but realised importance of symptoms in hindsight

From 2016, it has just been one thing after another, one thing after another and I really just thought I'm not firing on all cylinders because of the stress in my life. But prior to that, about four years ago, I was having some oral surgery and the anaesthetist sent me off for a routine ECG. I did it, come back and I got a phone call from my GP saying to me, 'PARTICIPANT, we think you've had a heart attack.' My response was, 'When would I have had time to have had that?'. Participant 001ATR

Well, I didn't know they were symptoms of amyloidosis until I was diagnosed, so really, I haven't got the faintest idea when the symptoms started. I took early retirement in 2001 because I wasn't feeling 100%, but I wasn't prepared to commit for a five-year project. Then in 2008, in about eight or nine months I lost about 30, 35 kilos. Participant 002ALX

Yes, there were things that happened way back to 1999 that I now know was part of it. I had also had problems with my back and operations on my back, which I now know that's probably related to it. The first time that words were used that maybe a really astute cardiologist would've gone onto within 2009, I was told after a heart scan- - They came back and they said, "Look, everything's fine, but there is moderate thickening of the heart all." Participant 013ATR

Seeking medical attention: Experienced symptoms and did not seek medical attention initially (other)

Well, he was feeling particularly tired and not a lot of energy. He wasn't able to do some of the things he'd always done very comfortably. I kept saying, but you are aging, so maybe there's some of that in there too. Then we went on a family hike and our daughter was with us and she said afterwards that he really struggled walking up the mountain and that was not typical of NAME HUSBAND. We live on three acres of land, which is a sloped property and we garden intensively. On that note, I think she might have coerced NAME HUSBAND into seeking some further advice, but it was really breathlessness, not having stamina and tiredness. Participant 001CA

I first noticed it when I started to get a little bit out of breath. I am usually been fairly fit. I'm retired now. I'm 71 years old, then I retired. Before that, I was pretty fit. I noticed we went away on holidays about six months after I retired over to Canada. I noticed that I was getting a bit out of breath carrying luggage and stuff around. Where I shouldn't normally have been. Participant 008ATR

Well, my first I think was shortness of breath. My family noticed that my eyes had a twitch and the skin started to drop…Then I had a lot of trouble with shortness of breath. It sort of crept up on me within 6 to 12 months. Participant 009ATR

Seeking medical attention: Experience symptoms and sought medical attention relatively soon

The principal symptom was just shortness of breath and sort of a gripping thirst the whole way up for the first sort of ten, fifteen minutes. Very unusual. I consulted my GP here in LOCATION REGIONAL and he says, 'Oh, you might have diabetes or some other renal condition' and sent me for a bunch of tests, but anyway no diabetes. Nothing was obvious in the renal stuff, but he sent me to a physician who diagnosed a disease called-- It was a form of diabetes, but it was essentially a disease of the pituitary gland and prescribed some medications for that. Participant 004AL

First time I started to notice something wasn't right was in August 2017, when I was getting out of breath. As a result of that, everyone thought I was having a heart attack, so they sent me to a cardiologist. The cardiologist did a whole lot of tests and said 'No, you're not having a heart attack', and that's where that stopped. They never actually tested for amyloidosis. Participant 004ATR

It all just started to keep building up and I knew there was something wrong, but I couldn't get to where they would understand what I was saying. The GP kept fobbing me off and sending me to-- I went to a rheumatologist, and I went to an immunologist and they all virtually said it was just in my head and there was nothing wrong and things like that. I started to get bad pains through my feet. I was eventually sent to a neurologist and he picked up. Participant 005AL

Seeking medical attention: No experience or did not notice symptoms prior to diagnosis

I didn't notice any symptoms until after I was given the information that I had an imbalance in my light chains, which I found that information out in February about two months after the urologist phoned me. Participant 003AL

Yes. I noticed things actually after I had already had the diagnosis of the disease, already through my father had it. I remember that very, very clearly. He was convinced that his father had had it. I finally found somewhere I could actually get a type testing done. I went to the NAME CLINIC. Around about the same time I had carpal tunnel in both wrists. When I had the carpal tunnel clearance, they tested for the-- they did the analysis and they did it on the material they took away from my wrists about the same time as I got the information genetically though the NAME CLINIC. Participant 015ATR

Given the fact that we had this report from 23andMe-- my brother was diagnosed a week before this, and I lined up and went along to my GP, and he said, "Yes, it looks like you've got carpal tunnel syndrome." All of those things came together, virtually, in a week or two, together. Participant 016ATR

Table 3.4 Symptoms leading to diagnosis

Symptoms leading to diagnosis	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 having excessive weight loss, which led to their diagnosis	8	22.22	3	16.67	5	20.00	3	30.00	2	25.00	3	13.64	5	35.71	1	11.11	7	25.93
Participant describes having breathlessness, which led to their diagnosis	7	19.44	3	16.67	5	20.00	2	20.00	2	25.00	4	18.18	3	21.43	2	22.22	5	18.52
Participant describes having tiredness, which led to their diagnosis	4	11.11	2	11.11	2	8.00	0	0.00	2	25.00	1	4.55	3	21.43	1	11.11	3	11.11
Participant describes having another specified physical sensation, which led to their diagnosis e.g. numbness or tingling	4	11.11	2	11.11	2	8.00	0	0.00	2	25.00	1	4.55	3	21.43	2	22.22	2	7.41

Symptoms leading to diagnosis	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 having excessive weight loss, which led to their diagnosis	8	22.22	2	25.00	4	21.05	2	25.00	3	21.43	3	21.43	1	9.09	7	28.00
Participant describes having breathlessness, which led to their diagnosis	7	19.44	1	12.50	6	31.58	0	0.00	4	28.57	1	7.14	2	18.18	5	20.00
Participant describes having tiredness, which led to their diagnosis	4	11.11	0	0.00	3	15.79	1	12.50	2	14.29	0	0.00	3	27.27	1	4.00
Participant describes having another specified physical sensation, which led to their diagnosis e.g. numbness or tingling	4	11.11	1	12.50	3	15.79	0	0.00	2	14.29	0	0.00	3	27.27	1	4.00

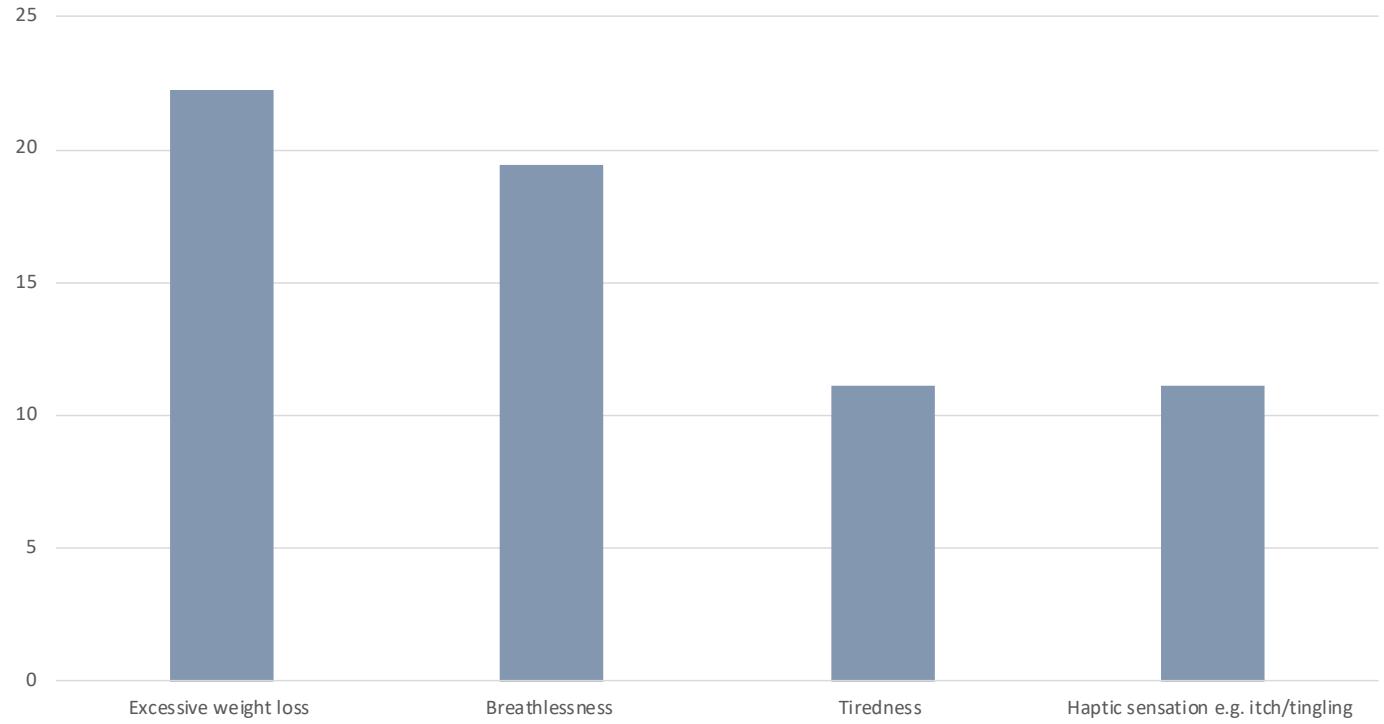


Figure 3.4: Symptoms leading to diagnosis

Table 3.5: Seeking medical attention

Seeking medical attention	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 having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	3	13.64	2	14.29	0	0.00	5	18.52
Participant describes having symptoms and not seeking medical attention initially	3	8.33	2	11.11	2	8.00	0	0.00	1	12.50	2	9.09	1	7.14	2	22.22	1	3.70
Participant describes having symptoms and seeking medical attention relatively soon	18	50.00	9	50.00	14	56.00	7	70.00	2	25.00	11	50.00	7	50.00	3	33.33	15	55.56
Participant describes having symptoms and not seeking medical attention initially: Total	8	22.22	5	27.78	5	20.00	1	10.00	2	25.00	5	22.73	3	21.43	2	22.22	6	22.22
Participant describes having no symptoms or not noticing any symptoms before diagnosis	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

Seeking medical attention	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 having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	5	13.89	1	12.50	2	10.53	2	25.00	2	14.29	2	14.29	0	0.00	5	20.00
Participant describes having symptoms and not seeking medical attention initially	3	8.33	0	0.00	3	15.79	0	0.00	2	14.29	0	0.00	1	9.09	2	8.00
Participant describes having symptoms and seeking medical attention relatively soon	18	50.00	2	25.00	10	52.63	6	75.00	9	64.29	7	50.00	6	54.55	12	48.00
Participant describes having symptoms and not seeking medical attention initially: Total	8	22.22	1	12.50	5	26.32	2	25.00	4	28.57	2	14.29	1	9.09	7	28.00
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	13.89	3	37.50	1	5.26	0	0.00	0	0.00	4	28.57	2	18.18	3	12.00

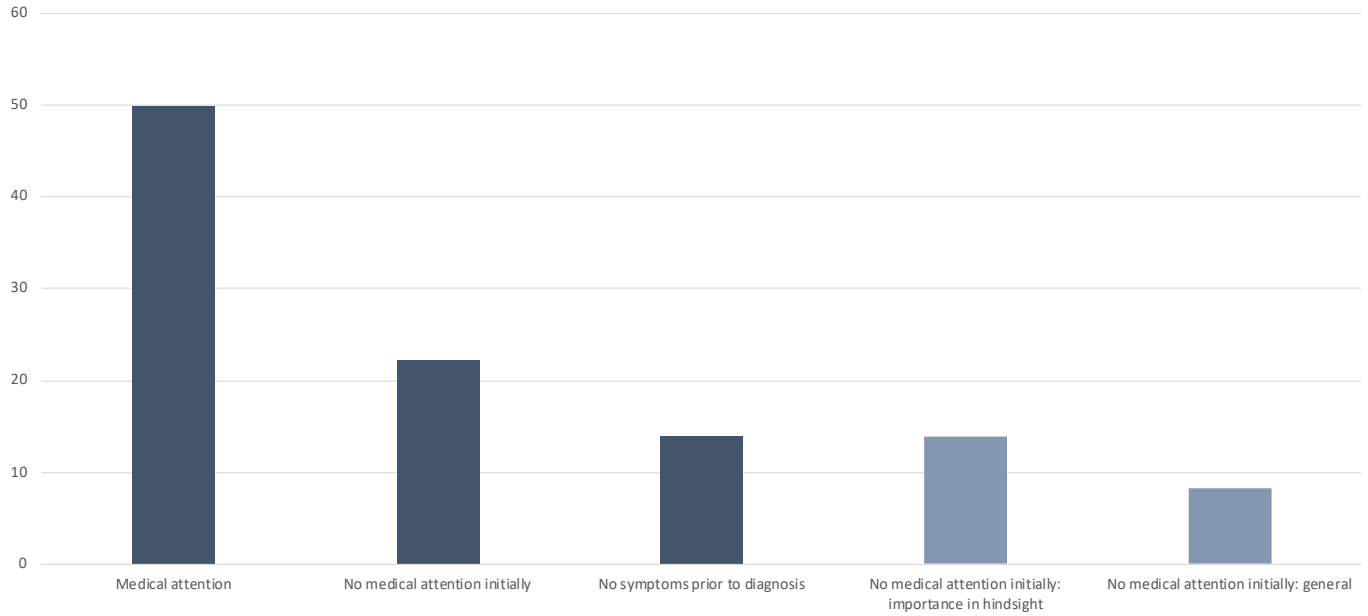


Figure 3.5: Seeking medical attention

Table 3.6: Description of diagnostic pathway

Path to diagnosis	All participants		ATTR-cardiac		All-cardiac		AL Amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=14	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis Total	9	25.00	4	22.22	8	32.00	5	50.00	0	0.00	9	40.91	0	0.00	3	33.33	6	22.22
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis Total	9	25.00	4	22.22	5	20.00	2	20.00	3	37.50	3	13.64	6	42.86	2	22.22	7	25.93
Participant describes being diagnosed through tests their specialist ordered	6	16.67	4	22.22	4	16.00	1	10.00	1	12.50	4	18.18	2	14.29	2	22.22	4	14.81

Path to diagnosis	All participants		55 to 64		65 to 74		75 and older		Trade or high school		University		Mid to low SEIFA		High SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis Total	9	25.00	0	0.00	6	31.58	2	25.00	3	21.43	6	42.86	2	18.18	7	28.00
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis Total	9	25.00	4	50.00	4	21.05	1	12.50	2	14.29	4	28.57	2	18.18	7	28.00
Participant describes being diagnosed through tests their specialist ordered	6	16.67	1	12.50	2	10.53	3	37.50	3	21.43	2	14.29	3	27.27	3	12.00

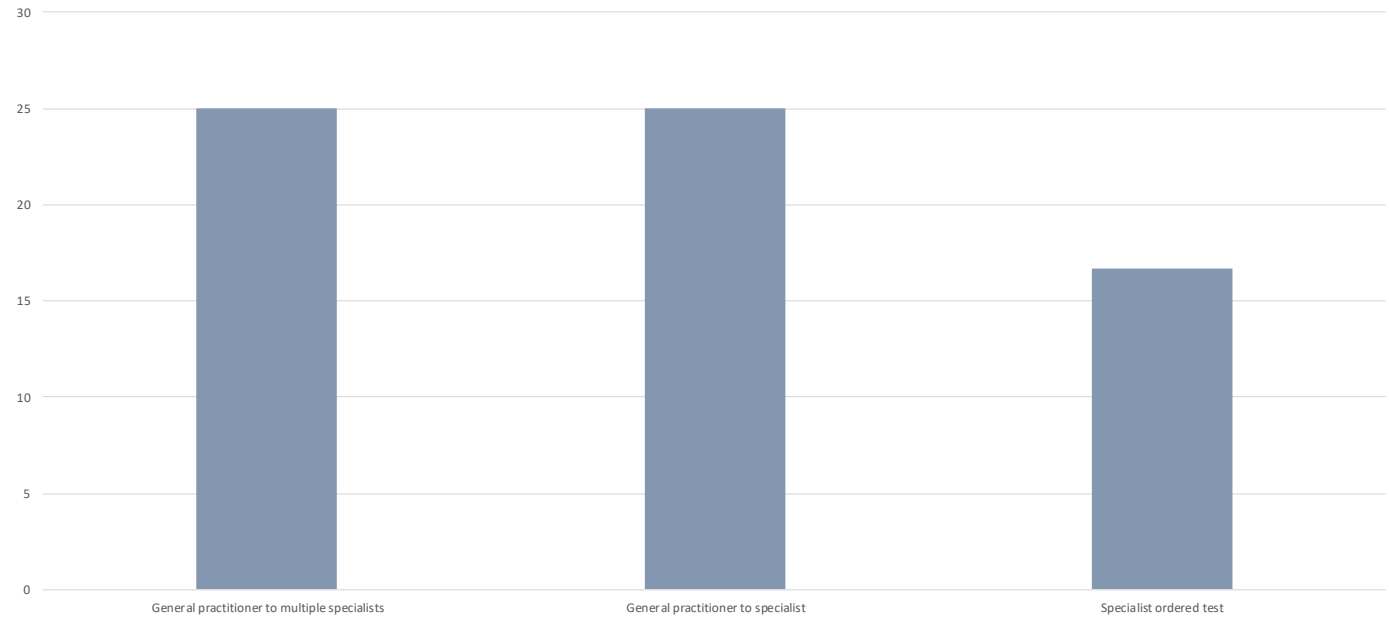


Figure 3.6: Description of diagnostic pathway

Table 3.7: Symptom recall

Symptom recall	All participants		ATTR-cardiac		All-cardiac		AL Amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=14	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	25	69.44	14	77.78	18	72.00	6	60.00	5	62.50	14	63.64	11	78.57	6	66.67	19	70.37
Participant describes not experience any symptoms that contributed to their diagnosis	4	11.11	3	16.67	4	16.00	1	10.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41

Symptom recall	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 symptoms leading to diagnosis in a clear way (strong recall)	25	69.44	4	50.00	14	73.68	7	87.50	11	78.57	9	64.29	8	72.73	17	68.00
Participant describes not experience any symptoms that contributed to their diagnosis	4	11.11	2	25.00	1	5.26	0	0.00	0	0.00	4	28.57	1	9.09	3	12.00

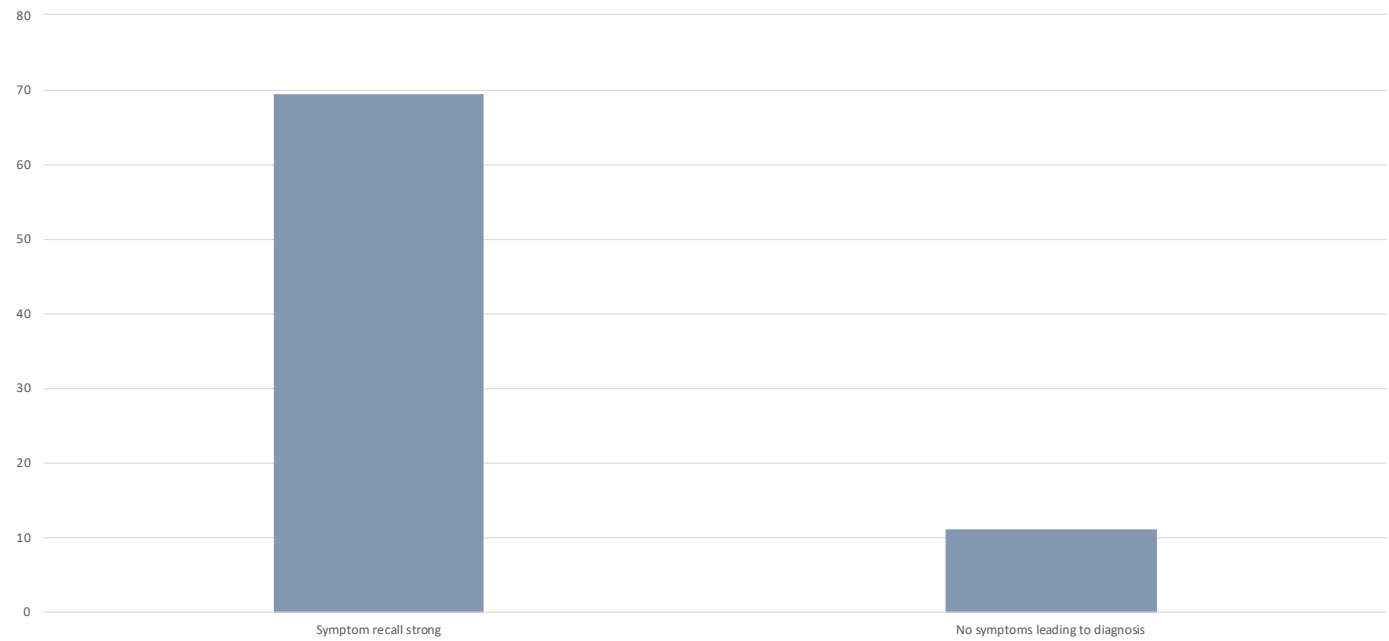


Figure 3.7: Symptom recall

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with amyloidosis. They could choose from a set list of diagnostic tests and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants had between one and 11 diagnostic tests, most commonly five to six tests (n=11, 39.29%) (Median = 6.5, IQR = 3.25) (Table 3.8, Figure 3.8). The most common diagnostic tests were blood tests (n=23, 82.14%), electrocardiogram (n=18, 64.29%), and echocardiogram (n=16, 57.14%) (Table 3.9, Figure 3.9).

Table 3.8: Number of diagnostic tests

Number of diagnostic tests per participant	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
1 to 2	4	14.29	3	16.67	4	16.00	1	10.00
3 to 4	3	10.71	3	16.67	3	12.00	0	0.00
5 to 6	11	39.29	7	38.89	5	20.00	4	40.00
7 to 8	9	32.14	4	22.22	10	40.00	5	50.00
9 or more	1	3.57	1	5.56	3	12.00	0	0.00

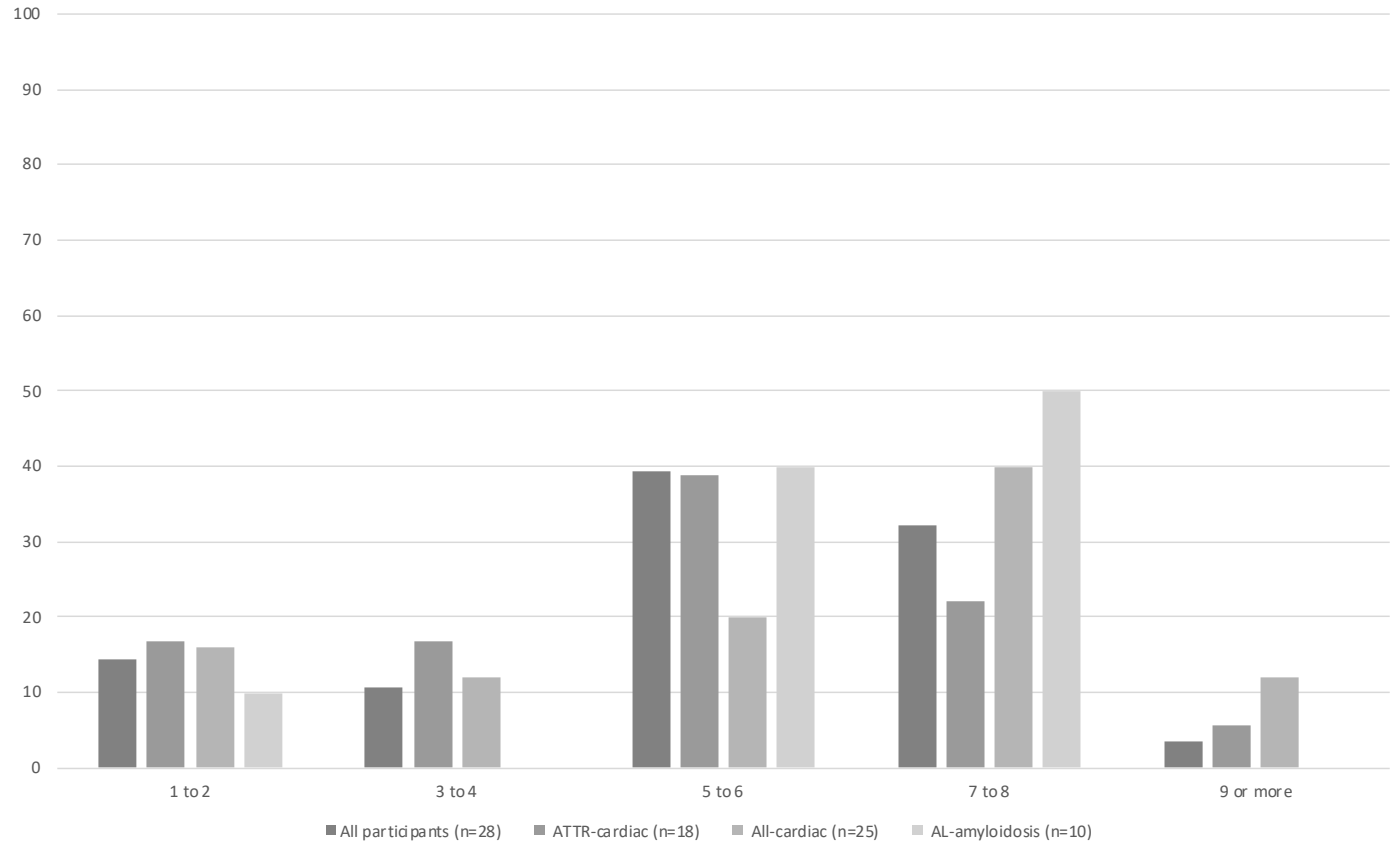
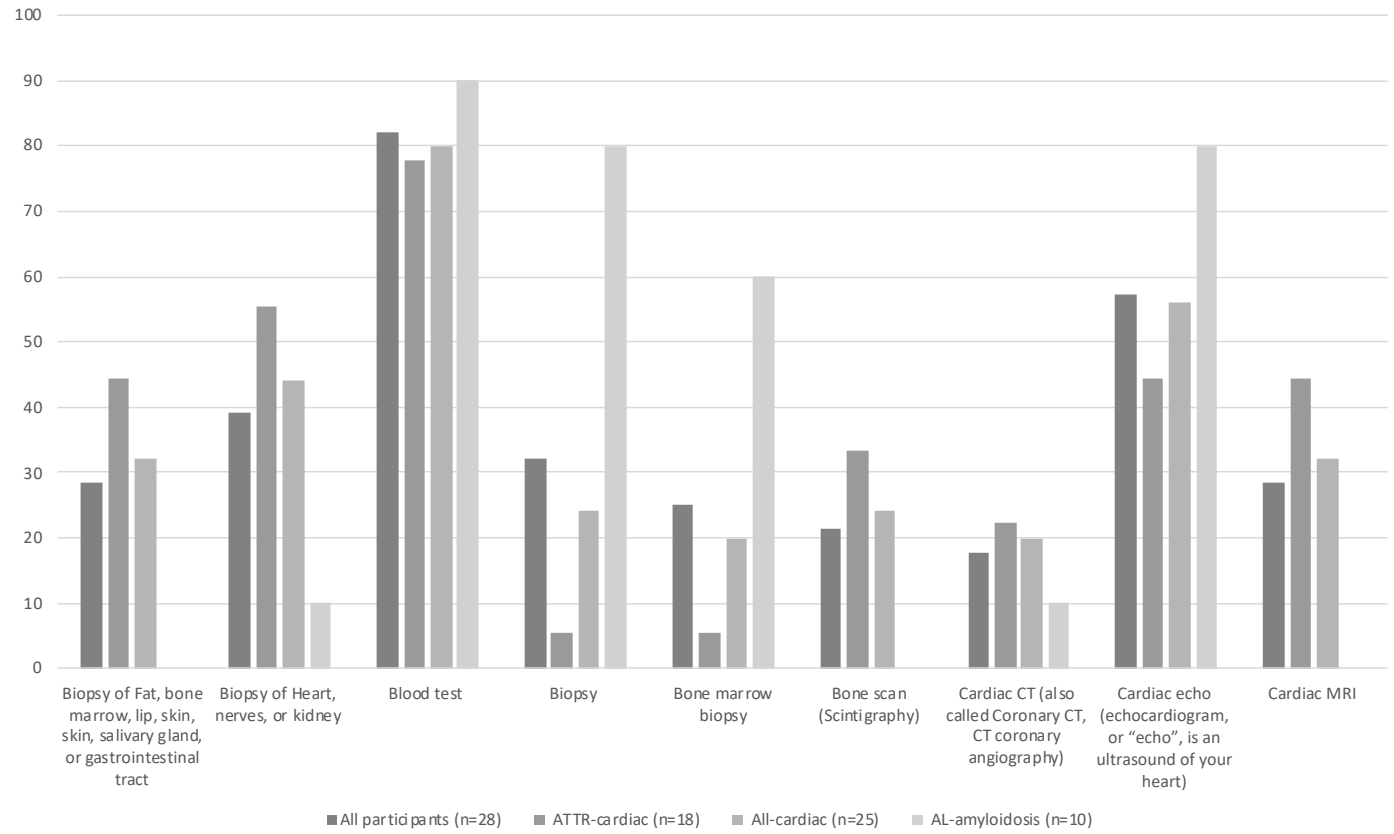


Figure 3.8: Number of diagnostic tests

Table 3.9: Diagnostic tests

Diagnostic test	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
Biopsy of Fat, bone marrow, lip, skin, skin, salivary gland, or gastrointestinal tract	8	28.57	8	44.44	8	32.00	0	0.00
Biopsy of Heart, nerves, or kidney	11	39.29	10	55.56	11	44.00	1	10.00
Blood test	23	82.14	14	77.78	20	80.00	9	90.00
Biopsy	9	32.14	1	5.56	6	24.00	8	80.00
Bone marrow biopsy	7	25.00	1	5.56	5	20.00	6	60.00
Bone scan (Scintigraphy)	6	21.43	6	33.33	6	24.00	0	0.00
Cardiac CT	5	17.86	4	22.22	5	20.00	1	10.00
Cardiac echo	16	57.14	8	44.44	14	56.00	8	80.00
Cardiac MRI	8	28.57	8	44.44	8	32.00	0	0.00
Electrocardiogram (EKG)	18	64.29	12	66.67	16	64.00	6	60.00
Nuclear heart scan/Nuclear Stress Test/Radionuclide Scan	9	32.14	9	50.00	9	36.00	0	0.00
CT Scan	4	14.29	0	0.00	2	8.00	4	40.00
MRI	5	17.86	0	0.00	3	12.00	5	50.00
Physical exam	9	32.14	8	44.44	9	36.00	1	10.00
Urine test	15	53.57	7	38.89	12	48.00	8	80.00
Genetic sequencing	5	17.86	4	22.22	5	20.00	1	10.00
Medical history/ family medical history	9	32.14	7	38.89	9	36.00	2	20.00
Other	3	10.71	2	11.11	3	12.00	1	10.00



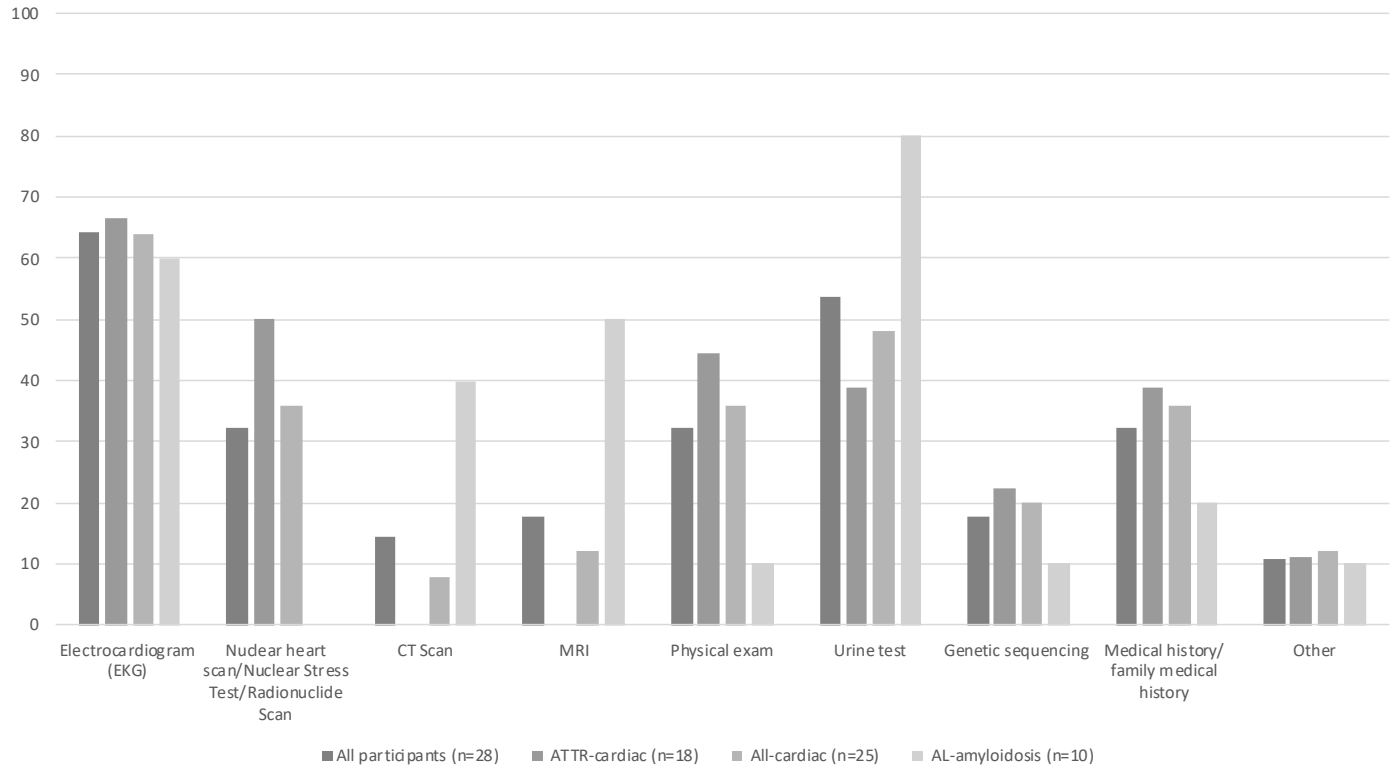


Figure 3.9: Diagnostic tests

Time from symptoms to diagnosis

Participants were asked in the online questionnaire to estimate the date when they first noticed symptoms and to estimate the date when they were diagnosed. Where both dates were given, an estimate of the length of time between noticing symptoms and getting a diagnosis was calculated.

There were 26 participants with enough data to estimate the length of time between noticing symptoms and receiving a diagnosis. Participants most commonly had more than a year between noticing symptoms and being diagnosed (n=11, 42.31%), followed by between 6 months and a year (n=7, 26.92%). There were five participants (19.23%) that had noticed symptoms between one and six months before getting diagnosed, and three participants (11.54%) that had less than one month.

Table 3.10: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=28)	Percent
Less than 1 month	3	11.54
1 month to 6 months	5	19.23
6 months to 1 year	7	26.92
More than 1 year	11	42.31

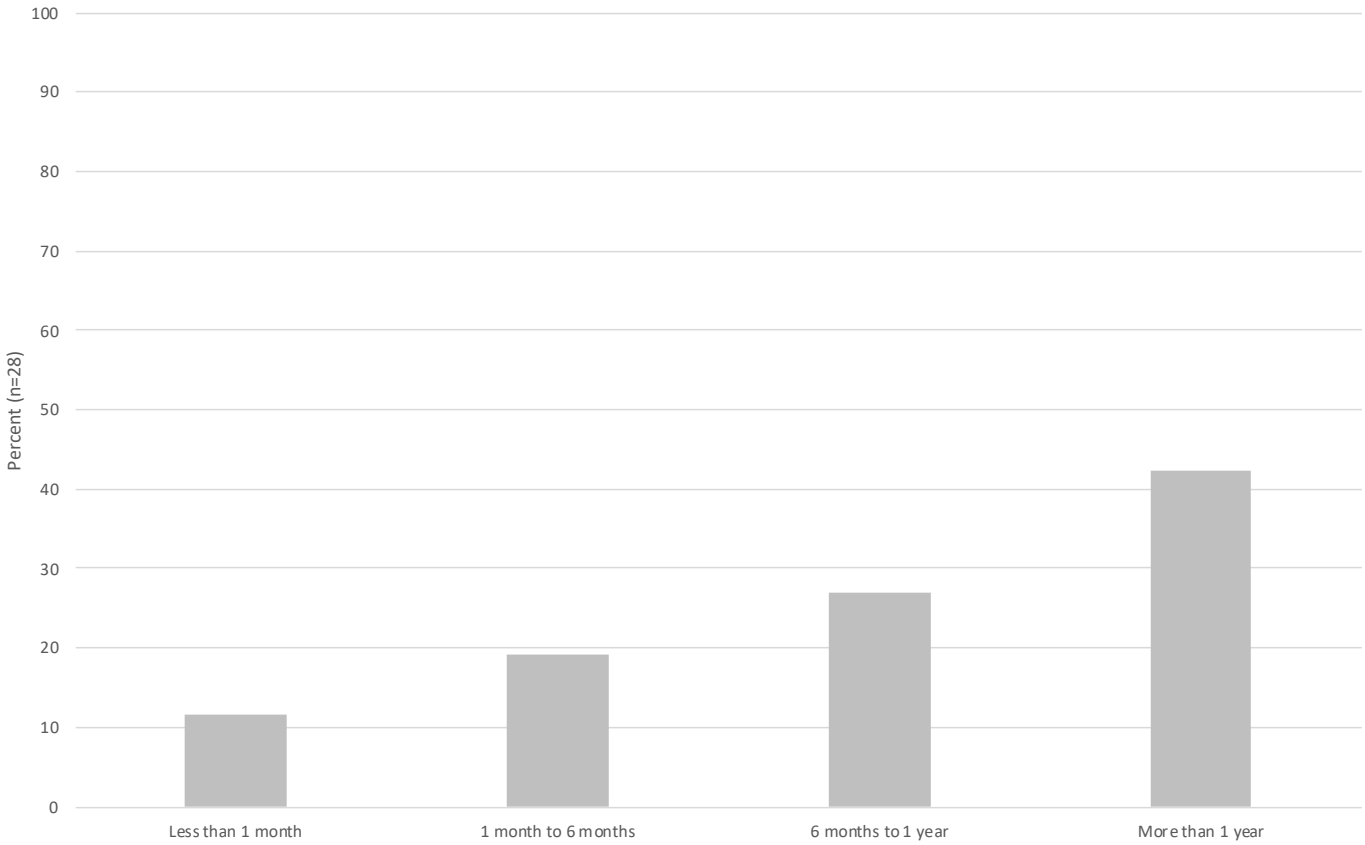


Figure 3.10: Time from symptoms to diagnosis

Time from diagnostic tests to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

The majority of participants waited between two and three weeks (n=8, 28.57%) or more than four weeks (n=8, 28.57%) (Table 3.11, Figure 3.11).

Table 3.11: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=28	Percent
Diagnosed immediately at the consultation	2	7.14
Less than 1 week	4	14.29
Between 1 and 2 weeks	4	14.29
Between 2 and 3 weeks	8	28.57
4 weeks or more	8	28.57
Not sure	2	7.14

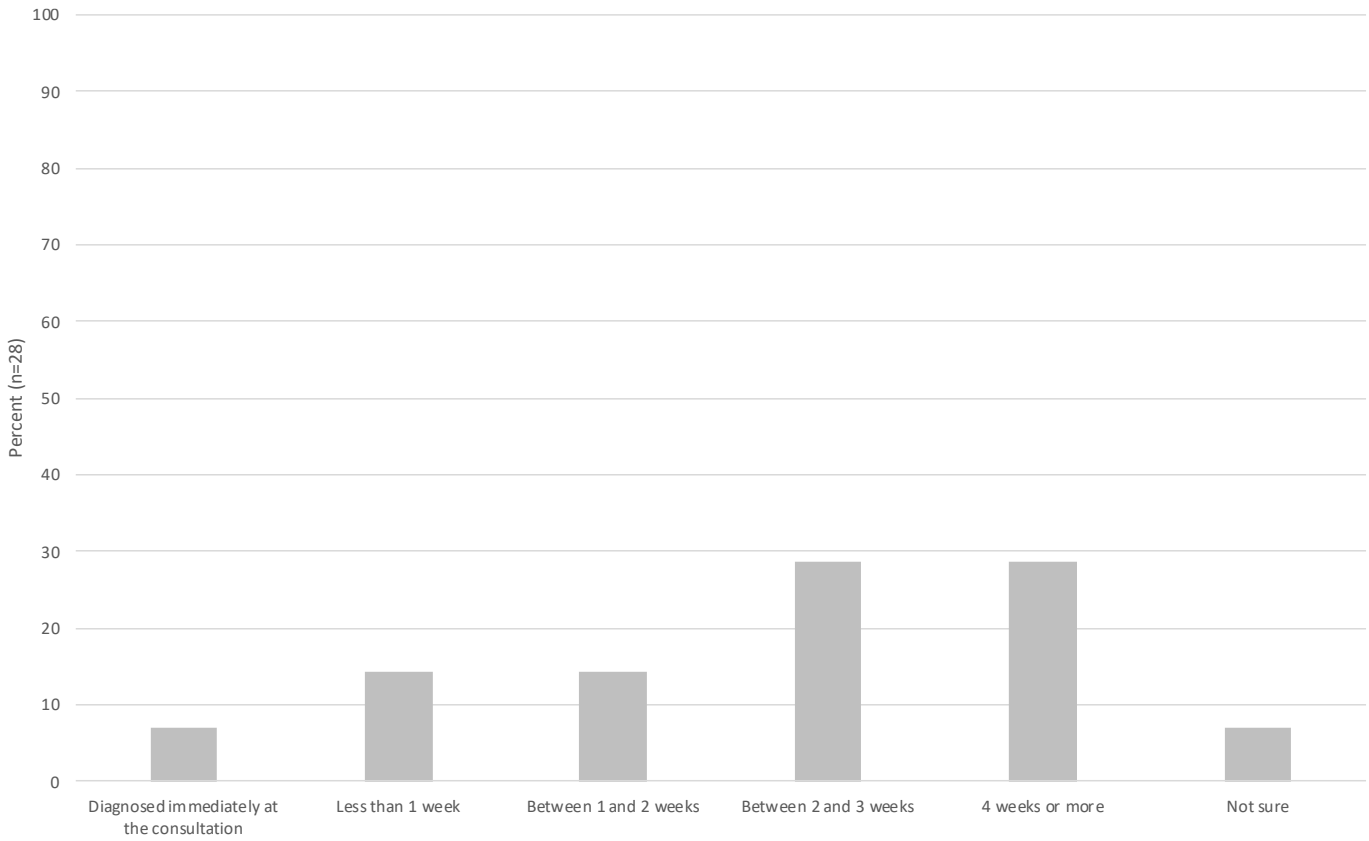


Figure 3.11: Time from diagnostic test to diagnosis

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

The diagnosis was given most commonly by the haematologist (n=9, 32.14%), followed by a cardiologist (n=7, 25.00%) (Table 3.12, Figure 3.12). The diagnosis was most commonly given at a specialist clinic (n=19, 67.86%). (Table 3.13, Figure 3.13).

Table 3.12: Diagnosis provider

Health professional gave diagnosis	Number (n=28)	Percent
Haematologist	9	32.14
Cardiologist	7	25.00
Neurologist	4	14.29
Nephrologist	3	10.71
Gastroenterologist	1	3.57
Other	4	14.29

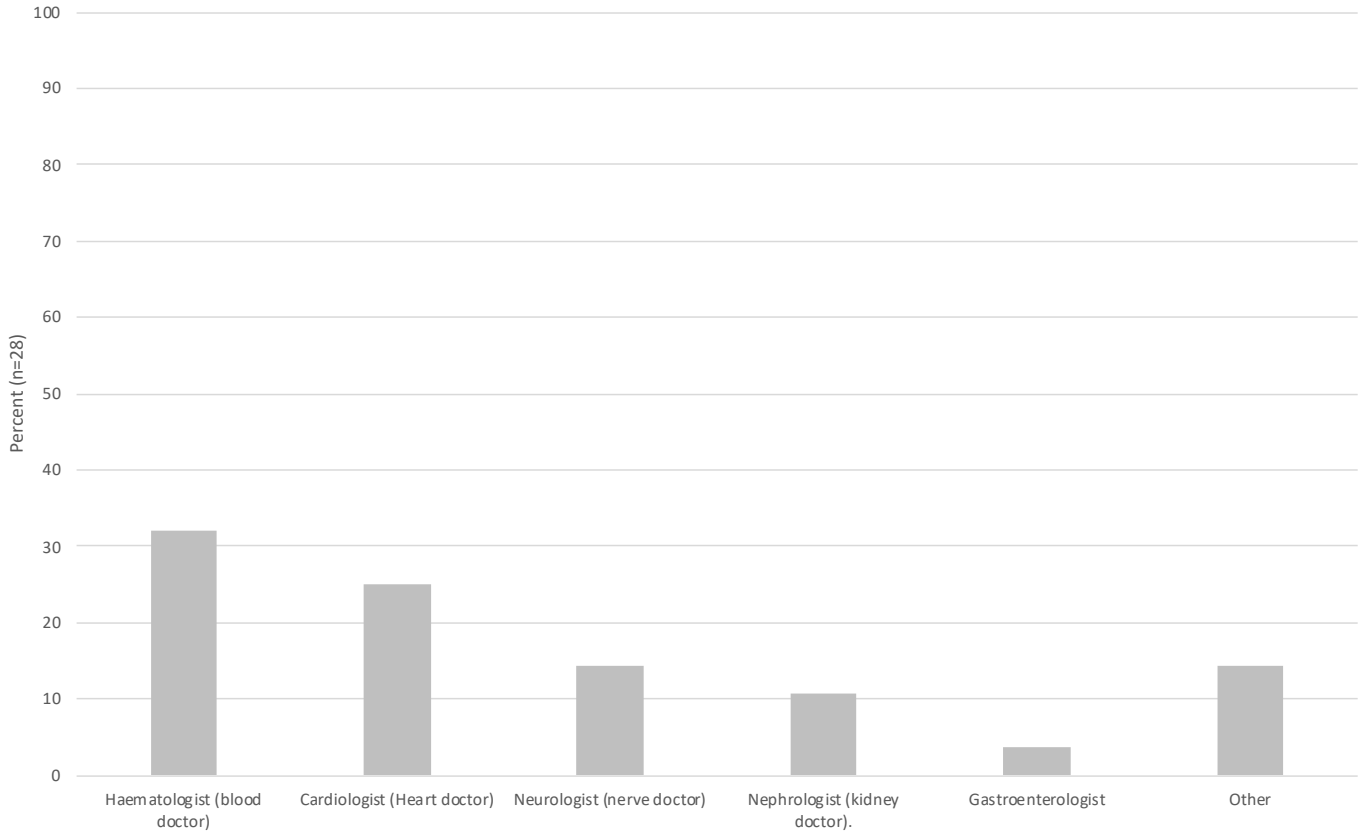


Figure 3.12: Diagnosis provider

Table 3.13: Diagnosis location

Location of diagnosis	Number (n=28)	Percent
Specialist clinic	19	67.86
Hospital	6	21.43
General practice (GP)	1	3.57
Home/phone call	2	7.14
Gastroenterologist	1	3.57
Other	4	14.29

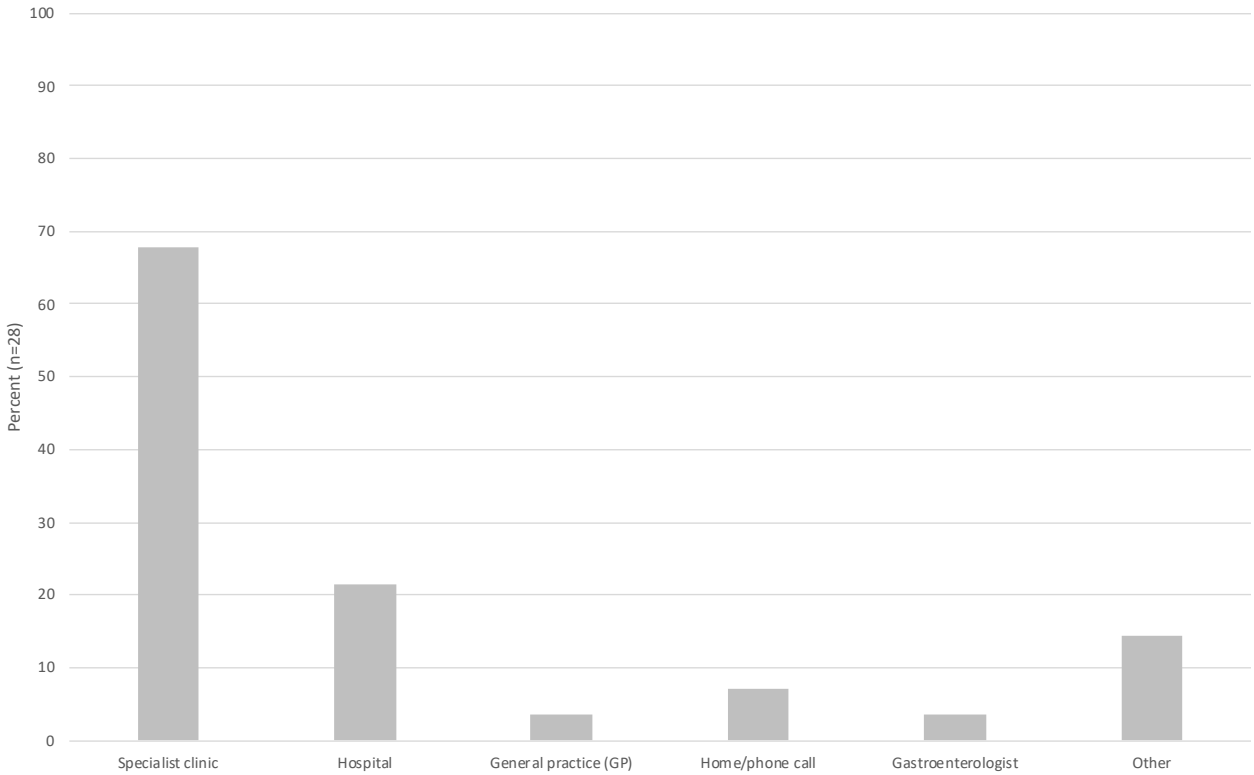


Figure 3.13: Diagnosis location

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis and the reason for their level of knowledge. There were 15 participants (41.67%) that gave no specific reason for their level of knowledge. There were eight participants (22.22%) who said they came to understand their condition more over time and through lived experience, and four participants (11.11%) described knowing very little about their condition at diagnosis, but that they were aware of family history with the condition.

Overall, there were 27 participants (75.00%) that described knowing nothing or very little at diagnosis and these were the most common themes. There were three participants (8.33%) that noted that they knew a good amount about the condition at diagnosis.

In relation to subgroup variations, participants in the *Carer* (25.00%), *Aged 55 to 64* (12.50%), *Female* (28.57%), and *Regional or remote* (11.11%) subgroups described no specific reason for their level of knowledge less frequently than the general population (41.67%), while those in the *Aged 65 to 74* (52.63%), *Trade or high school* (64.29%) and *Metropolitan* (51.85%) subgroup described this more frequently.

Participants in the *ATTR-cardiac* (11.11%), and the *Male* (9.09%) subgroups described knowing about their condition over time through lived experience, but not at diagnosis, less frequently than the general population (22.22%), while those in the *Carer* (37.50%), *Aged 75 or older* (37.50%), *Female* (42.86%), and *Regional or remote* (33.33%) subgroups described this more frequently.

No participants in the *AL amyloidosis* (0.00%), *Carer* (0.00%) and *Aged 75 or older* (0.00%) subgroups described having little knowledge but having a family history of the condition. Participants in the *ATTR-cardiac* (22.22%) and *Regional or remote* (22.22%) subgroups described this more frequently than the general population (11.11%).

Participants in the *ATTR-cardiac* (38.89%) *Aged 55 to 64* (37.50%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) subgroups described knowing nothing about the condition at diagnosis less frequently than the general population (55.56%). Participants in the *AL amyloidosis* (80.00%), and *Aged 75 or older* (75.00%) subgroups described this more frequently.

No participants in the *Al amyloidosis* (0.00%) or *Carer* (0.00%) subgroups described knowing very little about the condition at diagnosis. Participants in the *ATTR-cardiac* (38.89%) and *Trade or high school* (35.71%) subgroups described this more frequently than the general population (19.44%).

Participants in the *University* (21.43%) subgroups described knowing a good amount about the condition at diagnosis more frequently than the general population (8.33%).

No reason to level of knowledge

Zero. Nothing. I was aware of myeloma, but vaguely, but not AL. I'd not heard of it. It was just a brand-new word. Participant 004AL

I didn't know anything. Participant 005ATR

Nothing. Never heard of it. Participant 011ATR

Understanding over time through lived experience

Yes, has been very good. To be honest, I've just been bombarded with information overload in the last eight weeks, basically that's how long it's been since I've been diagnosed, really. Participant 001ATR

Nothing. But I very quickly learned quite a lot. My career back then, I've retired since, was a SCIENTIST. I had access to lots of journals and publications. I must admit, when I first started to look, it was rather frightening but the more that you look at it, the more you can see that there isn't an average or a normal or necessarily an expectation of outcomes. Everybody's very different. Participant 002AL

Absolutely nothing, in terms of I was soon referred to NAME HOSPITAL and NAME DOCTOR provided me with quite a lot of material. Initially, you're asking me immediately. I'm a retired vet, so I'm used to reviewing articles and taking all things, and so you immediately go and look up whatever you can. Participant 007ATR

Knew very little, but has family history of condition

Just what it had done to my mum, really. I saw my mum go through it basically her whole six or seven years before she passed away. Really that was the only-- very different to what happened to me. She had cysts and things, but the rapid weight loss she got necessarily before she got quite sick and then lost weight and also a bit of pain. I was really young, so I wasn't really interviewing her. I didn't really want to know; I was just a kid. Participant 006ATR

I had a little bit of an idea because my mom had this condition, and her brother. I had a little bit of an idea of what was going on once it sort of started to affect me. Participant 009ATR

Not a lot. Only that I knew my mother had it and she passed away about 20 years ago and the sign that she had it in her brain and apparently, she had it in sort of lots of different parts of the body and different organs and that was the same one. Participant 014ATR

Knew nothing prior to diagnosis

Nothing. Initially nothing. I just went on a steep learning curve. Participant 004AL

I had never heard of it and I thought we were quite well-read and quite knowledgeable people. I had never heard of amyloidosis, so that put me as an ex-school librarian and researcher that put me in the fast track of having to find out as much about this as I possibly could. Participant 001CA

Nothing at all. Nothing at all. NAME HUSBAND probably told you, I think he did tell you this, that the haematologists we saw at the beginning was very abrupt, very non-empathetic basically said, "Oh, yes, it's this. You better get your affairs in order and take off your bucket list," and that's it. We saw our future go from somewhere in the distance straight up in front of our faces, then we both came home and got onto the internet. Participant 002CA

Knew very little prior to diagnosis

Just what it had done to my mum, really. I saw my mum go through it basically her whole six or seven years before she passed away. Really that was the only-- very different to what happened to me. She had cysts and things, but the rapid weight loss she got necessarily before she got quite sick and then lost weight and also a bit of pain. I was really young, so I wasn't really interviewing her. I didn't really want to know; I was just a kid. Participant 006ATR

I had a little bit of an idea because my mum had this condition, and her brother. I had a little bit of an idea of what was going on once it sort of started to affect me. Participant 009ATR

Not a lot. Only that I knew my mother had it and she passed away about 20 years ago and the sign that she had it in her brain and apparently, she had it in sort of lots of different parts of the body and different organs and that was the same one. Participant 014ATR

Good knowledge of condition prior to diagnosis

By the time I got the final diagnosis, I knew a lot. I've done a lot of reading. When I was first told about it, I knew absolutely nothing. When the first hints came through, I knew absolutely nothing. It was easy enough to find because the Mayo Clinic has got wonderful stuff. The London Free Hospital has got lots of stuff online. Of course, we're getting a web page in Australia. I've told by now; it's going to do the same thing. Once you get onto that, there is a lot of information out there. Participant 013ATR

A fair bit because, again, I had seen it with my dad. I had seen exactly what happened with him. I watched him go downhill, and I've, over the years, read more and more about what there was on the web. In fact, for about the past four GPs as I have been somewhat moving around, I've been teaching them about amyloidosis to try and get somewhere with accessing et cetera. Participant 015ATR

Table 3.14 Understanding of disease at diagnosis

Understanding of disease at diagnosis	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 knowing/not knowing about the condition but no specific reason for the level of knowledge	15	41.67	8	44.44	11	44.00	5	50.00	2	25.00	11	50.00	4	28.57	1	11.11	14	51.85
Participant describes knowing about the condition over time through lived experience but not at diagnosis	8	22.22	2	11.11	4	16.00	3	30.00	3	37.50	2	9.09	6	42.86	3	33.33	5	18.52
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	3	13.64	1	7.14	2	22.22	2	7.41
Participant describes knowing nothing about the condition at diagnosis	20	55.56	7	38.89	12	48.00	8	80.00	5	62.50	13	59.09	7	50.00	4	44.44	16	59.26
Participant describes knowing very little about the condition at diagnosis	7	19.44	7	38.89	7	28.00	0	0.00	0	0.00	3	13.64	4	28.57	2	22.22	5	18.52
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	8.33	2	11.11	3	12.00	1	10.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41

Understanding of disease at diagnosis	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 knowing/not knowing about the condition but no specific reason for the level of knowledge	15	41.67	1	12.50	10	52.63	4	50.00	9	64.29	4	28.57	4	36.36	11	44.00
Participant describes knowing about the condition over time through lived experience but not at diagnosis	8	22.22	2	25.00	3	15.79	3	37.50	2	14.29	3	21.43	2	18.18	6	24.00
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	4	11.11	1	12.50	2	10.53	0	0.00	2	14.29	2	14.29	2	18.18	2	8.00
Participant describes knowing nothing about the condition at diagnosis	20	55.56	3	37.50	11	57.89	6	75.00	8	57.14	7	50.00	5	45.45	15	60.00
Participant describes knowing very little about the condition at diagnosis	7	19.44	1	12.50	4	21.05	1	12.50	5	35.71	2	14.29	3	27.27	4	16.00
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	8.33	1	12.50	1	5.26	1	12.50	0	0.00	3	21.43	0	0.00	3	12.00

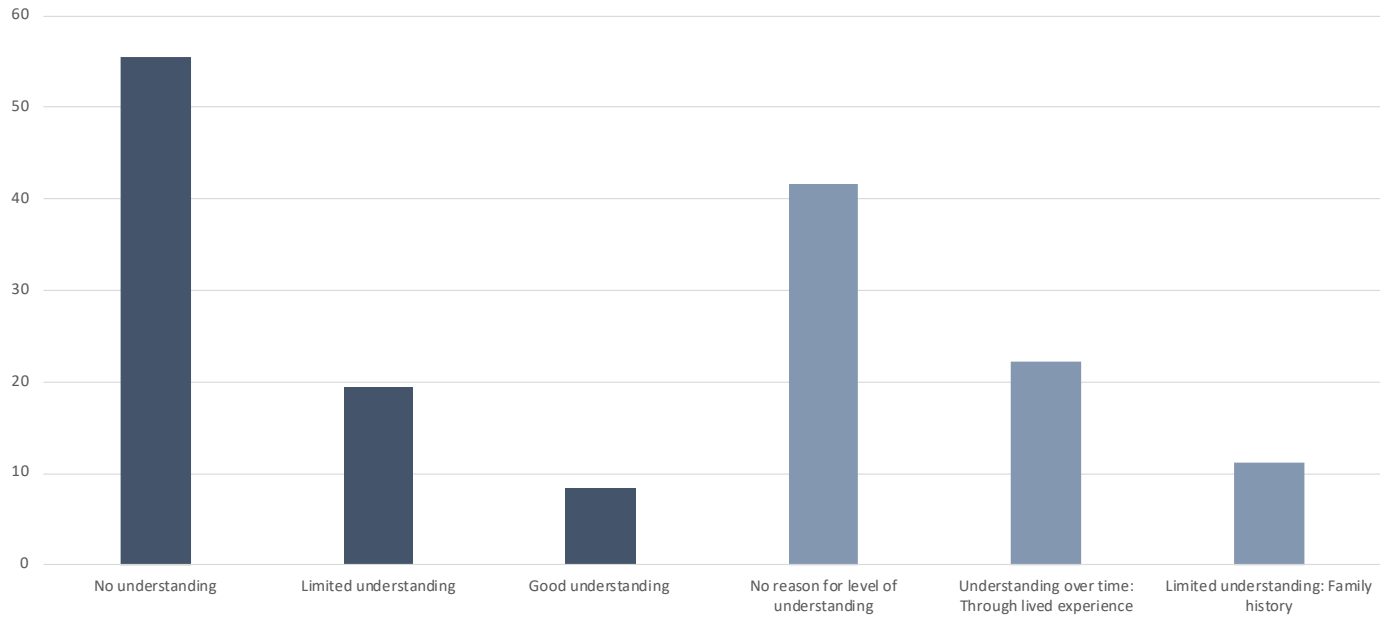


Figure 3.14 Understanding of disease at diagnosis

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

Almost half of participants (including carers) had enough support (n=17, 47.22%), six participants (16.67%) had no support, and 13 participants (36.11%) had some support but it wasn't enough (Table 3.15, Figure 3.15).

In relation to subgroup variations, participants in the *AL amyloidosis* (70.00%), *75 or older* (62.50%), and *Mid to low SEIFA* (63.63%) subgroups had enough support between testing and diagnosis compared to the general population (47.22%), and *Carers* (25.00%), and those in the *Regional or remote* (33.33%) subgroup had less support.

There were no participants in the *AL amyloidosis* subgroup who stated they had some support, but it wasn't enough, compared to the general population (16.67%).

In the study population, there were 36.11% participants who had no support between diagnostic tests and diagnosis, compared to *Carers* (62.50%), *Females* (50.00%), and those who lived in *Regional or remote* areas (55.56%) who had no support more often, and those in the *Aged 75 or older* (25.00%) subgroup who had no support less often.

Table 3.15: Emotional support at diagnosis

Support at diagnosis	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=7	%	n=9	%	n=27	%
I/we had enough support	17	47.22	8	44.44	13	52.00	7	70.00	2	25.00	11	50.00	6	42.86	3	33.33	14	51.85
I/we had some support but it wasn't enough	6	16.67	5	27.78	5	20.00	0	0.00	1	12.50	5	22.73	1	7.14	1	11.11	5	18.52
I/we had no support	13	36.11	5	27.78	7	28.00	3	30.00	5	62.50	6	27.27	7	50.00	5	55.56	8	29.63

Support at diagnosis	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	%
I/we had enough support	17	47.22	3	37.50	9	47.37	5	62.50	8	57.14	7	50.00	7	63.64	10	40.00
I/we had some support but it wasn't enough	6	16.67	2	25.00	3	15.79	1	12.50	2	14.29	3	21.43	1	9.09	5	20.00
I/we had no support	13	36.11	3	37.50	7	36.84	2	25.00	4	28.57	4	28.57	3	27.27	10	40.00

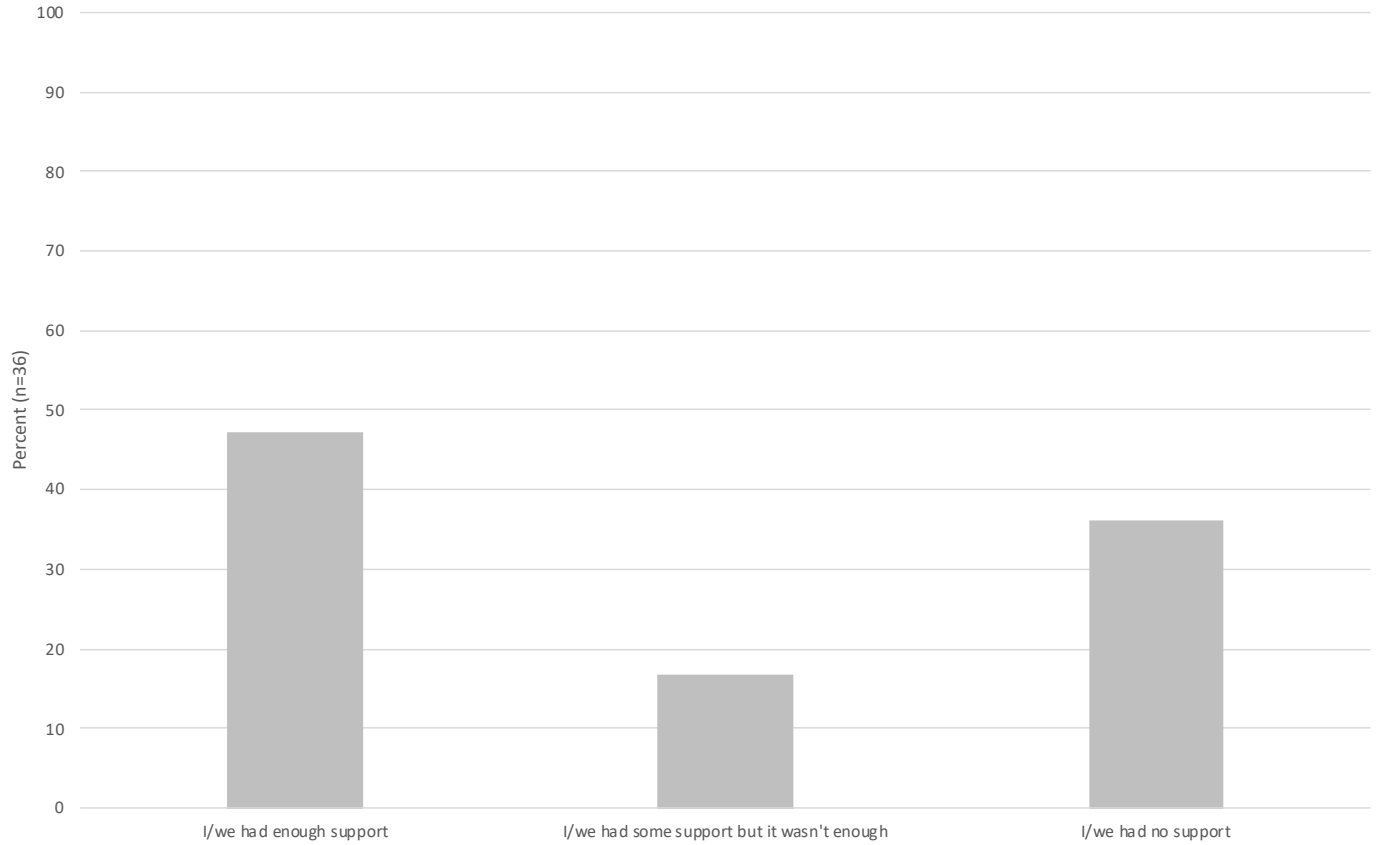


Figure 3.15: Emotional support at diagnosis

Information at diagnosis

Participants (excluding carers) were asked in the online questionnaire how much information they or their family received at diagnosis.

The majority of had enough information (n=20, 71.43%), eight participants (28.57%) had some information but not enough, and there were no participants that had no information (0.00%) (Table 3.16, Figure 3.16).

In relation to subgroup variations, the subgroups did not differ more or less than 10% of the general population.

Table 3.16: Information at diagnosis

Information at diagnosis	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=7	%	n=9	%	n=27	%
I/we had enough information	20	71.43	13	72.22	19	76.00	7	70.00	NA	NA	15	71.43	5	71.43	4	66.67	16	72.73
I/we had some information but it wasn't enough	8	28.57	5	27.78	6	24.00	3	30.00	NA	NA	6	28.57	2	28.57	2	33.33	6	27.27
I/we had no information	0	0.00	0	0.00	0	0.00	0	0.00	NA	NA	0	0.00	0	0.00	0	0.00	0	0.00

Information at diagnosis	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	%
I/we had enough information	20	71.43	4	66.67	10	76.92	5	62.50	9	64.29	11	78.57	5	62.50	15	75.00
I/we had some information but it wasn't enough	8	28.57	2	33.33	3	23.08	3	37.50	5	35.71	3	21.43	3	37.50	5	25.00
I/we had no information	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00

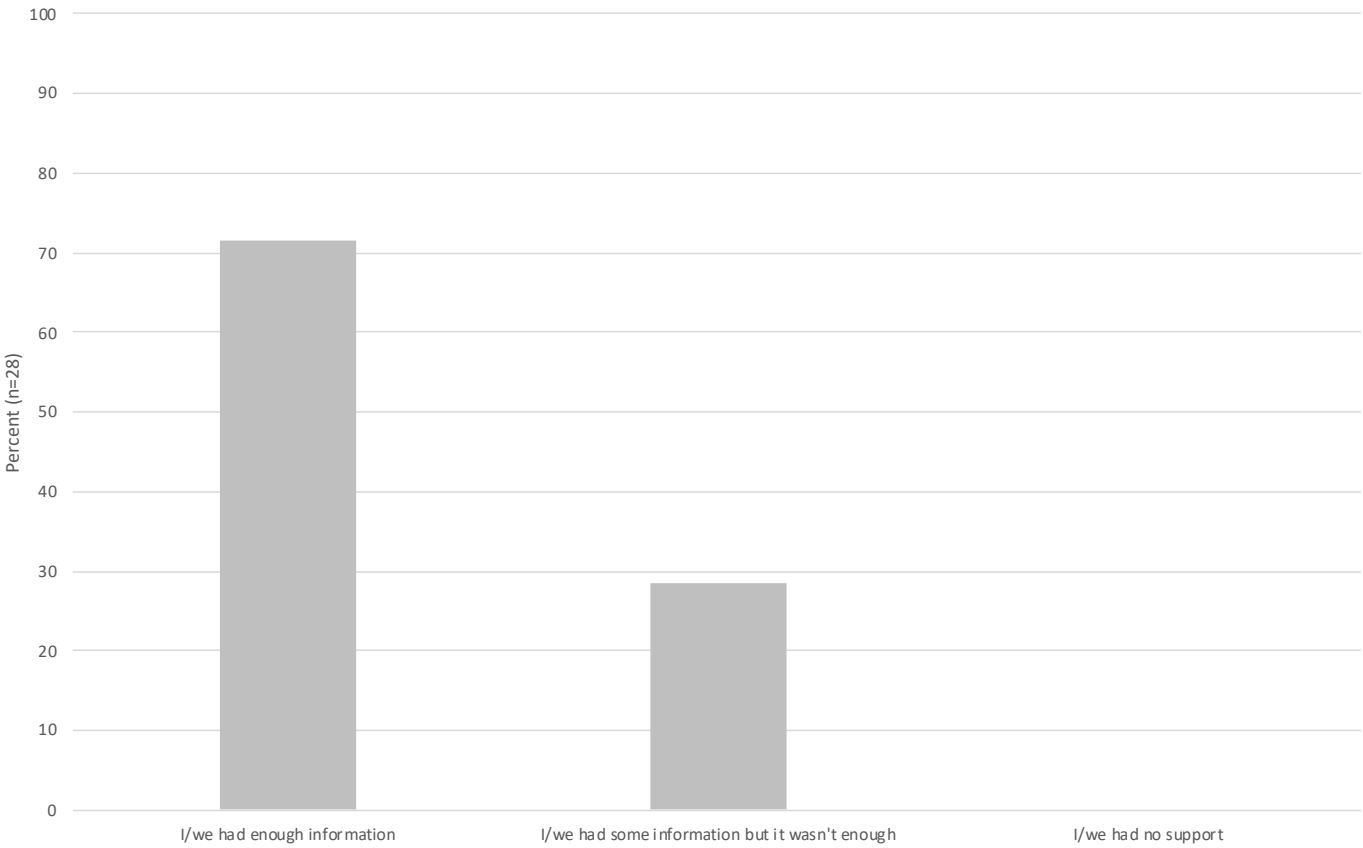


Figure 3.16: Information at diagnosis

Costs at diagnosis

Participants noted in the online questionnaire the amount of out of pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 12 participants (42.86%) who could recall the out of pocket expenses at diagnosis. There were eight participants who had no out of pocket expenses at diagnosis (28.57%), two that spent between $100 and $500 (7.14%), four who spent between $500 and $1000 (14.29%), and two who spent more than $1000 (7.14%) in out of pocket expenses (Table 3.17, Figure 3.17).

As a follow up question, participants were asked how much of a burden the out of pocket expenses at diagnosis were.

For 12 participants (60.00%) the cost was either slightly significant or not significant at all. For five participants (25.00%) the out of pocket expenses were somewhat significant, and for three participants (15.00%), the burden of out of pocket expenses were moderately significant (Table 3.18, Figure 3.18).

Table 3.17: Costs at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=28)	Percent
$0	8	28.57
$100 - $500	2	7.14
$500 to $1000	4	14.29
More than $1000	2	7.14
Unsure	12	42.86

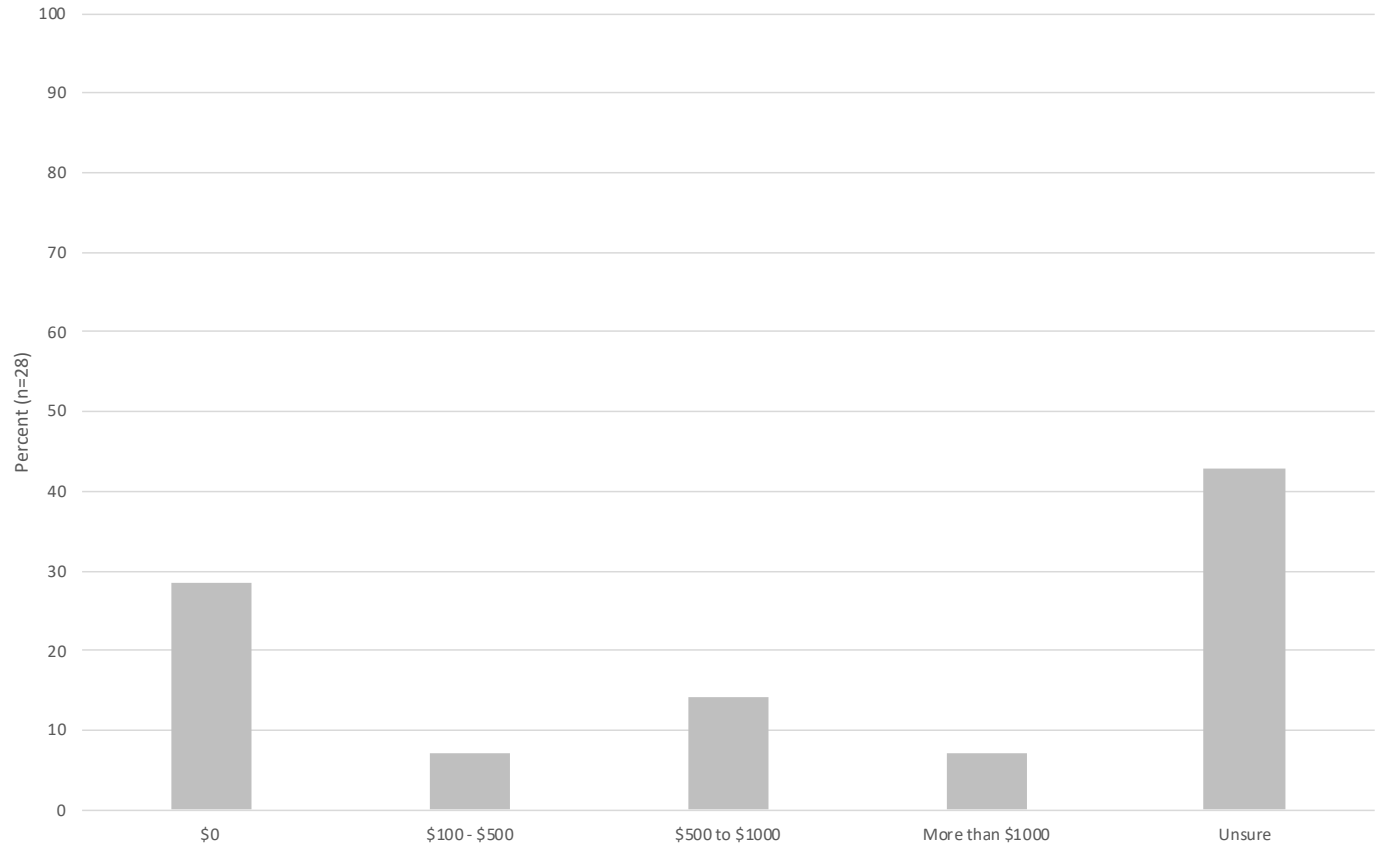


Figure 3.17: Costs at diagnosis

Table 3.18: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=20)	Percent
Not at all significant	7	35.00
Slightly significant	5	25.00
Somewhat significant	5	25.00
Moderately significant	3	15.00
Extremely significant	0	0.00

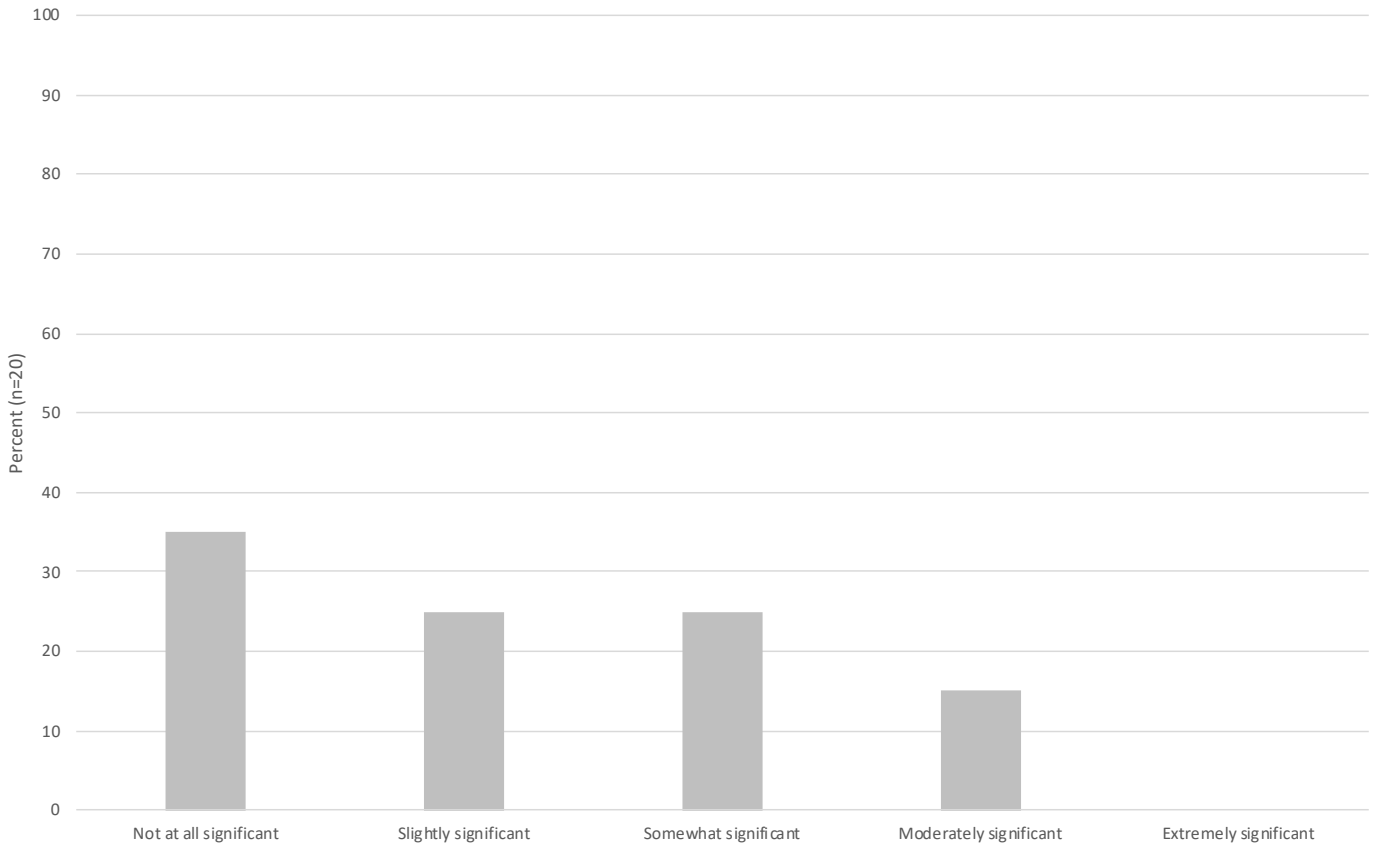


Figure 3.18: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

The majority of participants had no conversation about biomarker, genomic or gene testing that might be relevant to treatment (n=17, 60.71%). There were three participants who brought up the topic with their doctor (10.71%), and eight whose doctor brought up the topic (28.57%) (Table 3.19, Figure 3.19).

In relation to subgroup variations, participants in the Trade or high school (78.85%) subgroup did not have discussions about biomarkers, genomic and gene testing more frequently than in the general population (60.71%), while in the *Regional or remote* (50,00%), *Aged 55 to 64* (16.67%), and *University* (42.86%) subgroups did not have these discussions less often.

Table 3.19: Discussions about biomarkers

Discussions about biomarkers	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=28	%	n=18	%	n=25	%	n=10	%	n=8	%	n=21	%	n=7	%	n=6	%	n=22	%
I brought up the topic with my doctor for discussion	3	10.71	1	5.56	3	12.00	2	20.00	NA	NA	1	4.76	2	28.57	1	16.67	2	9.09
My doctor brought up the topic with me for discussion	8	28.57	7	38.89	8	32.00	1	10.00	NA	NA	7	33.33	1	14.29	2	33.33	6	27.27
No one has ever spoken to me about this type of test	17	60.71	10	55.56	14	56.00	7	70.00	NA	NA	13	61.90	4	57.14	3	50.00	14	63.64

Discussions about biomarkers	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=28	%	n=6	%	n=13	%	n=8	%	n=14	%	n=14	%	n=8	%	n=20	%
I brought up the topic with my doctor for discussion	3	10.71	2	33.33	1	7.69	1	12.50	0	0.00	3	21.43	3	37.50	3	15.00
My doctor brought up the topic with me for discussion	8	28.57	3	50.00	4	30.77	7	87.50	3	21.43	5	35.71	5	62.50	5	25.00
No one has ever spoken to me about this type of test	17	60.71	1	16.67	8	61.54	0	0.00	11	78.57	6	42.86	0	0.00	12	60.00

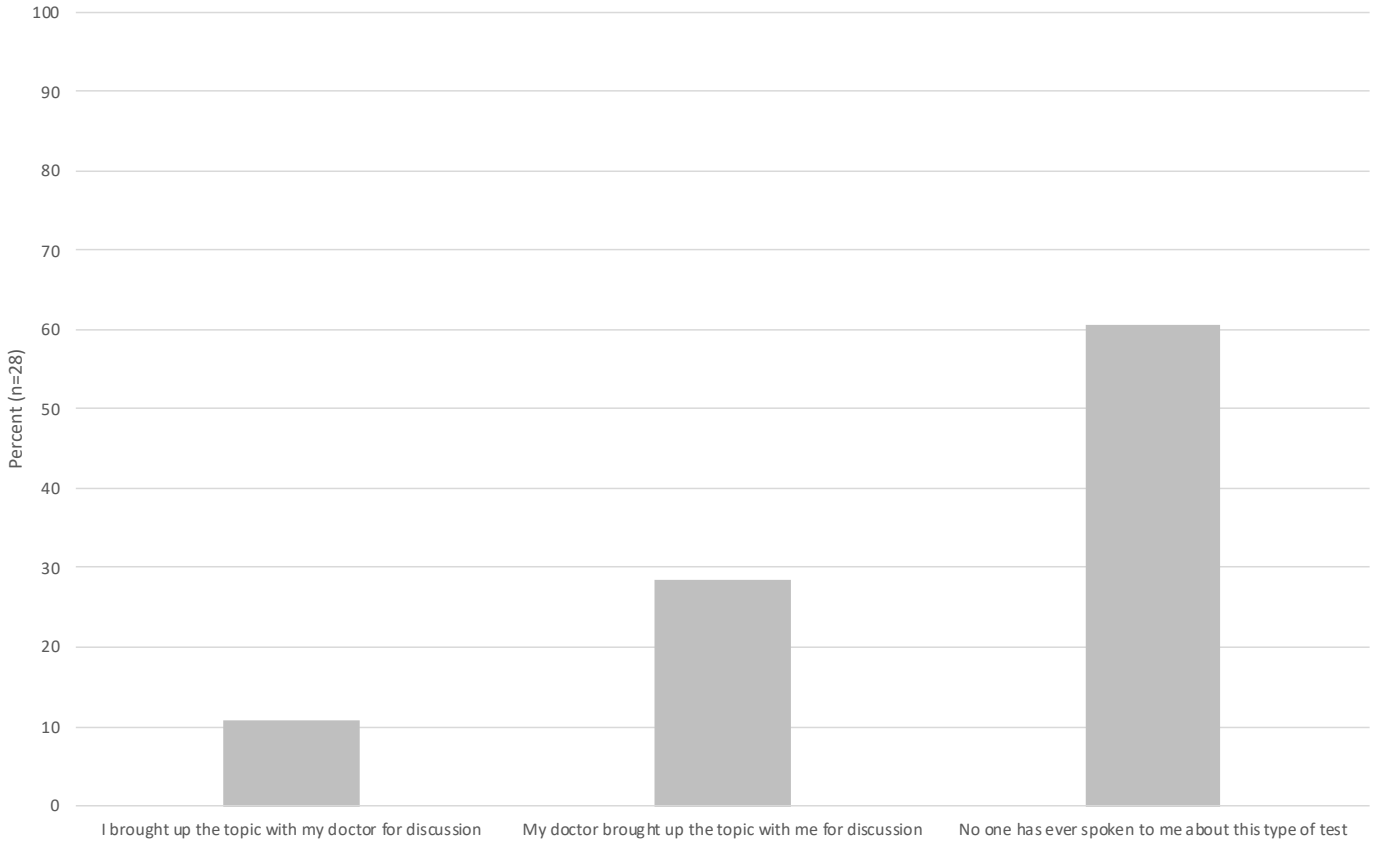


Figure 3.19: Discussions about biomarkers

Experience of genetic tests and biomarkers

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had with no out of pocket expenses, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Over half of the participants (not including carers) have not had any testing but would like to (n=15, 53.57%). There were a total of 10 participants that had the test, either paying for it themselves (n=5, 17.86%), or not paying out of pocket (n=5, 17.86%). Three participants did not have the test and had no interest in having one (10.71%) (Table 3.20, Figure 3.20).

In relation to subgroup variations, participants in the *Regional or remote* (66.67%), *Aged 65 to 74* (69.23%), and *Trade or high school* (64.29%) subgroups more frequently responded that they did not have the test but would like to, compared to the general population (53.57%), and participants in the *Female* (28.57%), *Aged 55 to 64* (16.67%) and *University* (42.86%) subgroups wanted this less often.

Table 3.20: Experience of genetic tests and biomarkers

Experience of biomarker tests	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=28	%	n=18	%	n=25	%	n=10	%	n=8	%	n=21	%	n=7	%	n=7	%	n=22	%
I have had this test and did not have to pay out of pocket for it	5	17.86	4	22.22	5	20.00	1	10.00	NA	NA	4	19.05	1	14.29	1	16.67	4	18.18
I have had this type of test and paid for it myself	5	17.86	2	11.11	4	16.00	3	30.00	NA	NA	3	14.29	2	28.57	1	16.67	4	18.18
I have not had this test and am not interested in it	3	10.71	2	11.11	2	8.00	1	10.00	NA	NA	1	4.76	2	28.57	0	0.00	3	13.64
I have not had this test but would like to	15	53.57	10	55.56	14	56.00	5	50.00	NA	NA	13	61.90	2	28.57	4	66.67	11	50.00

Experience of biomarker tests	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=28	%	n=6	%	n=15	%	n=8	%	n=14	%	n=14	%	n=8	%	n=20	%
I have had this test and did not have to pay out of pocket for it	5	17.86	2	33.33	2	15.38	1	12.50	1	7.14	4	28.57	1	12.50	4	20.00
I have had this type of test and paid for it myself	5	17.86	3	50.00	2	15.38	0	0.00	1	7.14	4	28.57	1	12.50	4	20.00
I have not had this test and am not interested in it	3	10.71	0	0.00	0	0.00	3	37.50	3	21.43	0	0.00	1	12.50	2	10.00
I have not had this test but would like to	15	53.57	1	16.67	9	69.23	4	50.00	9	64.29	6	42.86	5	62.50	10	50.00

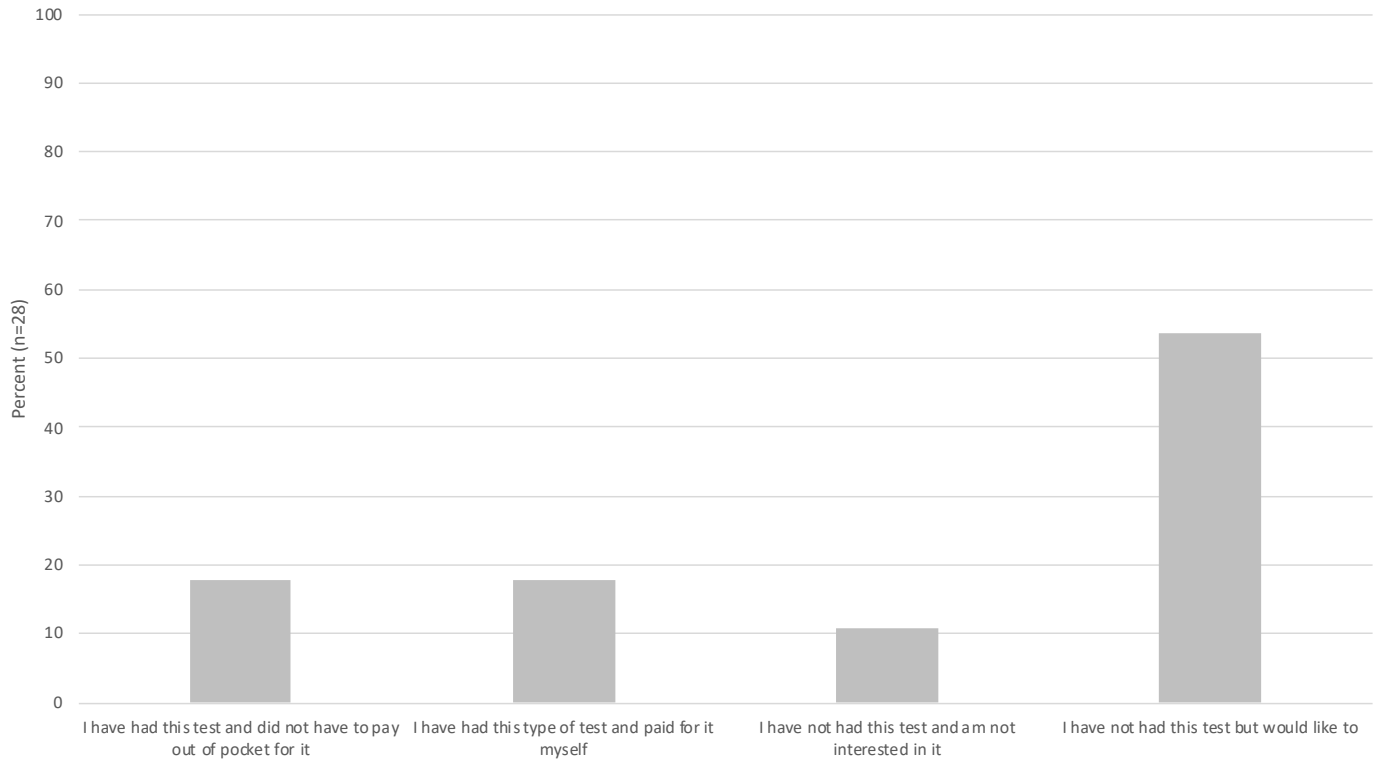


Figure 3.20: Experience of genetic tests and biomarkers

Specific biomarkers or genetic markers

For the final question about biomarkers, participants were asked about specific biomarkers that they had that are relevant to amyloidosis. Participants could choose biomarkers from a list, and specify other biomarkers not listed.

The majority of participants were not sure if they had specific biomarkers (n=15, 53.57%), there were five that stated they had no biomarkers (17.86%), and eight that were able to name specific markers that they had (Table 3.21, Figure 3.21).

Table 3.21: Specific biomarkers or genetic markers

Specific biomarkers	Number (n=18)	Percent
Not sure	15	53.57
I do not have any markers	5	17.86
Named marker	8	28.57

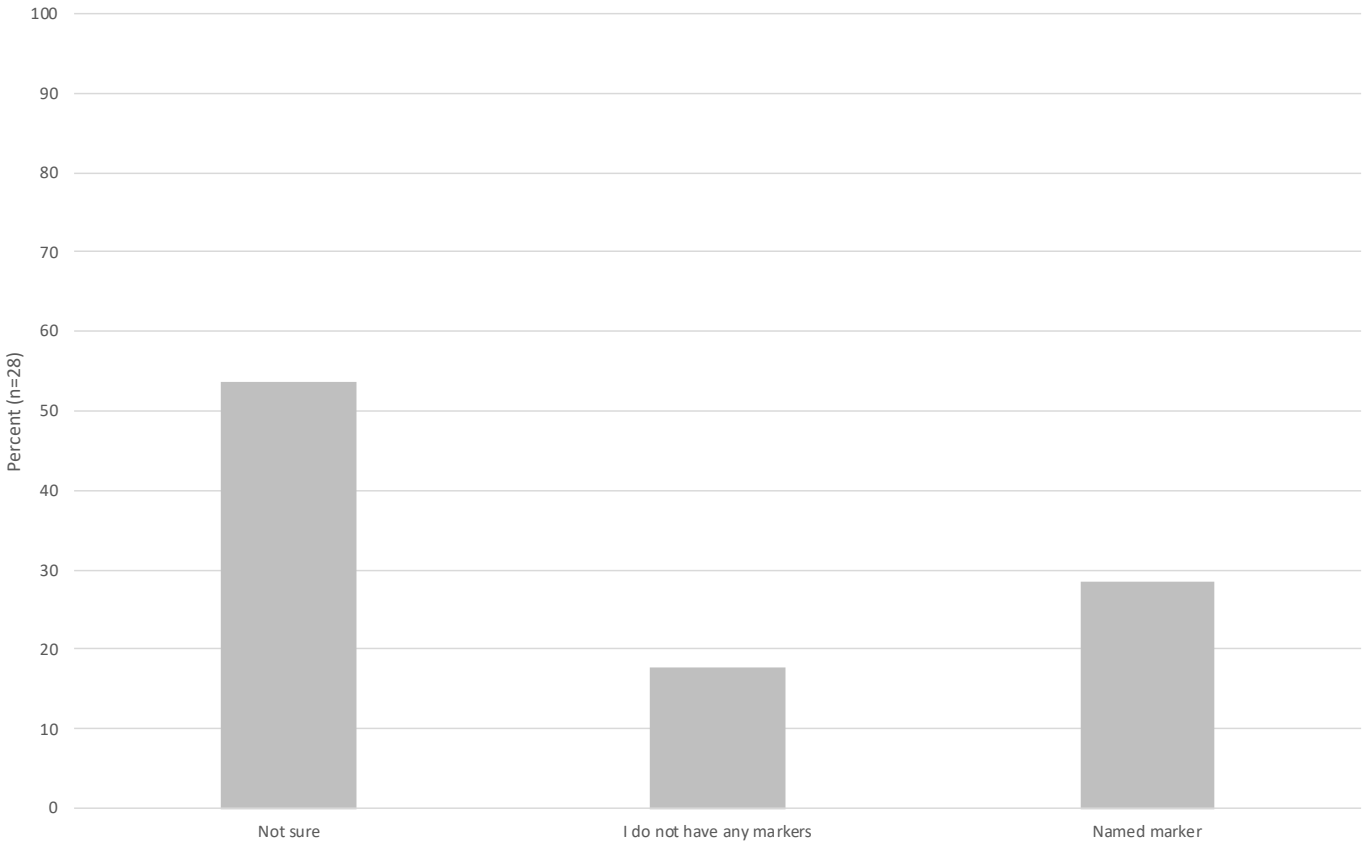


Figure 3.21: Specific biomarkers or genetic markers

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. There were 15 participants (41.67%) that described that they had a discussion about prognosis, and there were 14 participants (38.89%) did not mention having discussions about prognosis.

Overall, 18 participants (50.00%) described having a clear understanding of their prognosis and 11 described having an unclear understanding (30.56%).

There were two main themes that were equally reported, including participants describing their prognosis in relation to the specific medical interventions they need to manage their condition (n=9, 25.00%) and relating their prognosis to a specific timeframe that they are expected to live (n=9, 25.00%). There were eight participants (22.22%) that described their prognosis in relation to poor outcomes or as a terminal condition and five participants (13.89%) that understood their prognosis as positive and their condition as manageable.

In relation to subgroup variations, participants in the AL amyloidosis subgroup described having discussions about prognosis less frequently (30.00%) than the general population (41.67%), while those in *Regional or remote* (55.56%), and *Mid to low SEIFA* (54.55%) subgroups described this more frequently.

Participants in the *Carer* (25.00%), *Female* (21.43%), *Aged 55 to 64* (25.00%), and *Regional or remote* (27.27%) subgroups made no mention of discussions less often than the general population (38.89%), while participants in the *AL amyloidosis* (60.00%), and *Male* (50.00%) made no mention of discussions more often.

In relation to subgroup variations, participants in the *Carer* (25.00%), *Aged 75 or older* (37.50%) and *Female* (35.71%) subgroups described having a clear understanding of their prognosis overall less frequently than the general population (50.00%), whereas participants in the *ATTR-cardiac* (78.57%),

All cardiac (60.00%) and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *AL amyloidosis* (20.00%) and *Mid to low SEIFA* (18.18%) subgroups described having an unclear understanding of their prognosis less frequently than the general population (30.56%), whereas participants in the *ATTR-cardiac* (42.86%) and *Aged 75 or older* (62.50%) subgroups described this more frequently.

In relation to subgroup variations, participants in the *Mid to low SEIFA* subgroup described their prognosis in relation to medical interventions the need to manage their condition less frequently (9.09%) than the general population (25.00%), while those in the and *Aged 75 or older* (37.50%) subgroups described this more frequently.

Participants in the *Carer* (12.50%) and *Female* (7.14%) subgroups described their prognosis in relation to a specific timeframe that they are expected to live less frequently than the general population (25.00%), while those in the *Male* (36.36%), *Aged 75 or older* (37.50%), *University* (35.71%) and *Mid to low SEIFA* (36.36%) subgroups described this more frequently.

Participants in the AL amyloidosis (0.00%) and Higher SEIFA (8.00%) subgroups described their prognosis in relation to poor outcomes or as terminal less frequently than the general population (22.22%), while those in the ATTR-cardiac (33.33%), Aged 55 to 64 (37.50%), Regional or remote (44.44%) and Mid to low SEIFA (54.55%) described this more frequently.

No participants in the *Aged 75 or older* (0.00%) or *Mid to low SEIFA* (0.00%) subgroups described their prognosis as positive and their condition as manageable, compared to the general population (13.89%).

Participants in the *Carer* (25.00%), *Aged 75 or older* (37.50%) and *Female* (35.71%) subgroups described having a clear understanding of their prognosis overall less frequently than the general population (50.00%), whereas participants in the *ATTR-cardiac* (78.57%), *All cardiac* (60.00%) and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *AL amyloidosis* (20.00%) and *Mid to low SEIFA* (18.18%) subgroups described having an unclear understanding of their prognosis less frequently than the general population (30.56%), whereas participants in the *ATTR-cardiac* (42.86%) and *75 or older* (62.50%) subgroups described this more frequently.

Clear understanding of prognosis (Total)

The technician told me that, that was in 27th of July, '17. I said, 'I must have had very good medication, or my bone density must have been really good to start with, so there had been no effect on that.' Up until that last year until December when the light chain stated to go out of sync again. What then happened was that I've had monthly light chain tests and the full blood count, everything else is perfectly normal except for the light chains were out of balance, and it was decided that as the difference got to about 42 to 46 between the kappa and the lambdas, I decided that I should go on to ixazomib or Ninlaro, that's the same thing. They will start as soon as they can get the medication, the medication has been approved by the company, and it's must be on compassionate grounds because I won't have to pay for it. Participant 003AL

I think pretty good. I think it's pretty good, the treatment has got the light chain down to just a little bit above normal, the high range of normal. It's gone from being through the roof down to high range normal. All that means is that there's less stuff now sticking to different organs and my body failure. Participant 004ATR

They say that I am in haematological remission which means my light chains have stayed down and that's over a year since I finished my chemotherapy. Participant 012ATR

Unclear understanding of prognosis (Total)

No, I've no idea…I haven't really discussed it, I don't know. I guess if my congestive heart failure is managed then it may be reasonable. I was actually relieved that I didn't have AL, because that, to me, is pretty much like going down the path of multiple myeloma. Participant 001ATR

Now at this particular point in time, it's really hard because last time he saw NAME CLINICIAN, there was no proteins in the blood. It's been traced for a little while. We've managed to get it right down and keep it down. As far as his prognosis and how

it's all going to play out, I have no idea. Participant 003CA

No, not really. My local GP says, 'Look, just forget about it. I wouldn't worry about it.' I'm not having any treatment except the ophthalmologist checks me every probably six weeks to see how the eye is going. Participant 010ATR

What our understanding was, we were told then and there that it was terminal. That's what we were told…They did tell us at one stage that they thought that he had 12 to 18 months at that stage to live. As you can imagine we were rocketed. We didn't know what this was, we had no idea. Participant 004CA

I had to go to the docs or hospital to get into their book so that I could then use their pharmacy to get to doctors and all the medication. Literally, I was seeing him first thing Monday morning, 9:00 AM, first patient. I asked him, 'What is my outlook? How long have I got basically?' He said, 'Well, three years, that's it', which came as a bit of a shock. Participant 011ATR

From, again, the initial discussions with the team at the university clinic, from where we are now at my age, I've probably got about another 10 years. Of that 10 years, probably about six or seven of them will be useful. By useful I mean, I will actually be able to do things before I end up housebound or chair bound because I won't be able to do things. So, 10 years and so from now, seven years useful. Participant 015ATR

Prognosis related to poor outcomes or terminal condition

It's a fatal but slow disease. There could be more but I'm aware that there's 29 types of amyloidosis. I don't know if that's part of the hereditary AL or AA altogether, but the AL amyloidosis, and I think AA is a bit much quicker. For AL, if you're not diagnosed, get treatment, chemo and drugs within a year, your chances of living are very poor, and even if you do, your chances are very poor but this hATTR-V and N, N is the mutant type, it's much slower, but it's still fatal and there's still no cure. Participant 005CA

Yes. It's not very good. When you read about it. Well, when I went to say I had this stress test, the specialist said, 'Probably, there's no cure for it. You might only have a couple of months.' He wasn't very-- I was a bit disappointed with his attitude. That's the way some of them are. They're going to be straight to the point and let you know what's happening I supposed. Participant 014ATR

My treatment was in 2015. I'm five years down the track now. From my own perspective, I think that it won't flare up again, I guess, and that I'll have some heart failure or stroke. The last year, I had stents put in, and my heart efficiency was pretty low. It's only about 50% now. My kidneys are about 28%. They've been down to 18. I guess if it flares up again, it's going to be much harder next time to get through it. I don't think I'm going to die an old age, if that's what you mean. I think it's not going to be good. Participant 017ATR

Prognosis is positive: Condition manageable with treatment

It is. I feel it's great news at this point in time. My treatment has been carfilzomib plus dexamethasone. The holiday from that, because the vectors are stable, is good, but also because of side effects, I don't have to deal with them, is also very good. At the moment, life is good. Because my haemoglobin levels are up just inside the normal level at 120 or 125 or whatever it is, right on the lower threshold, life's a lot better. Participant 004AL

I think pretty good. I think it's pretty good, the treatment has got the light chain down to just a little bit above normal, the high range of normal. It's gone from being through the roof down to high range normal. All that means is that there's less stuff now sticking to different organs and my body failure. Participant 004ATR

My understanding is that you can get it under control and into the ordinary category of being prone to any one of the other conditions that affect the whole boat. Participant 006AL

Table 3.22: Understanding of prognosis: Discussion had

Understanding of prognosis: Discussion had	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 had discussion about prognosis	15	41.67	9	50.00	10	40.00	3	30.00	3	37.50	9	40.91	6	42.86	5	55.56	10	37.04
Participant made no mention of whether they discussed their prognosis	14	38.89	6	33.33	11	44.00	6	60.00	2	25.00	11	50.00	3	21.43	3	33.33	11	40.74
Other or unclear	5	13.89	1	5.56	2	8.00	1	10.00	3	37.50	2	9.09	3	21.43	1	11.11	4	14.81
Participant describes having no discussion about prognosis	2	5.56	2	11.11	2	8.00	0	0.00	0	0.00	0	0.00	2	14.29	0	0.00	2	7.41

Understanding of prognosis: Discussion had	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 had discussion about prognosis	15	41.67	4	50.00	7	36.84	4	50.00	6	42.86	6	42.86	6	54.55	9	36.00
Participant made no mention of whether they discussed their prognosis	14	38.89	2	25.00	8	42.11	3	37.50	5	35.71	7	50.00	3	27.27	11	44.00
Other or unclear	5	13.89	2	25.00	3	15.79	0	0.00	1	7.14	1	7.14	2	18.18	3	12.00
Participant describes having no discussion about prognosis	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	0	0.00	2	8.00

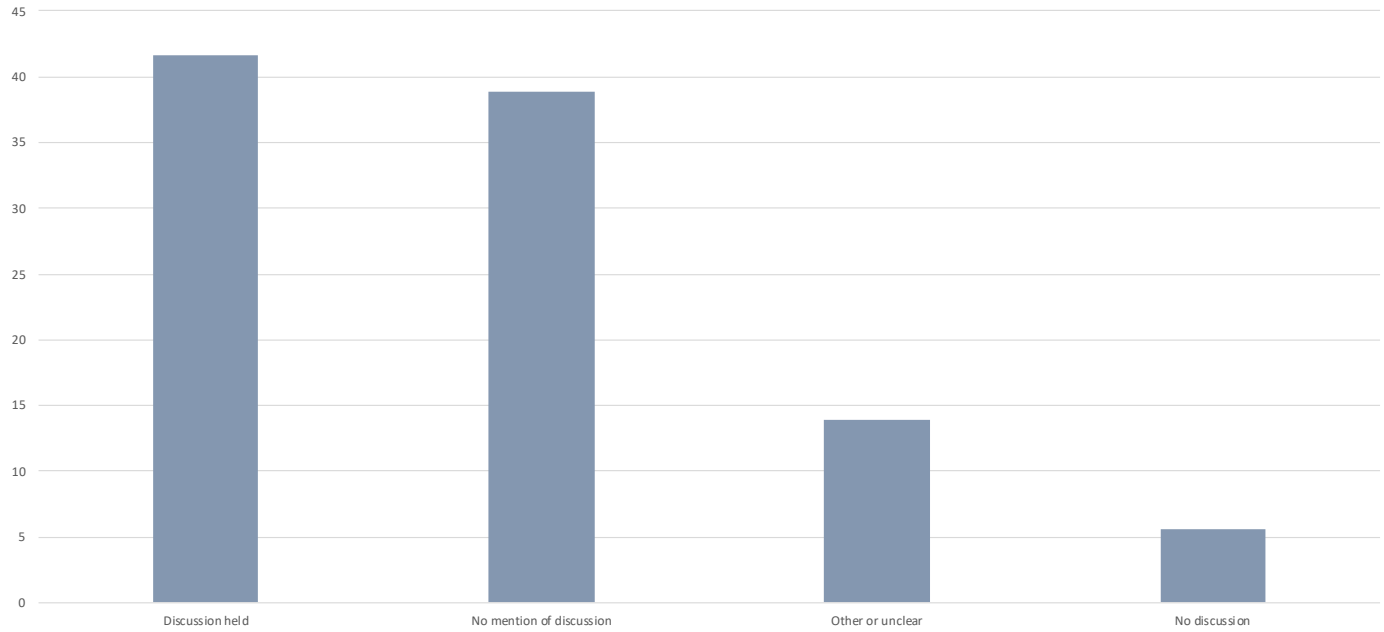


Figure 3.22: Understanding of prognosis: Discussion had

Table 2.23: Understanding of prognosis: Clear or unclear understanding

Understanding of prognosis: Clear or unclear understanding	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 having a discussion about prognosis and they have a clear understanding	9	25.00	5	27.78	6	24.00	2	20.00	2	25.00	4	18.18	5	35.71	3	33.33	5	20.00
Participant does not mention any discussion about their prognosis, but has a clear understanding	9	25.00	6	33.33	9	36.00	3	30.00	0	0.00	9	40.91	0	0.00	2	22.22	6	24.00
Participant describes having a discussion about prognosis but still has an unclear understanding and/or would like further discussions	6	16.67	4	22.22	4	16.00	1	10.00	1	12.50	5	22.73	1	7.14	2	22.22	4	16.00
Participant does not mention any discussion about their prognosis, and has an unclear understanding	3	8.33	0	0.00	1	4.00	1	10.00	2	25.00	1	4.55	2	14.29	1	11.11	3	12.00
Participant does not mention any discussion about their prognosis (general)	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	8.00
Participant describes having no discussion about prognosis and they do not have a clear understanding	2	5.56	2	11.11	2	8.00	0	0.00	0	0.00	0	0.00	2	14.29	0	0.00	2	8.00

Understanding of prognosis: Clear or unclear understanding	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 having a discussion about prognosis and they have a clear understanding	9	25.00	3	37.50	5	26.32	1	12.50	3	21.43	4	28.57	4	36.36	5	20.00
Participant does not mention any discussion about their prognosis, but has a clear understanding	9	25.00	1	12.50	5	26.32	2	25.00	5	35.71	4	28.57	3	27.27	6	24.00
Participant describes having a discussion about prognosis but still has an unclear understanding and/or would like further discussions	6	16.67	1	12.50	2	10.53	3	37.50	3	21.43	2	14.29	2	18.18	4	16.00
Participant does not mention any discussion about their prognosis, and has an unclear understanding	3	8.33	1	12.50	1	5.26	1	12.50	0	0.00	1	7.14	0	0.00	3	12.00
Participant does not mention any discussion about their prognosis (general)	2	5.56	0	0.00	2	10.53	0	0.00	0	0.00	2	14.29	0	0.00	2	8.00
Participant describes having no discussion about prognosis and they do not have a clear understanding	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	0	0.00	2	8.00

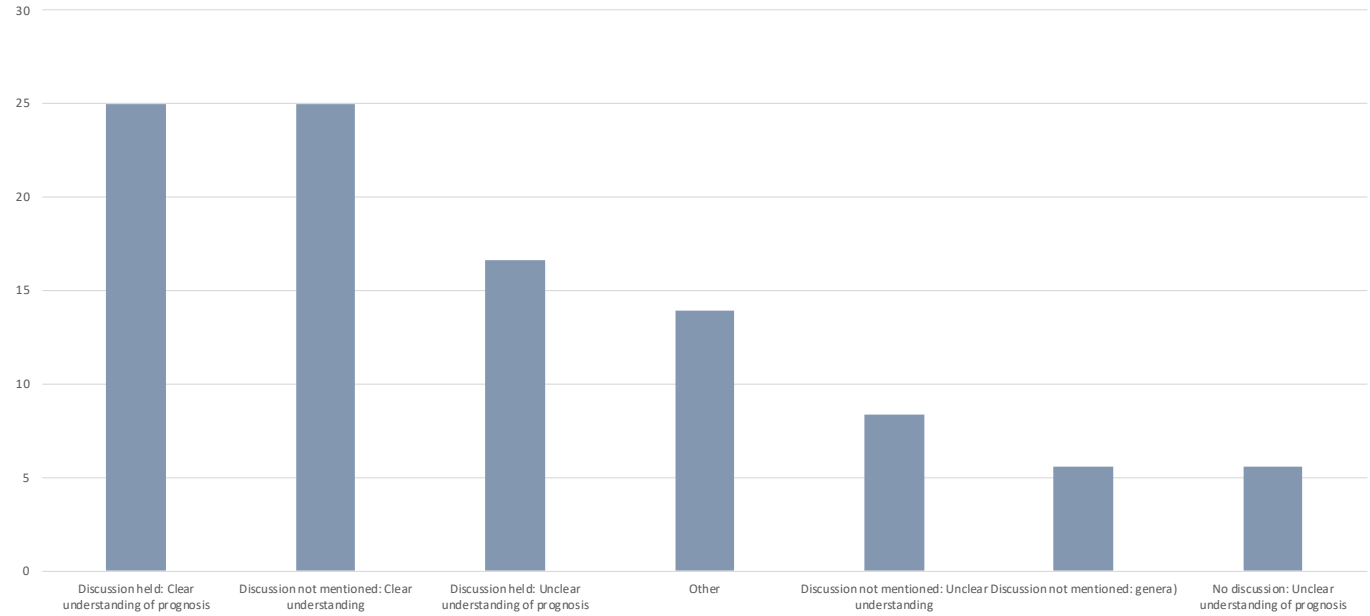


Figure 3.23: Understanding of prognosis: Clear or unclear understanding

Table 2.24: Understanding of prognosis: Specific

Understanding of prognosis: Specific	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 prognosis in relation to the specific medical interventions they need to manage their condition	9	25.00	5	27.78	7	28.00	2	20.00	2	25.00	6	27.27	3	21.43	2	22.22	7	25.93
Participant describes prognosis in relation to a specific timeframe that they are expected to live	9	25.00	6	33.33	8	32.00	2	20.00	1	12.50	8	36.36	1	7.14	2	22.22	7	25.93
Participant describes prognosis in relation to poor outcomes/terminal condition	8	22.22	6	33.33	6	24.00	0	0.00	2	25.00	6	27.27	2	14.29	4	44.44	4	14.81
Participant describes prognosis in relation to it being positive: Condition is manageable	5	13.89	2	11.11	4	16.00	2	20.00	1	12.50	3	13.64	2	14.29	2	22.22	3	11.11
Participant describes prognosis in relation to no evidence of disease or that they are in remission	3	8.33	1	5.56	2	8.00	2	20.00	0	0.00	1	4.55	2	14.29	0	0.00	3	11.11
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	3	8.33	2	11.11	2	8.00	1	10.00	0	0.00	1	4.55	2	14.29	1	11.11	2	7.41

Understanding of prognosis: Specific	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 prognosis in relation to the specific medical interventions they need to manage their condition	9	25.00	2	25.00	3	15.79	3	37.50	3	21.43	4	28.57	1	9.09	8	32.00
Participant describes prognosis in relation to a specific timeframe that they are expected to live	9	25.00	2	25.00	4	21.05	3	37.50	3	21.43	5	35.71	4	36.36	5	20.00
Participant describes prognosis in relation to poor outcomes/terminal condition	8	22.22	3	37.50	3	15.79	2	25.00	3	21.43	3	21.43	6	54.55	2	8.00
Participant describes prognosis in relation to it being positive: Condition is manageable	5	13.89	1	12.50	4	21.05	0	0.00	3	21.43	1	7.14	0	0.00	5	20.00
Participant describes prognosis in relation to no evidence of disease or that they are in remission	3	8.33	0	0.00	3	15.79	0	0.00	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	3	8.33	0	0.00	0	0.00	3	37.50	2	14.29	1	7.14	1	9.09	2	8.00

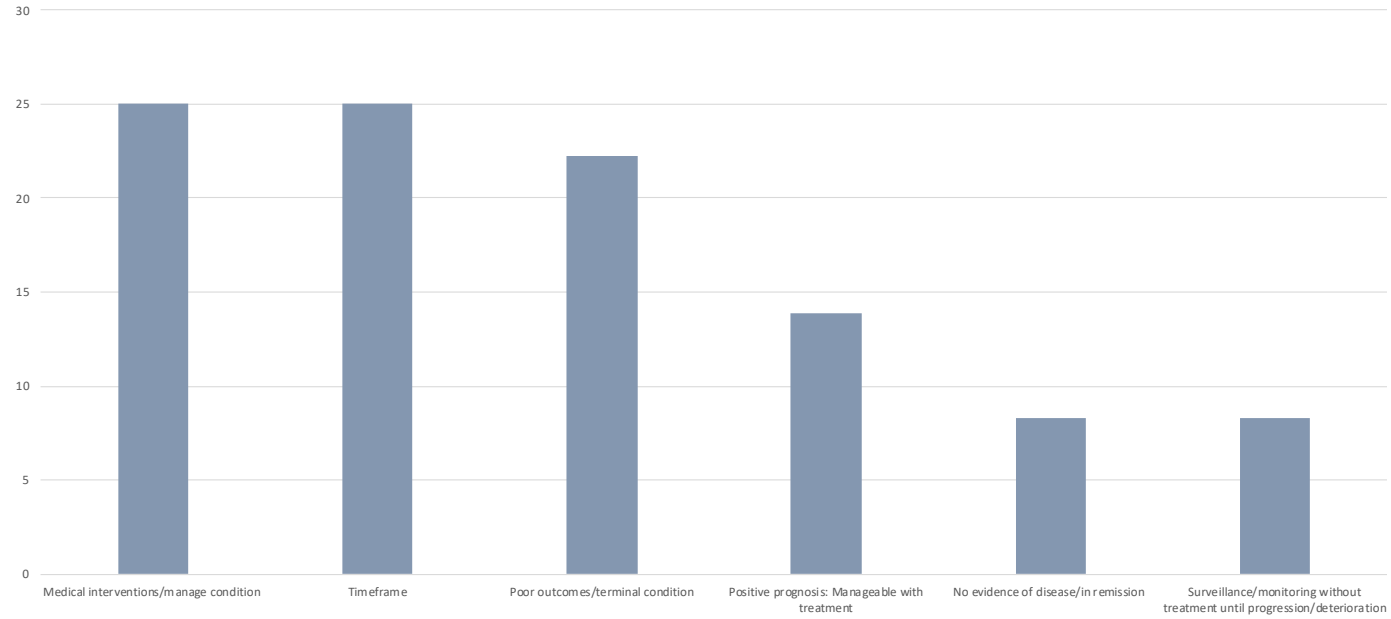


Figure 3.24: Understanding of prognosis: Specific