Section 9 Expectations and messages

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

Expectations of future treatments

- The most common theme described by participants was that cost was an important consideration in relation to future treatments (n=18, 36.00%). This was followed by the need for effective treatments for mitochondrial disease, where participants may have also noted that there are no or limited treatments available (n=16. 36.00%). There were seven participants (14.00%) that described the need for clinical trials in mitochondrial disease and six participants (12.00%) that described the need for treatments that reduce muscle fatigue/improve muscle strength.
- In relation to sub-group variations, participants from low socio-economic areas (52.17%) described cost as a consideration more frequently than the general population (36.00%), while those from high socio-economic areas (25.93%) reported this less frequently. Participants from metropolitan areas (46.67%) and those with low emotional well-being (45.83%) reported the need for effective treatments for mitochondrial disease, more frequently than the general population (32.00%), while those from rural areas (15.00%) reported this less frequently.
- 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 were tiredness and fatigue, muscle symptoms and nervous system symptoms; the least important were underactive thyroid or parathyroid, and excess body hair.
- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were safety of treatment/weighing up risks and benefits, and severity of side effects. The least important were ability to stick to treatment, and including family in decision-making.
- 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 patient,s and access for all patients to all treatments and services; the least important was economic value to government.

Expectation of future information provision

- The most common theme was that participants described being satisfied with current information and therefore had no recommendation (n=11, 22.00%). There were nine participants (18.00%) that described the need for information about their specific type of mitochondrial disease, and nine participants (18.00%) that described the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information. There were also six participants (12.00%) that described the need for centralised and reliable information.
- In relation to sub-group variations, participants with high general health (31.82%) described the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information), more frequently than the general population (18.00%).

Expectation of future healthcare professional communication

- The most common theme was that participants recommend healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition (n=16, 32.00%). This was followed by the recommendation that healthcare professionals are more proactive and attentive (n=9, 18.00%). There were also nine participants (18.00%) that did not have a recommendation as they have been satisfied with communication. Where participants were satisfied with communication it was primarily because communication had been open communication. There were seven participants (14.00%) that recommended that healthcare professionals need to have more empathy.
- In relation to sub-group variations, participants from rural areas (45.00%) and those from low socio-economic areas (43.48%) recommended healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition, more frequently than the general population (32.00%).

Expectation of future care and support

- The most common recommendation was for centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) (n=13, 26.00%). In a similar theme, there were also six participants (12.00%) that recommended caseworkers be employed to support patients navigate health, medical and emotional needs. This was followed by the recommendation for support groups to help patients noting that it is difficult due to the diversity within the patient population (n=7, 14.00%) and more equity in access to services and support for adults with rare disease (n=7, 14.00%).
- In relation to sub-group variations, participants with a university education (50.00%) and those with a hearing impairment (45.83%) recommended centralised and coordinated care across specialists and allied health professionals, more frequently than the general population (26.00%), while those with a high school or trade education (3.85%) recommended this less frequently.

What participants are grateful for in the Australian health system

- The most common theme was participants describing being grateful for Medicare in relation to access to specialists (n=17, 34.00%), followed by being grateful for the compassion and support shown by healthcare professionals (n=16, 32.00%). There were 10 participants (20.00%) that described being grateful for Medicare in relation to access to allied health professionals and seven participants (14.00%) described being grateful for their healthcare card and the financial relief it provides. Other aspects of the health system that participants spoke about being grateful for were subsidised diagnostic tests (n=6, 12.00%), government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services) (n=6, 12.00%) and the quality of specialist expertise in Australia (n=5, 10.00%).
- In relation to sub-group variations, participants from rural areas (45.00%) described being grateful for Medicare (Access to specialists) more frequently than the general population (34.00%). Participants with a university education (45.83%), those with high physical function (54.55%), and those with high general health (50.00%) reported being grateful for the compassion and support shown by healthcare professionals more frequently than the general population (32.00%), while those with low physical function (17.86%) reported this less frequently. Participants from rural areas (25.00%), those with a hearing impairment (25.00%) and those with low physical function (25.00%) described being grateful for their healthcare card and the financial relief it provides, more frequently than the general population (14.00%), while there we no participants with high physical function (0.00%) that reported this.

Messages

- The most common message is to support more research (n=20, 40.00%), however this was a general statement with no specific area noted. The next most common theme was to provide more education to the healthcare professionals, particularly education about managing the condition (n=15, 30.00%), and this was followed by the message to increase awareness of mitochondrial disease among the community (n=12, 24.00%). There were 12 participants (24.00%) whose message is to provide more holistic and multidisciplinary/allied health care, and eight participants (16.00%) whose message is to improve treatments by following the example of other countries that have more advanced systems.
- In relation to sub-group variations, participants from rural areas (55.00%) called for more research more frequently than the general population (40.00%). Participants with a hearing impairment (41.67%) had the message to provide more education to the healthcare professionals, more frequently than the general population (30.00%). Participants with a university education (12.50%) called for more awareness less frequently than the general population (24.00%). Participants with a university education (33.33%) and those with a hearing impairment (37.50%) had the message to support more funding (in general), more frequently than the general population (22.00%), while those with a high school or trade education reported this less frequently (11.54%). Participants with high physical function (13.64%) had the message to provide more holistic and multidisciplinary/allied health care less frequently than the general population (24.00%).

Expectations of future treatment

Participants were asked a series of questions about their expectations for future treatments, information, health professional communication, and care and support.

When asked about their expectations of future treatment, there were a number of themes that emerged. The most common theme described by participants was that cost was an important consideration in relation to future treatments (n=18, 36.00%).

Participant describes cost as a consideration in access to treatments

Lending more information of what treatment help people and cost is a big one because some of my medication is not on the PBS so it's expensive. Participant 19

Cost is a huge one. Recently, I had to go to the bank and through the financial assistance because I'd just hit a wall. The amount that I get in remuneration is about a third of what my salary was. I've never been good with money and I'd hit a wall.. Participant 20

Hopefully, some extra treatments. Hopefully, they're not too expensive for us. That chronic comes into play pretty much. Participant 22

Well, the cost is very steep. We're outlaid few thousand dollars already. We try not to outlay any more money. [laughs] Participant 35

It would be good if all treatments were on the PBS. I take a very high dose coenzyme Q10 and it does cost. If I could get it through PBS, it would be cheaper and for my son as well. Participant 43

This was followed by the need for effective treatments for mitochondrial disease, where participants may have also noted that there are no or limited treatments available (n=16. 36.00%).

Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)

Any treatment for mito would be great. For LHON, there are two main types of treatment, both of which are still in clinical trials. There's the idebenone program (vitamins), which is available on a very limited basis in Australia, and gene therapy trials, available only overseas. The latter may be promising but it's too expensive and laborious to take part in. Bringing trials to Aus would be incredible, as would getting past trial stage. Participant 8

I'll just like to see that new treatments are actually...have got good evidence behind them and not being rushed through. Seems to be a lot of new treatments suddenly emerging on the market, which just the evidence could be quite questionable and really the effectiveness is quite questionable too, and even the way the trials are run are quite questionable. I'd like to see the same standard applied to trials and stuff for and treatments for mitochondrial disease as would be set for general population. Participant 13

There were seven participants (14.00%) that described the need for clinical trials in mitochondrial disease and six participants (12.00%) that described the need for treatments that reduce muscle fatigue/improve muscle strength.

Participant describes the need for clinical trials in mitochondrial disease

I'll just like to see that new treatments are actually...have got good evidence behind them and not being rushed through. Seems to be a lot of new treatments suddenly emerging on the market, which just the evidence could be quite questionable and really the effectiveness is quite questionable too, and even the way the trials are run are quite questionable. I'd like to see the same standard applied to trials and stuff for and treatments for mitochondrial disease as would be set for general population. Participant 13

Well, I'd like to see more research done into it. I realize there is some research but it all seems to be more for the younger people, not when you're being diagnosed as an adult. I don't know. Just don't know what to say there. Participant 31

Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength

That is...My biggest is moving again. Not so unbalanced and we used to play fully for a long time. They're doing that now. Kind of run. Participant 6

If they had some treatment that would make my muscles not so tired then that would be the main thing. Participant 10

For me personally, if there was a medication to help me get over my fatigue and reduce that lactic acid so that I could live a bit better and do the things that I'd like to do, yeah. Anything that can do stuff like that would be fantastic. Participant 15

In relation to sub-group variations, participants from low socio-economic areas (52.17%) described cost as a consideration more frequently than the general population (36.00%), while those from high socio-economic areas (25.93%) reported this less frequently. Participants from metropolitan areas (46.67%) and those with low emotional well-being (45.83%) reported the need for effective treatments for mitochondrial disease, more frequently than the general population (32.00%), while those from rural areas (15.00%) reported this less frequently.

Table 9.1: Expectations of future treatment

Expectations of future treatments	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant describes cost as a consideration in access to treatments	18	36.00	11	36.67	8	40.00	7	**25.93**	12	**52.17**
Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)	16	32.00	14	**46.67**	3	**15.00**	9	33.33	8	34.78
Participant describes the need for clinical trials in mitochondrial disease	7	14.00	4	13.33	3	15.00	4	14.81	3	13.04
Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength	6	12.00	4	13.33	2	10.00	3	11.11	3	13.04
Participant describes not being sure because they haven't had any treatments to compare to	5	10.00	2	6.67	3	15.00	4	14.81	1	4.35
Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)	5	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease	5	10.00	3	10.00	2	10.00	2	7.41	3	13.04
Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms	5	10.00	5	16.67	0	0.00	4	14.81	1	4.35

Expectations of future treatments	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant describes cost as a consideration in access to treatments	18	36.00	11	42.31	8	33.33	9	37.50	13	38.24
Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)	16	32.00	7	26.92	10	41.67	9	37.50	9	26.47
Participant describes the need for clinical trials in mitochondrial disease	7	14.00	5	19.23	2	8.33	3	12.50	4	11.76
Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength	6	12.00	3	11.54	3	12.50	2	8.33	5	14.71
Participant describes not being sure because they haven't had any treatments to compare to	5	10.00	3	11.54	2	8.33	1	4.17	4	11.76
Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)	5	10.00	4	15.38	1	4.17	2	8.33	4	11.76
Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease	5	10.00	3	11.54	2	8.33	2	8.33	5	14.71
Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms	5	10.00	2	7.69	3	12.50	2	8.33	2	5.88

Expectations of future treatments	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant describes cost as a consideration in access to treatments	18	36.00	10	45.45	9	32.14	10	38.46	9	37.50
Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)	16	32.00	9	40.91	8	28.57	6	23.08	11	45.83
Participant describes the need for clinical trials in mitochondrial disease	7	14.00	4	18.18	3	10.71	5	19.23	2	8.33
Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength	6	12.00	3	13.64	3	10.71	4	15.38	2	8.33
Participant describes not being sure because they haven't had any treatments to compare to	5	10.00	1	4.55	4	14.29	1	3.85	4	16.67
Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)	5	10.00	2	9.09	3	10.71	3	11.54	2	8.33
Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease	5	10.00	3	13.64	2	7.14	3	11.54	2	8.33
Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms	5	10.00	2	9.09	3	10.71	3	11.54	2	8.33

Expectations of future treatments	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant describes cost as a consideration in access to treatments	18	36.00	6	30.00	13	43.33	8	36.36	11	39.29
Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)	16	32.00	6	30.00	11	36.67	9	40.91	8	28.57
Participant describes the need for clinical trials in mitochondrial disease	7	14.00	4	20.00	3	10.00	5	22.73	2	7.14
Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength	6	12.00	4	20.00	2	6.67	4	18.18	2	7.14
Participant describes not being sure because they haven't had any treatments to compare to	5	10.00	1	5.00	4	13.33	1	4.55	4	14.29
Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14
Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14
Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms	5	10.00	3	15.00	2	6.67	4	18.18	1	3.57

Expectations of future treatments	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant describes cost as a consideration in access to treatments	18	36.00	4	66.67	7	50.00	1	11.11	4	36.36	3	30.00
Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available)	16	32.00	4	66.67	6	42.86	3	33.33	1	9.09	3	30.00
Participant describes the need for clinical trials in mitochondrial disease	7	14.00	0	0.00	2	14.29	2	22.22	2	18.18	1	10.00
Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength	6	12.00	0	0.00	2	14.29	2	22.22	0	0.00	2	20.00
Participant describes not being sure because they haven't had any treatments to compare to	5	10.00	0	0.00	1	7.14	0	0.00	4	36.36	0	0.00
Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)	5	10.00	0	0.00	0	0.00	2	22.22	2	18.18	1	10.00
Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease	5	10.00	0	0.00	3	21.43	0	0.00	1	9.09	1	10.00
Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms	5	10.00	1	16.67	2	14.29	1	11.11	0	0.00	1	10.00

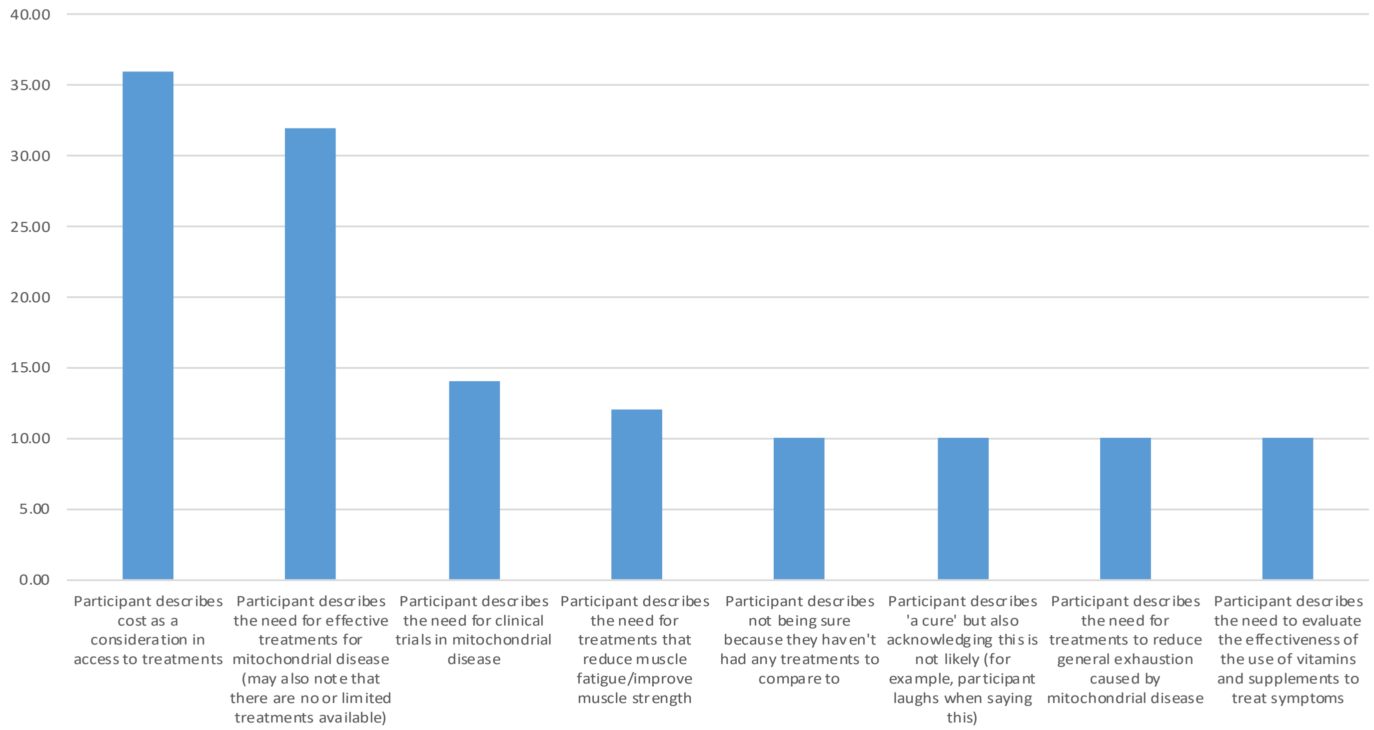

Figure 9.1: Expectations of future treatment (% of all participants)

Values when making decisions about treatment

Symptoms/aspects of quality of life important for treatments

Participants were asked about the value of access to treatments that reduce symptoms and improve quality of life even if they do not offer a cure. The majority of participants thought that it would be of very significant or significant value (n=44, 88.00%),five participants (10.00%) felt it would be of moderate or some value, and 1 participants (2.00%) felt it would be of or no value.

Table 9.2: Value of treatment to improve symptoms and quality of life

Value of access to treatment that reduces symptoms, improves quality of life but may not offer cure	N=50	Percentage of participants
No value at all to me	1	2.00
Some value to me	2	4.00
Moderate value to me	3	6.00
Significant value to me	7	14.00
Very significant value to me	37	74.00

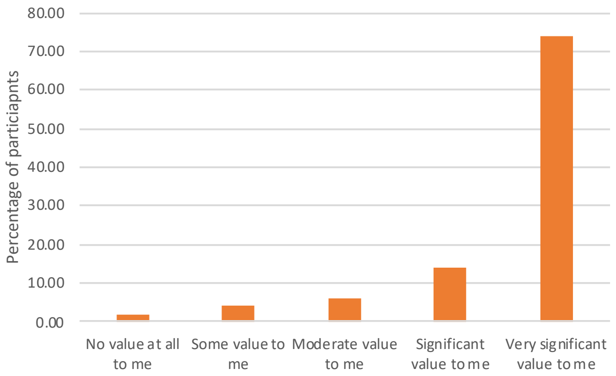

Figure 9.2: Value of treatment to improve symptoms and quality of life

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 12 is the least important. A weighted average is presented in Figure 9.3. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported were tiredness and fatigue, muscle symptoms, and nervous system symptoms; the least important were underactive thyroid or parathyroid, and excess body hair. Figures 9.4 to 9.12 show the weighted rank by general health, physical functioning, emotional well-being, social functioning, hearing problems, eye problems, location, education and SEIFA, the symptoms and aspects of quality of life are similar within sub groups and follow much the same pattern as the entire cohort.

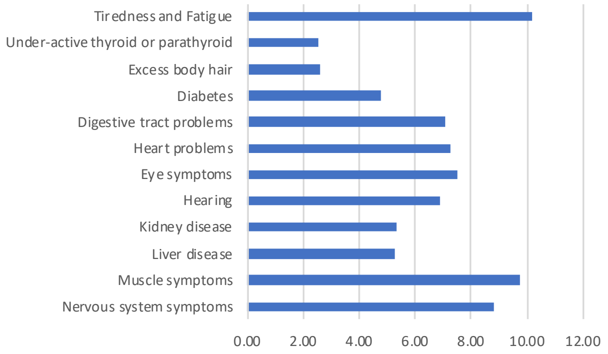

Figure 9.3: Symptoms/aspects of quality of life important for treatments all participants

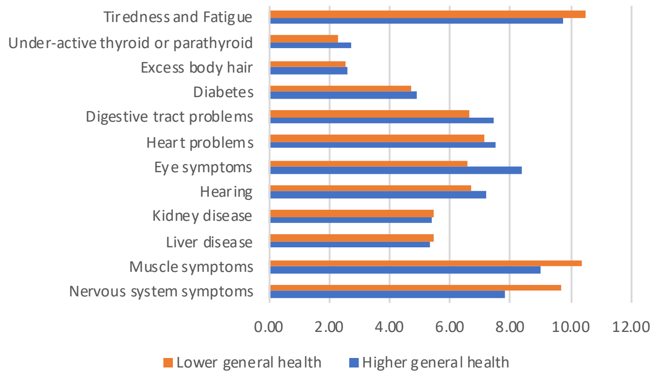

Figure 9.4: Symptoms/aspects of quality of life important for treatments by general health

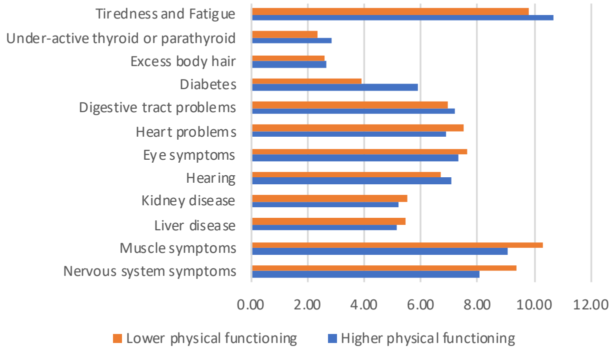

Figure 9.5: Symptoms/aspects of quality of life important for treatments by physical functioning

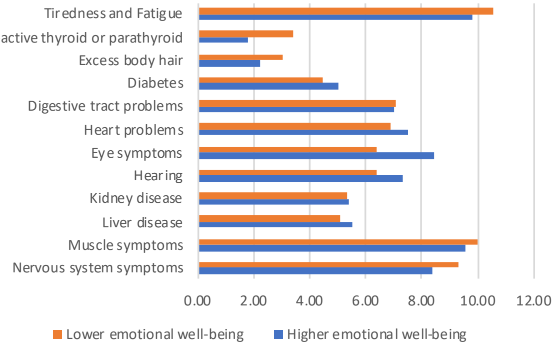

Figure 9.6: Symptoms/aspects of quality of life important for treatments by emotional well-being

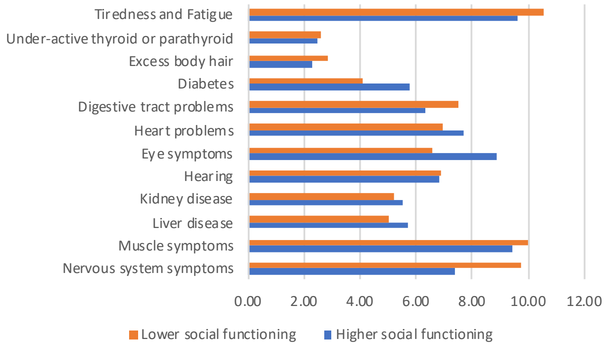

Figure 9.7: Symptoms/aspects of quality of life important for treatments by social functioning

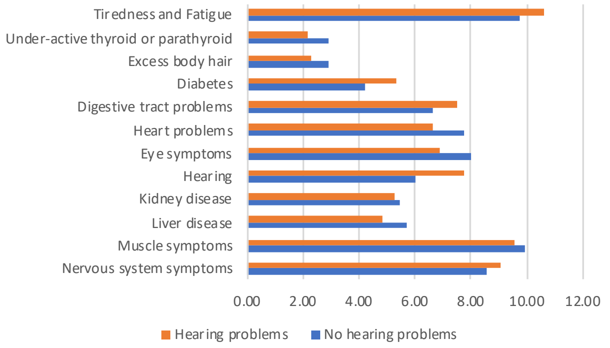

Figure 9.8: Symptoms/aspects of quality of life important for treatments by hearing problems

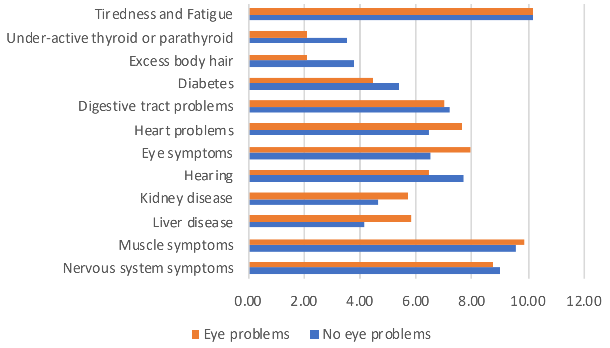

Figure 9.9: Symptoms/aspects of quality of life important for treatments by eye problems

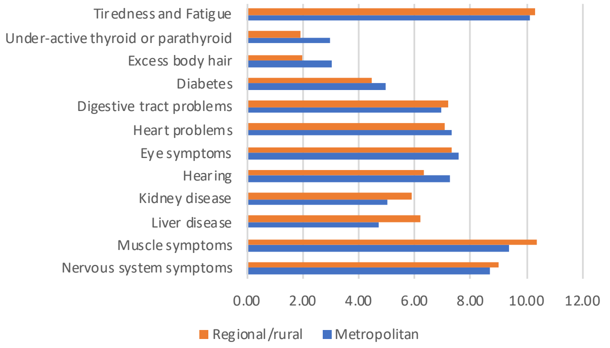

Figure 9.10: Symptoms/aspects of quality of life important for treatments by location

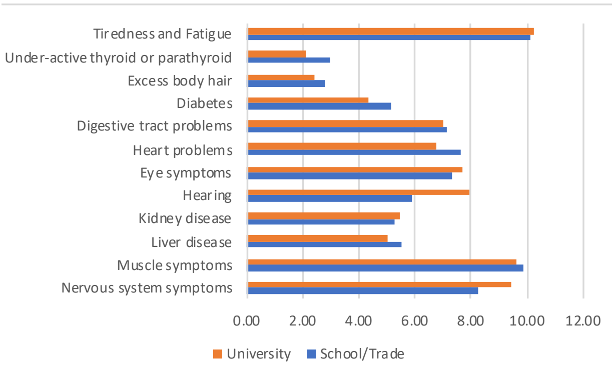

Figure 9.11: Symptoms/aspects of quality of life important for treatments by education

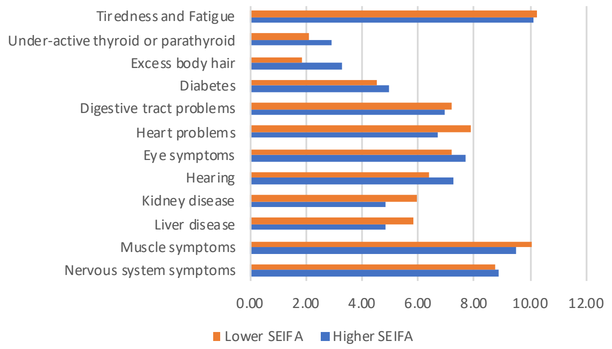

Figure 9.12: Symptoms/aspects of quality of life important for treatments by SEIFA

Values that are important to patients when 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 9.13. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects were safety of treatment/weighing up risks and benefits, and severity of side effects. The least important were ability to follow and stick to a treatment, and including family in decision-making. Figures 9.14 to 9.22 show the weighted rank by general health, physical functioning, emotional well-being, social functioning, hearing problems, eye problems, location, education and SEIFA, the values for making treatment decisions are similar within sub groups and are similar to the overall cohort.

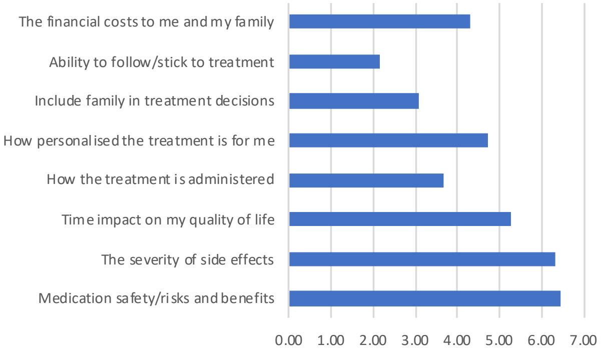

Figure 9.13: Values important when making decisions all participants

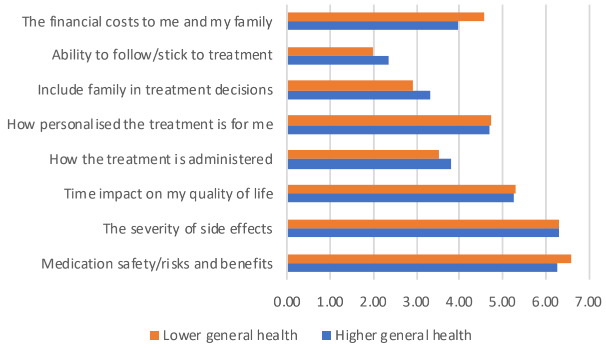

Figure 9.14: Values important when making decisions by general health

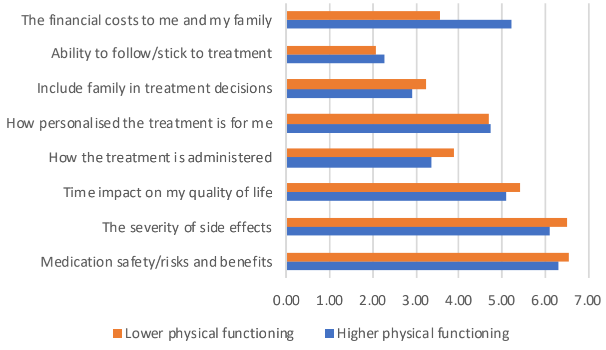

Figure 9.15: Values important when making decisions by physical functioning

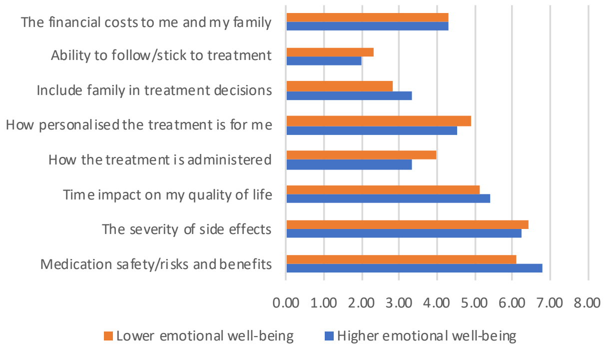

Figure 9.16: Values important when making decisions by emotional well-being

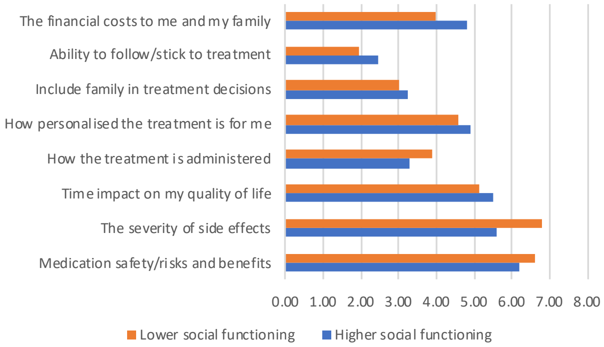

Figure 9.17: Values important when making decisions by social functioning

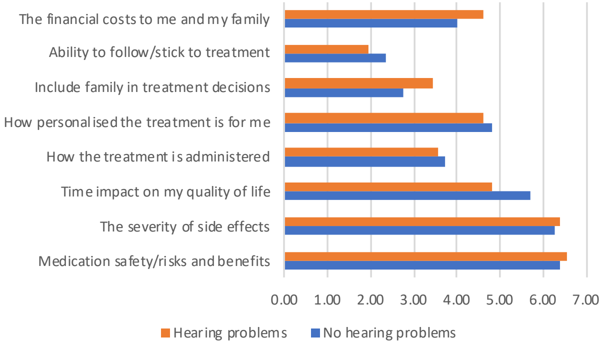

Figure 9.18: Values important when making decisions by hearing problems

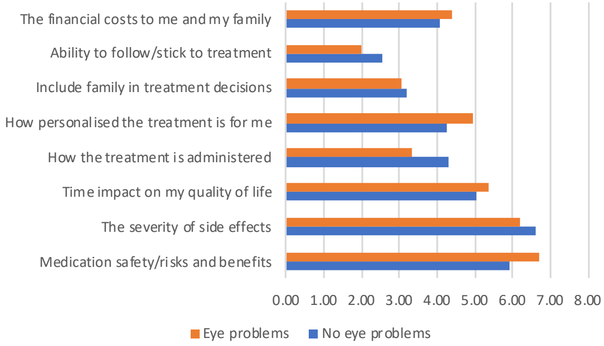

Figure 9.19: Values important when making decisions by eye problems

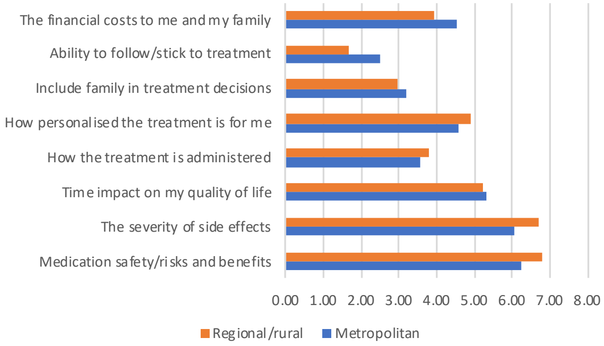

Figure 9.20: Values important when making decisions by location

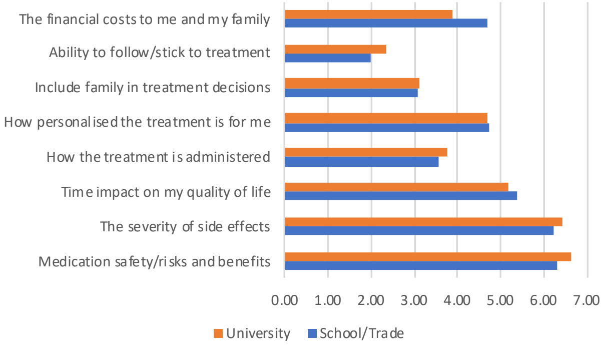

Figure 9.21: Values important when making decisions by education

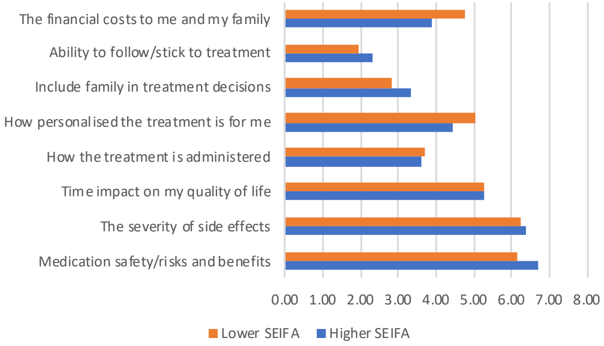

Figure 9.22: Values important when making decisions by SEIFA

Values that are important to patients when others are making decisions on their behalf

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 9.23. 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. Figures 9.24 to 9.32 show the weighted rank by general health, physical functioning, emotional well-being, social functioning, hearing problems, eye problems, location, education and SEIFA, the values for making decisions on their behalf are similar within sub groups and are similar to the overall cohort.

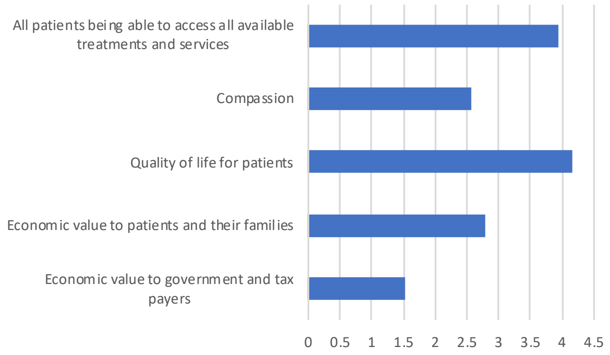

Figure 9.23: Values to consider on behalf of patients/families (weighted rank all participants)

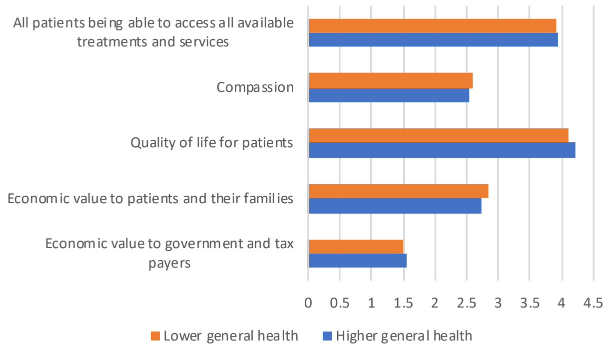

Figure 9.24: Values to consider on behalf of patients/families (weighted rank by general health)

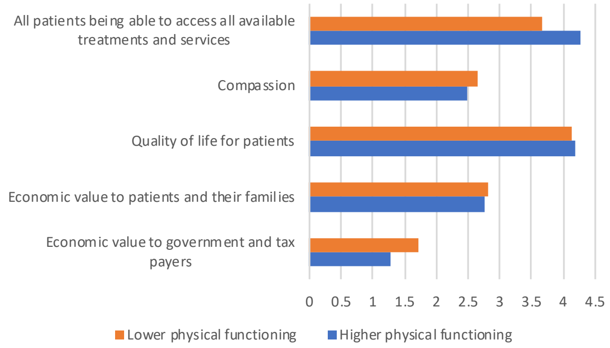

Figure 9.25: Values to consider on behalf of patients/families (weighted rank by physical functioning)

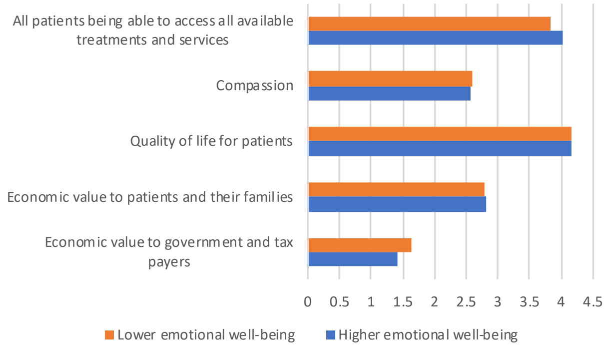

Figure 9.26: Values to consider on behalf of patients/families (weighted rank by emotional well-being)

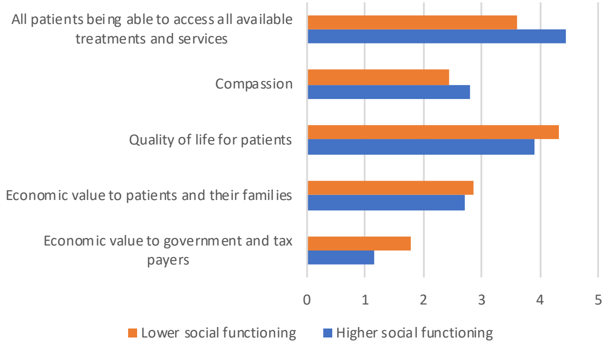

Figure 9.27: Values to consider on behalf of patients/families (weighted rank by social functioning)

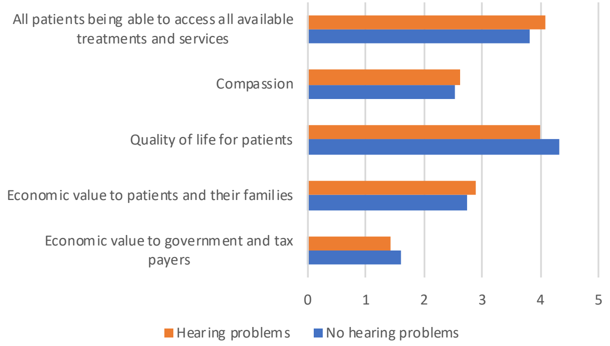

Figure 9.28: Values to consider on behalf of patients/families (weighted rank by hearing problems)

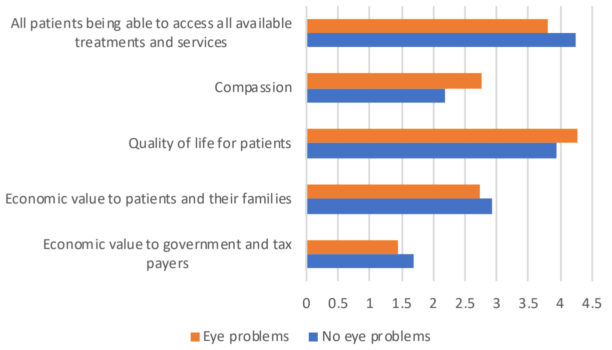

Figure 9.29: Values to consider on behalf of patients/families (weighted rank by eye problems)

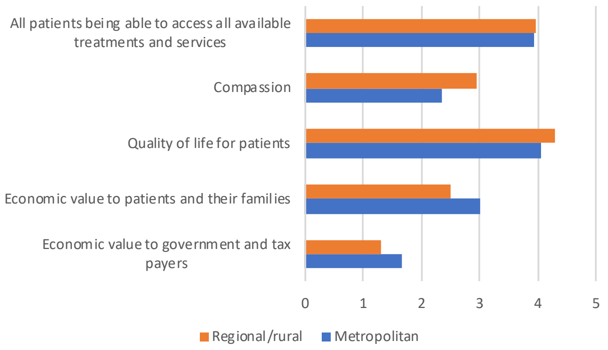

Figure 9.30: Values to consider on behalf of patients/families (weighted rank by location)

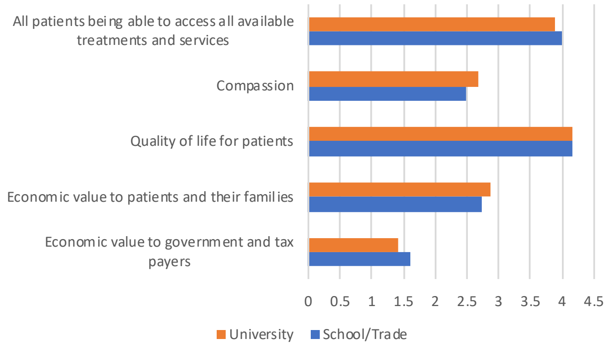

Figure 9.31: Values to consider on behalf of patients/families (weighted rank by education)

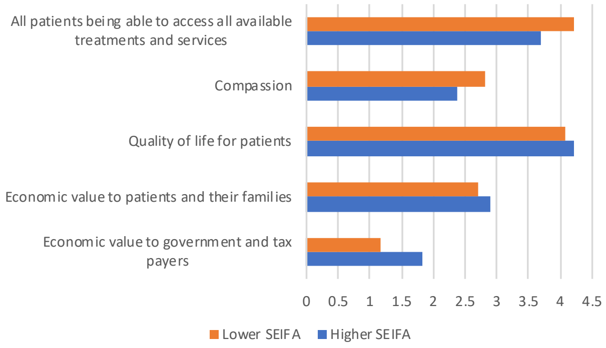

Figure 9.32: Values to consider on behalf of patients/families (weighted rank by SEIFA)

Expectation of information provision

Participants were asked what they would like to see in the future in relation to information provision. The most common theme was that participants described being satisfied with current information and therefore had no recommendation (n=11, 22.00%).

Participant describes being satisfied with current information. No recommendation.

No, I think that AMDF was one of the best examples of explaining a medical condition or a physical condition about the same. I don't think I need more than that. Participant 20

Well, seeing most of ours comes from the internet anyway or from, well, it's still on the emails from the Mitochondrial Foundation. No. Where we're, I don't think….What we've got's suitable. Participant 31

I know everything was...The internet was a great help. Then the AMDF, Australian Mitochondrial Federation has been a great help. They send all the literature in paper form so that was fine. I preferred that than an email. Participant 35

There were nine participants (18.00%) that described the need for information about their specific type of mitochondrial disease, and nine participants (18.00%) that described the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information. There were also six participants (12.00%) that described the need for centralised and reliable information.

Participant describes the need for information about their specific type of mitochondrial disease

I think that map thing I was talking about before would be really useful. Some decision tree type thing online where you go like, "Have you just been diagnosed with mitochondrial disease?" "Yes." Then this is the basic information that you'll need to know. Then breaking it down further, instead of like, "Are you an adult or are you a parent? We'll read this information." Participant 5

I just like to see more on MELAS. There seemed to be lots...I don't know whether this is general, but I know that the Murdoch Institute when they have found stuff they were working on Leigh's disease, which I understand is a huge major thing. Never seems to be anything on MELAS as much. Maybe they've done all there is to know about MELAS. I don't know, but there's nothing ever seem to come up about MELAS. I have the vested interest in. Participant 21

Well, I suppose having a concise…Mitochondrial is so very…some in different strains, but perhaps some streamlining each different one so that you don't have to find out, get all the information about everything about mitochondria, just your specific strain would be the most helpful. Participant 48

Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)

No, not really. Probably something that if it had interested me at the time or I didn't get any information on was having children. I've never wanted to have kids, which turned out to be a really good thing because I wouldn't be able to now anyway seeing that I would pass it on. If I was one of these people that had a raging maternal instinct and really wanted to have babies, that would have been something that should have been discussed when I was being diagnosed. Although, maybe somebody that's not me would have asked. Definitely, I was never asked what my thoughts were about having a family. That's probably something that needs to be talked about a little bit more and about testing, and stuff that maybe can be done before hand to say whether you're going to be passing stuff or not. Participant 10

Well, really and fairly, we don't get a lot of information from the health people or not at all. it's mainly what I read on the internet and whatnot so basically that hasn't changed much. I would like to, like in LOCATION, I'd probably like him to have got back to us like he said he was going to do and things like that and see what actually was in his study, any findings or whatever about that at all. That hasn't been followed up. I haven't heard anything. I have tried to look something up on the internet and haven't found anything. Participant 14

It's not a nice diagnosis. But it's a label that people can see, oh you've got something real. And then there's doctors that diagnose Mitochondrial Disease when it's not. And in fact, I know a patient, she was in contact with me. And she was told by a GP she had Mito. Anyway, she was recommended and referred to the LOCATION hospital neurologist there. And NAME had to tell her that she didn't have it, she was so angry. She was angry. Instead of being relieved and saying, "All right, well what do I do now? Who do I see to find out what I have." Anyway, so that's my thing. Education, widely and broadly. Participant 24

> *Yes, obviously if the patients had tests that come back and show this organ system or that organ system has been affected and it's obviously not working, it's not really sneakily work, that should be conveyed to the patient with a far more honest picture of where they likely to end up. What the process is likely to be so that when the patient or some patients would just wouldn't accept that they wouldn't keep it in the context of as it is, "I'm trying to help you. If you get this symptom it just says that a few more of your cells are not doing so well." Gives people realistic ...likely outcome that if something goes wrong with one of the organ systems, the patient isn't left thinking, "What on earth is wrong with me?" compared to a tiny that that's part of the course and not panic. It's not something else it's likely to be this. Participant 27*

In relation to sub-group variations, participants with high general health (31.82%) described the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information), more frequently than the general population (18.00%).

Table 9.3: Expectations of information provision

Expectations of future information	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes being satisfied with current information. No recommendation.	11	22.00	5	16.67	6	30.00	7	25.93	4	17.39
Participant describes the need for information about their specific type of mitochondrial disease	9	18.00	6	20.00	3	15.00	5	18.52	4	17.39
Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)	9	18.00	6	20.00	4	20.00	6	22.22	4	17.39
Participant describes the need for centralised and reliable information	6	12.00	3	10.00	3	15.00	4	14.81	2	8.70
Participant describes the need for information in relation to genetic predisposition and/or hereditary factors	4	8.00	2	6.67	2	10.00	3	11.11	1	4.35
Participant describes the need to increase public awareness with more information available on the condition	4	8.00	3	10.00	2	10.00	5	18.52	0	0.00
Participants describes the need to provide information about research programs for treatments	4	8.00	2	6.67	2	10.00	3	11.11	1	4.35
Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease	4	8.00	4	13.33	0	0.00	2	7.41	2	8.70

Expectations of future information	All participants		High school or trade		University		Hearing impairment		Eye or visual impairment	
	n=50	%	n=26	%	n=24	%	n=24	%	n=34	%
Participant describes being satisfied with current information. No recommendation.	11	22.00	5	19.23	6	25.00	4	16.67	6	17.65
Participant describes the need for information about their specific type of mitochondrial disease	9	18.00	5	19.23	4	16.67	2	8.33	6	17.65
Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)	9	18.00	5	19.23	5	20.83	4	16.67	7	20.59
Participant describes the need for centralised and reliable information	6	12.00	4	15.38	2	8.33	5	20.83	4	11.76
Participant describes the need for information in relation to genetic predisposition and/or hereditary factors	4	8.00	2	7.69	2	8.33	2	8.33	4	11.76
Participant describes the need to increase public awareness with more information available on the condition	4	8.00	3	11.54	2	8.33	3	12.50	3	8.82
Participants describes the need to provide information about research programs for treatments	4	8.00	4	15.38	0	0.00	3	12.50	4	11.76
Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease	4	8.00	1	3.85	3	12.50	3	12.50	3	8.82

Expectations of future information	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant describes being satisfied with current information. No recommendation.	11	22.00	4	18.18	7	25.00	5	19.23	6	25.00
Participant describes the need for information about their specific type of mitochondrial disease	9	18.00	3	13.64	6	21.43	4	15.38	5	20.83
Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)	9	18.00	4	18.18	6	21.43	7	26.92	3	12.50
Participant describes the need for centralised and reliable information	6	12.00	4	18.18	2	7.14	2	7.69	4	16.67
Participant describes the need for information in relation to genetic predisposition and/or hereditary factors	4	8.00	1	4.55	3	10.71	4	15.38	0	0.00
Participant describes the need to increase public awareness with more information available on the condition	4	8.00	2	9.09	3	10.71	4	15.38	1	4.17
Participants describes the need to provide information about research programs for treatments	4	8.00	3	13.64	1	3.57	2	7.69	2	8.33
Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease	4	8.00	1	4.55	3	10.71	3	11.54	1	4.17

Expectations of future information	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant describes being satisfied with current information. No recommendation.	11	22.00	3	15.00	8	26.67	5	22.73	6	21.43
Participant describes the need for information about their specific type of mitochondrial disease	9	18.00	4	20.00	5	16.67	3	13.64	6	21.43
Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)	9	18.00	3	15.00	7	23.33	7	**31.82**	3	10.71
Participant describes the need for centralised and reliable information	6	12.00	2	10.00	4	13.33	2	9.09	4	14.29
Participant describes the need for information in relation to genetic predisposition and/or hereditary factors	4	8.00	2	10.00	2	6.67	2	9.09	2	7.14
Participant describes the need to increase public awareness with more information available on the condition	4	8.00	3	15.00	2	6.67	2	9.09	3	10.71
Participants describes the need to provide information about research programs for treatments	4	8.00	3	15.00	1	3.33	2	9.09	2	7.14
Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease	4	8.00	2	10.00	2	6.67	1	4.55	3	10.71

Expectations of future information	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant describes being satisfied with current information. No recommendation.	11	22.00	0	0.00	2	14.29	2	22.22	4	36.36	3	30.00
Participant describes the need for information about their specific type of mitochondrial disease	9	18.00	2	33.33	3	21.43	2	22.22	2	18.18	0	0.00
Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information)	9	18.00	3	50.00	2	14.29	0	0.00	3	27.27	2	20.00
Participant describes the need for centralised and reliable information	6	12.00	1	16.67	1	7.14	1	11.11	1	9.09	2	20.00
Participant describes the need for information in relation to genetic predisposition and/or hereditary factors	4	8.00	0	0.00	2	14.29	0	0.00	1	9.09	1	10.00
Participant describes the need to increase public awareness with more information available on the condition	4	8.00	2	33.33	1	7.14	0	0.00	0	0.00	2	20.00
Participants describes the need to provide information about research programs for treatments	4	8.00	0	0.00	0	0.00	2	22.22	1	9.09	1	10.00
Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease	4	8.00	1	16.67	2	14.29	1	11.11	0	0.00	0	0.00

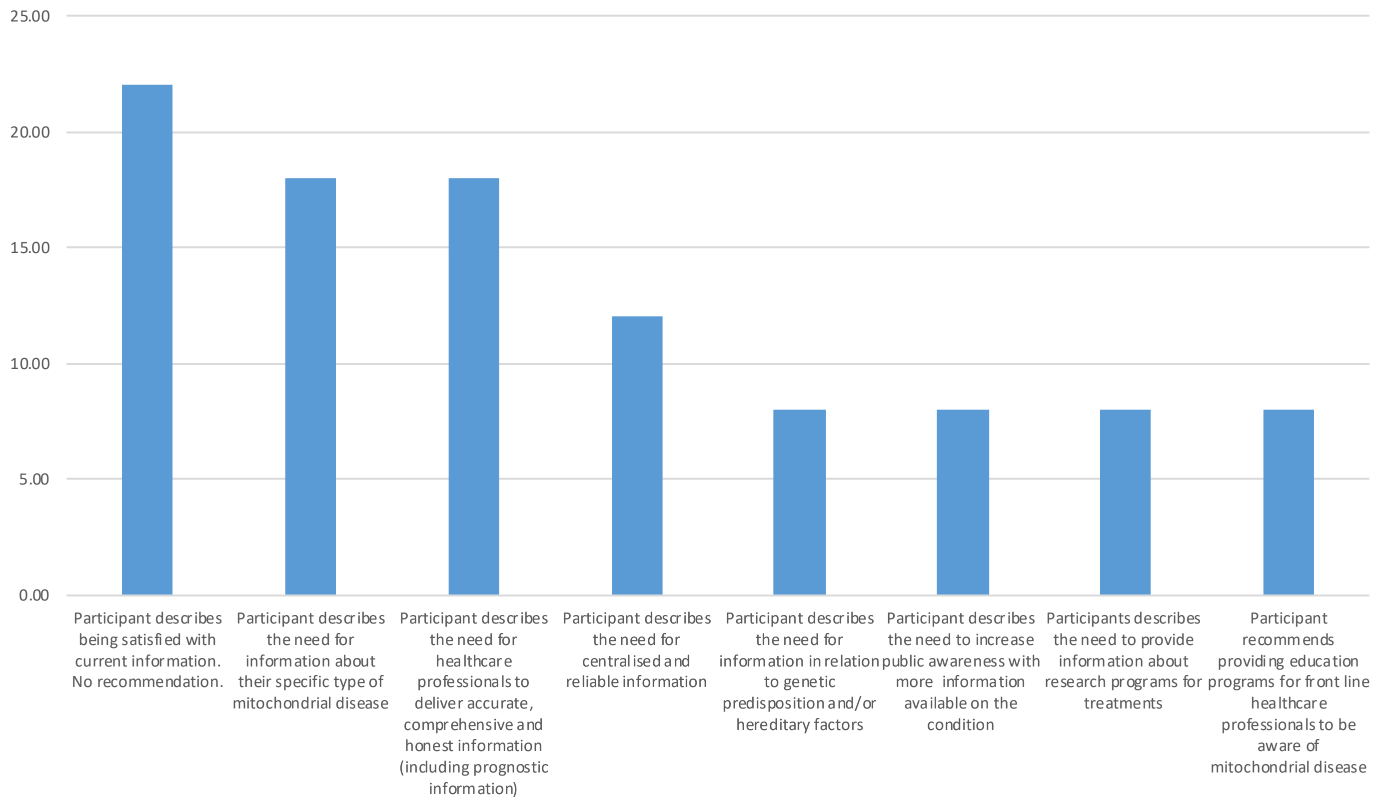

Figure 9.33: Expectations of information provision (% of all participants)

Expectation of health professional communication

Participants were asked whether there was anything they would like to see improved in the future in relation to the way that health professionals communicate with patients. The most common theme was that participants recommend healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition (n=16, 32.00%).

Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition

Well, obviously GPs and other health specialists have limited to negligible knowledge about the disease. If there was a brochure that was distributed to every other doctor or was put in the GP's magazine, a summary update on it regularly. Because I'm sick of telling doctors what it is, or what I can't take and what I can take … I'm sick of having that fight with doctors, and then they think they'll tell me this that and the rest and they don't anymore. Participant 3

Yes. Definitely. I think, for example, and I think it comes back to educate and inform. For example, the GP who just said, "I don't know anything about it. I don't have a booklet. Well, I don't know what to do." I thought, well, you know, that's really not good enough, and I think that problem is GPs are overburdened already. It's that whole vicious circle that is often associated with medical professionals, so they need to educate general practitioners, educate specialists. Participant 7

Well I'd like all the Doctors that I see to understand more. A lot of them don't understand what my limitations and stuff are. I feel a bit alone. I had to instigate to get my mobility sticker, I had to ask. "Oh, well what do you need that for?" Then I had to ask how do I get a key for disabled toilet access. "Oh, they don't have keys do they?" "Yes, they do. How do I do it?" Everything's been a struggle and I've had to instigate it. Participant 36

This was followed by the recommendation that healthcare professionals are more proactive and attentive (n=9, 18.00%).

Participant recommends healthcare professionals being more proactive and attentive

I think you just get told you have an appointment at a day at a particular date, but knowing what to expect out of that appointment, it would also be useful. Sometimes, you get really high expectations over something and it's not helpful at all. I know they're specialists, but it would be good sometimes if they did think about or at least bothered to ask like, "Are you getting support here or there?" Who else is going to ask. Participant 5

Yes. That they understand it. That they are able to be, basically ... speak to their clients and understand what their clients want, what their patients need from them. Participant 40

[laughs] One thing, they never ask questions about what your symptoms are and how it's affecting you. You have to go in there with a problem and they try and scratch their head and see what they can do about it. They should..they don't come up with a plan. I actually ask the GP after a bit of management and she just shook her head and said, "I don't know." Participant 42

There were also nine participants (18.00%) that did not have a recommendation as they have been satisfied with communication. Where participants were satisfied with communication it was primarily because communication had been open communication.

Participant does not have a recommendation as they have been satisfied with communication (Open communication)

No because my professor had been really good. He's been really open with me. He's never given up on me. He never gave up looking for what I had. He is always been open with me. Participant 12

I'd say most healthcare professionals I've dealt with have been pretty good. I think more and more these days they are more patient centered than they once were, so they actually do listen to the patient more than they once might have. Generally, I think the help has been in the right direction. Participant 13

No, I think I've had pretty good communication really. My GP always gives me a print out of any tests I've had done. My, what do you call it? Everything to-date that's on my file, I know there are a lot of problems with, what's the health record that you're supposed to be able to access online, and all that sort of stuff? Participant 34

There were seven participants (14.00%) that recommended that healthcare professionals need to have more empathy.

Participant recommends healthcare professionals need to have more empathy

Just that the health professionals...I don't know is a bit of a understanding of what we go through. Where there's condition. I reckon it also needs to be more info with the general community to be aware of what we go through and then. Participant 6

Just a little bit more understanding when you say something that they actually believe you rather than not believing that what you said is true, but I guess that's just a matter of finding the right doctor. Participant 19

Yes, no. I definitely would I think and I've had run ins over the years with various ones and thankfully, well, they've basically got to the point ... there was on health care professional I refused to see again because I think some times and this happens in some of these younger people that are very knowledgeable. They know the ins and the outs of the condition but they forget that they're talking to a parent and that your child is just a not a case study. It's actually your child. Participant 45

In relation to sub-group variations, participants from rural areas (45.00%) and those from low socio-economic areas (43.48%) recommended healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition, more frequently than the general population (32.00%).

Table 9.4: Expectations of health professional communication

Expectations of future health professional communication	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition	16	32.00	8	26.67	9	**45.00**	7	25.93	10	**43.48**
Participant recommends healthcare professionals being more proactive and attentive	9	18.00	6	20.00	3	15.00	5	18.52	4	17.39
Participant does not have a recommendation as they have been satisfied with communication (Open communication)	9	18.00	5	16.67	4	20.00	4	14.81	5	21.74
Participant recommends healthcare professionals need to have more empathy	7	14.00	3	10.00	4	20.00	4	14.81	3	13.04
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	6	12.00	3	10.00	3	15.00	3	11.11	3	13.04
Participant recommends that healthcare professionals ensure information is easily accessible	6	12.00	4	13.33	2	10.00	2	7.41	4	17.39

Expectations of future health professional communication	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition	16	32.00	10	38.46	7	29.17	9	37.50	10	29.41
Participant recommends healthcare professionals being more proactive and attentive	9	18.00	4	15.38	5	20.83	6	25.00	7	20.59
Participant does not have a recommendation as they have been satisfied with communication (Open communication)	9	18.00	4	15.38	5	20.83	3	12.50	7	20.59
Participant recommends healthcare professionals need to have more empathy	7	14.00	3	11.54	4	16.67	4	16.67	6	17.65
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	6	12.00	3	11.54	3	12.50	3	12.50	4	11.76
Participant recommends that healthcare professionals ensure information is easily accessible	6	12.00	1	3.85	5	20.83	2	8.33	5	14.71

Expectations of future health professional communication	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition	16	32.00	8	36.36	9	32.14	7	26.92	10	41.67
Participant recommends healthcare professionals being more proactive and attentive	9	18.00	3	13.64	6	21.43	5	19.23	4	16.67
Participant does not have a recommendation as they have been satisfied with communication (Open communication)	9	18.00	4	18.18	5	17.86	6	23.08	3	12.50
Participant recommends healthcare professionals need to have more empathy	7	14.00	4	18.18	3	10.71	5	19.23	2	8.33
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	6	12.00	1	4.55	5	17.86	3	11.54	3	12.50
Participant recommends that healthcare professionals ensure information is easily accessible	6	12.00	3	13.64	3	10.71	2	7.69	4	16.67

Expectations of future health professional communication	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition	16	32.00	7	35.00	10	33.33	8	36.36	9	32.14
Participant recommends healthcare professionals being more proactive and attentive	9	18.00	4	20.00	5	16.67	2	9.09	7	25.00
Participant does not have a recommendation as they have been satisfied with communication (Open communication)	9	18.00	5	25.00	4	13.33	2	9.09	7	25.00
Participant recommends healthcare professionals need to have more empathy	7	14.00	3	15.00	4	13.33	3	13.64	4	14.29
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	6	12.00	2	10.00	4	13.33	2	9.09	4	14.29
Participant recommends that healthcare professionals ensure information is easily accessible	6	12.00	2	10.00	4	13.33	4	18.18	2	7.14

Expectations of future health professional communication	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition	16	32.00	2	33.33	4	28.57	3	33.33	4	36.36	4	40.00
Participant recommends healthcare professionals being more proactive and attentive	9	18.00	1	16.67	2	14.29	3	33.33	2	18.18	1	10.00
Participant does not have a recommendation as they have been satisfied with communication (Open communication)	9	18.00	0	0.00	2	14.29	2	22.22	3	27.27	2	20.00
Participant recommends healthcare professionals need to have more empathy	7	14.00	1	16.67	2	14.29	2	22.22	2	18.18	0	0.00
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	6	12.00	1	16.67	3	21.43	1	11.11	0	0.00	1	10.00
Participant recommends that healthcare professionals ensure information is easily accessible	6	12.00	0	0.00	2	14.29	0	0.00	1	9.09	3	30.00

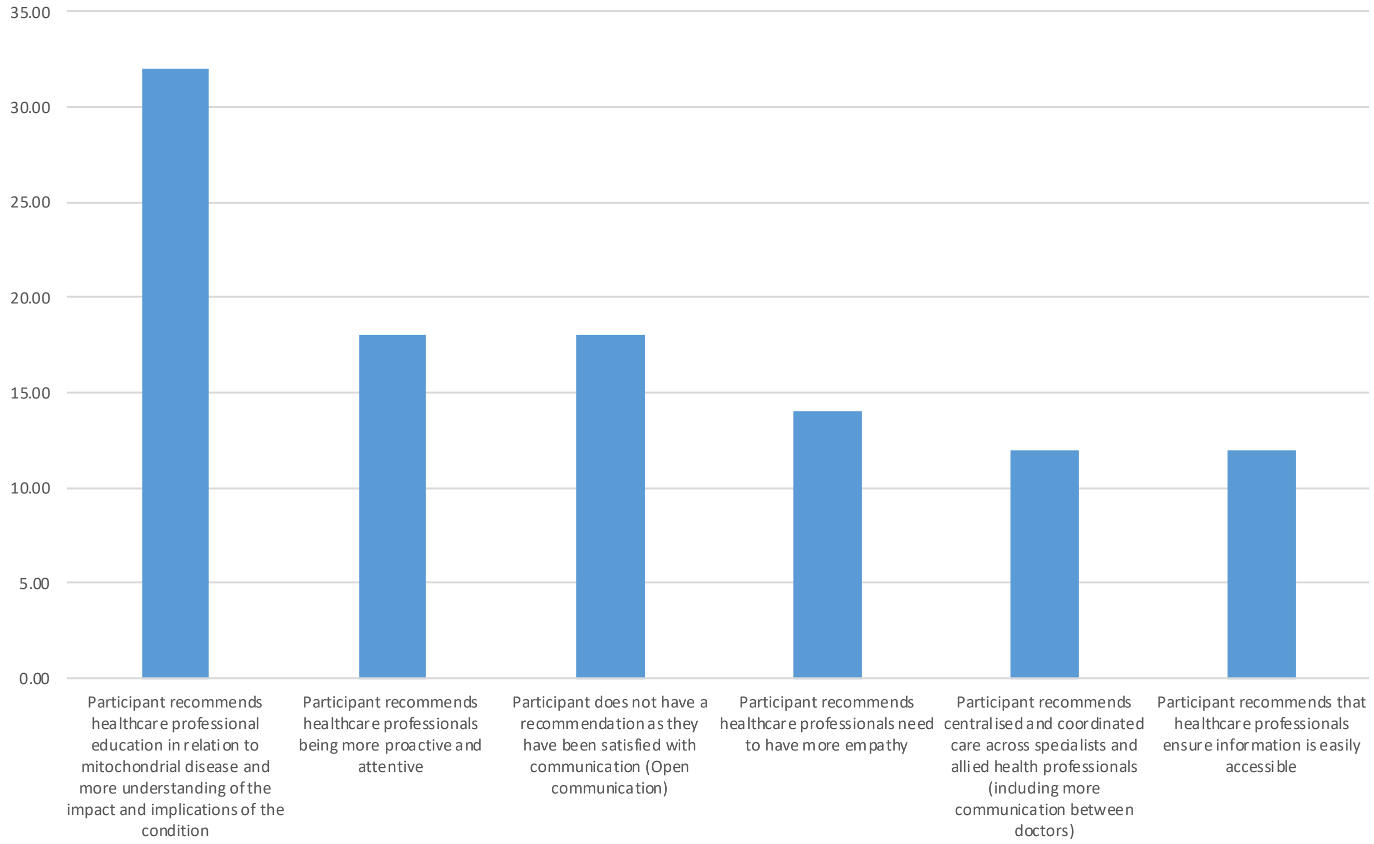

Figure 9.34: Expectations of health professional communication (% of all participants)

Expectation of care and support

Participants were asked whether there was anything they would like to see in relation to the care and support they receive. The most common recommendation was for centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) (n=13, 26.00%). In a similar theme, there were also six participants (12.00%) that recommended caseworkers be employed to support patients navigate health, medical and emotional needs.

Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)

Yes. I think a network in LOCATION METROPOLITAN would be useful and having some sort of specialist. Somebody, even if it's in the north or northwest of the state, somebody who is trained in this area would be really useful. Participant 26

I would love to see specialist educators set up that anyone can access. For example, they have contact staff who can give specific advice and help you understand things when you have cancer, diabetes, Chronic pain, mental health, etc. I would like to see the same for Mito, with different ones for paediatrics and others for adults. Participant 30

Yes. Well, I think there is already the one, the LOCATION Hospital which has a statewide service. I think it's pretty good. It's very difficult having so many different people to deal with. It is a bit conky sometimes and there's a lot of wasting time in between things. I've been on a wait for a motorized scooter. It's just never appeared. How long do you think, "Well, what's really going on here?" Because of my situation, I'm okay. I don't know what it would be like if you were really desperate. Participant 34

Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs

Yeah, just someone to, some health, somewhere you can actually go to, and how can I improve my condition, etc., sort of like being diagnosed and then you're left to your own, I guess is it…Yeah, so someone that, okay, well, even if that person can put you onto other things. Sometimes, also, you know, it would have been great to be able to talk to people that have certainly my type of condition, because, as you know, there's a lot of variances. People with my hearing and diabetes being able to have a, sort of, group *discussion about how they cope with it, etc. those sort of things. Like subcategories, especially mito, area support groups. Participant 15*

There should also be a social work help line which you can contact in your state to get support for sourcing equipment, funding, medical specialists, etc. Participant 30

Yeah I think social ... I haven't seen a social worker. I haven't had any assistance with setting up all these things that I've had to set up. I know I'm supposed to have seen social workers and speech pathologists and all the rest of it, and genetic counsellors, but that just hasn't happened. I know that there are things out there, and people out there that I could be seeing that might know more about treatment options, but I really haven't got there yet. Participant 36

This was followed by the recommendation for support groups to help patients noting that it is difficult due to the diversity within the patient population (n=7, 14.00%) and more equity in access to services and support for adults with rare disease (n=7, 14.00%).

Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population

The AMDF started a support groups, that would have been really beneficial to me in the early days, but because of the AMDF I only started the same year that I was diagnosed, really there. That stuff is more readily available now, which I would have found helpful back in the day. Participant 10

Sometimes, also, you know, it would have been great to be able to talk to people that have certainly my type of condition, because, as you know, there's a lot of variances. People with my hearing and diabetes being able to have a, sort of, group discussion about how they cope with it, etc. those sort of things. Like subcategories, especially mito, area support groups. Participant 15

Probably, when we first…when I was first diagnosed to understand it, perhaps a support group where you could go and have a big whinge with other people that are going through the same thing as you. Participant 41

Participant recommends more equity in access to services and support for adults with rare disease

Well, I think we have to move away from the charity system because that's the same with the problems that they're finding the funding between what was the state government and now the federal with NDIS. People are still locked into…how do I explain? Someone else nation the cost of things with like the NDIS won't they're selective and what they fund and so people are still being advised and works for children, children's charities raised lots of money that charities are provided and therefore you have to be grateful or you have to be in need and it's not a good system. I think as a society we could do a lot better than that. It's such ad hoc like that it's not equitable. You can have two people living next door to each other and one tubal child will get all that extra bit of funding and thing because they're newsworthy and people feel good about doing things which is great charities good in that sense but an adult with the same disease doesn't get anything because then they're not the cute child but they're still impacted by the disorder or disease. So, yes, I have lots of issues with charities and things like that. Mitochondrial disease, I don't know, analytics change because we don't have access like to it with NAME. There's nothing in the public health system for it. For individual's, like a body part, like you can just take a gastrointestinal system along with it, there's nothing. There's not a holistic thing. I don't know if there is purely for people that might just have something, that's a different thing. I don't know. Participant 4

I guess it's really just having a well-funded NDIS really would solve it. Making sure that all services--anything that someone needs, they have access to. I think it still takes…I still know few people who're just…it would just be fantastic if I they had a laptop computer in school for them, but it would take a year or two of applications here and applications there before they actually get it. I guess it's just that old people…whether it's me or young people at school with a disability or the mitochondrial disease, get the services that they require whenever they may be. Participant 13

In relation to sub-group variations, participants with a university education (50.00%) and those with a hearing impairment (45.83%) recommended centralised and coordinated care across specialists and allied health professionals, more frequently than the general population (26.00%), while those with a high school or trade education (3.85%) recommended this less frequently.

Table 9.5: Expectations of care and support

Expectations of future care and support	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	13	26.00	7	23.33	6	30.00	9	33.33	4	17.39
Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population	7	14.00	5	16.67	2	10.00	6	22.22	1	4.35
Participant recommends more equity in access to services and support for adults with rare disease	7	14.00	5	16.67	2	10.00	4	14.81	3	13.04
Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs	6	12.00	3	10.00	3	15.00	1	3.70	5	21.74
Participant recommends greater and/or more access to home care/support at home	4	8.00	3	10.00	1	5.00	3	11.11	1	4.35
Participant recommends having reliable information available (via patient organisations)	4	8.00	2	6.67	2	10.00	2	7.41	2	8.70

Expectations of future care and support	All participants		High school or trade		University		Hearing impairment		Eye or visual impairment	
	n=50	%	n=26	%	n=24	%	n=24	%	n=34	%
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	13	26.00	1	3.85	12	50.00	11	45.83	7	20.59
Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population	7	14.00	5	19.23	2	8.33	3	12.50	5	14.71
Participant recommends more equity in access to services and support for adults with rare disease	7	14.00	3	11.54	4	16.67	4	16.67	5	14.71
Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs	6	12.00	1	3.85	5	20.83	5	20.83	4	11.76
Participant recommends greater and/or more access to home care/support at home	4	8.00	3	11.54	1	4.17	2	8.33	2	5.88
Participant recommends having reliable information available (via patient organisations)	4	8.00	2	7.69	2	8.33	2	8.33	4	11.76

Expectations of future care and support	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	13	26.00	6	27.27	7	25.00	8	30.77	5	20.83
Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population	7	14.00	4	18.18	3	10.71	5	19.23	2	8.33
Participant recommends more equity in access to services and support for adults with rare disease	7	14.00	3	13.64	4	14.29	4	15.38	3	12.50
Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs	6	12.00	3	13.64	3	10.71	4	15.38	2	8.33
Participant recommends greater and/or more access to home care/support at home	4	8.00	1	4.55	3	10.71	1	3.85	3	12.50
Participant recommends having reliable information available (via patient organisations)	4	8.00	3	13.64	1	3.57	1	3.85	3	12.50

Expectations of future care and support	**All participants**		**Social functioning (High)**		**Social functioning (Low)**		**General health (High)**		**General health (Low)**	
	n=50	**%**	**n=20**	**%**	**n=30**	**%**	**n=22**	**%**	**n=28**	**%**
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	13	26.00	4	20.00	9	30.00	6	27.27	7	25.00
Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population	7	14.00	5	25.00	2	6.67	4	18.18	3	10.71
Participant recommends more equity in access to services and support for adults with rare disease	7	14.00	2	10.00	5	16.67	2	9.09	5	17.86
Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs	6	12.00	2	10.00	4	13.33	5	22.73	1	3.57
Participant recommends greater and/or more access to home care/support at home	4	8.00	0	0.00	4	13.33	1	4.55	3	10.71
Participant recommends having reliable information available (via patient organisations)	4	8.00	3	15.00	1	3.33	2	9.09	2	7.14

Expectations of future care and support	**All participants**		**Under 18**		**24-44**		**45-54**		**55-64**		**65-74+**	
	n=50	**%**	**n=6**	**%**	**n=14**	**%**	**n=9**	**%**	**n=11**	**%**	**n=10**	**%**
Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)	13	26.00	0	0.00	3	21.43	3	33.33	6	54.55	1	10.00
Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population	7	14.00	1	16.67	1	7.14	2	22.22	1	9.09	2	20.00
Participant recommends more equity in access to services and support for adults with rare disease	7	14.00	1	16.67	2	14.29	3	33.33	1	9.09	0	0.00
Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs	6	12.00	1	16.67	3	21.43	1	11.11	1	9.09	0	0.00
Participant recommends greater and/or more access to home care/support at home	4	8.00	1	16.67	0	0.00	0	0.00	2	18.18	1	10.00
Participant recommends having reliable information available (via patient organisations)	4	8.00	0	0.00	2	14.29	0	0.00	1	9.09	1	10.00

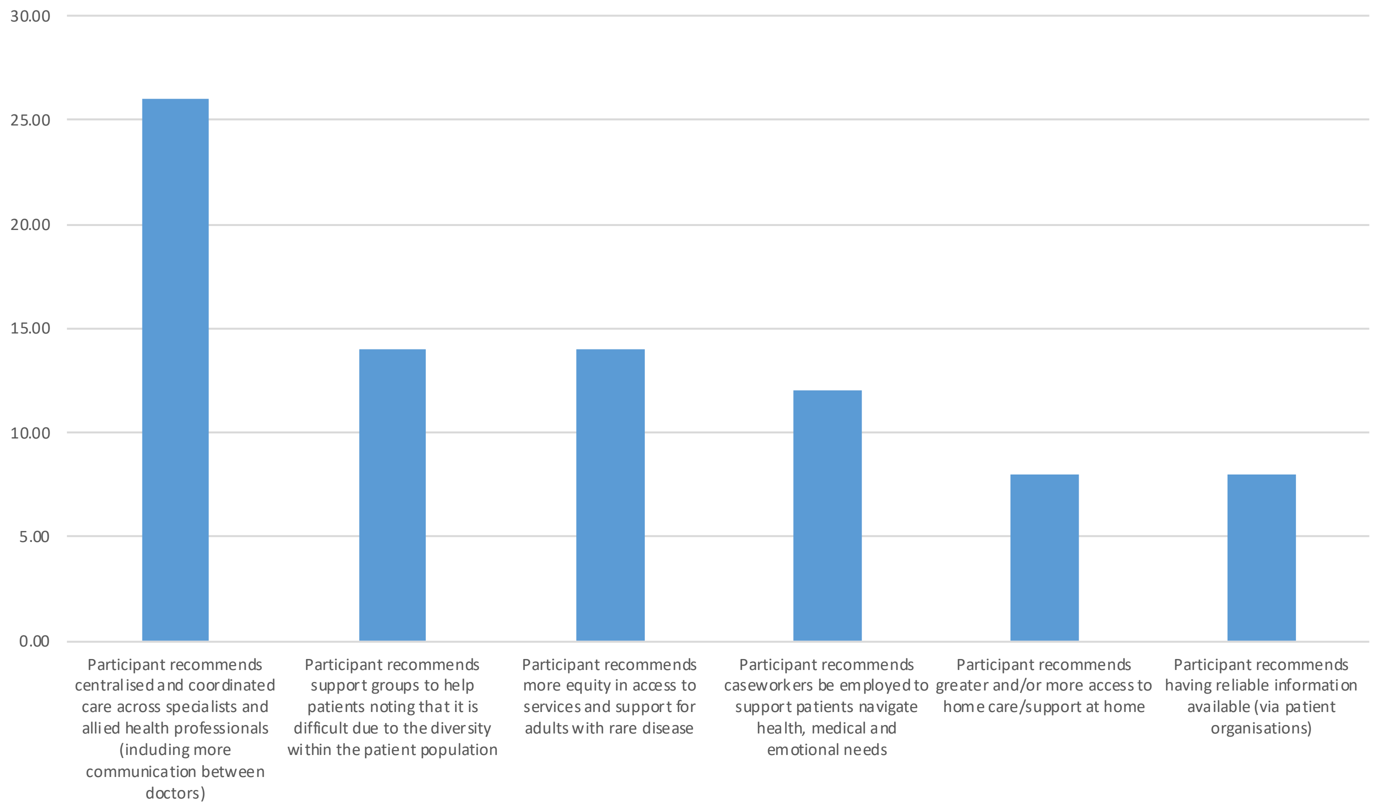

Figure 9.35: Expectations of care and support (% of all participants)

What participants are grateful for in the Australian health system

Participants were asked what they were grateful for in relation to the Australian health system. The most common theme was participants describing being grateful for Medicare in relation to access to specialists (n=17, 34.00%), followed by being grateful for the compassion and support shown by healthcare professionals (n=16, 32.00%).

Participant describes being grateful for Medicare (Access to specialists)

I think some of the small things have actually been the most useful like before I was diagnosed, when my rheumatologist said, "I don't know what you have. I'm going to refer you to a neurologist." That referral system, that made a very huge difference to my life, if she just said, "Oh, no. I think you've got fibromyalgia." I'd feel wonderful I have fibromyalgia, but wondering in the back of my head whether or not I need a second opinion. I think having very qualified people, but also refer to other very qualified people is really…I think the quality generally is very good. My doctor is amazing, I love her. She's great. Participant 5

Yes, it's easy to access to a specialist. That's a big plus and it is as…though this is become as known and treatment becomes clear, you find, technically, more and more specialists. But after I fight this disease, but speaking for myself, I can't speak loudly enough of the medical people at the hospital. Participant 23

The doctors I've seen have been excellent and it's affordable. I can go and see my neurologist and I can afford it. Participant 43

Opportunities, new technologies and stuff, and surgeries that we've had the opportunity to consider through our specialist. That's been especially good. Participant 47

Participant describes being grateful for the compassion and support shown by healthcare professionals

I think that being grateful, and it cost me a lot of money to get to the endpoint, I think some of the ability of the doctors, etc., continuing to try to get to the bottom of things rather than just, "Oh, well, I'm not quite sure how to go." Participant 15

I'm very pleased with the attitude of the workers in the health system. They're very kind and considerate. Thinking now, they've been rather generous with the benefits that I get, like a wheelchair…Participant 17

Yes. I have been very grateful for the expertise of the medical staff and their compassion. We understand they are trying to do whatever they can. There's nothing else really that they can do at this point in time. Participant 48

There were 10 participants (20.00%) that described being grateful for Medicare in relation to access to allied health professionals and seven participants (14.00%) described being grateful for their healthcare card and the financial relief it provides.

Participant describes being grateful for Medicare (Access to allied health professionals)

Early intervention. Early intervention. Absolutely that would be the number one thing. The physical, the OT, and the speech therapy. [Interviewer: He's improved?] Yeah, absolutely. We've had that since 11 months old, and I think that's been the biggest. Participant 46

It's really good being a pensioner and getting medication fairly cheaply, and it's really good being bulk-billed so I can go to the doctor any time. It's good having the Medicare plan to see psychologists at reduced rates. That's all been really good. Participant 47

I think the way they do things in the children's hospital where they gathered a team together, I think it was under the heading of Adolescent Medicine. It was, I think, a brilliant approach because this affects all body systems in every body system. I think that having a team around all of those systems accessible, people who are willing to be involved in mitochondrial care and understanding approach is invaluable. Participant 49

Participant describes being grateful for their healthcare card and the financial relief it provides

DVA have been wonderful. They sent the occupational therapy who happens to be the same lady who used to come to NAME. It's all very, very good. Their help for me has been invaluable. Participant 32

Yes, I've been very grateful that I was put onto disability support pension. Say in England, the National Health Service there is so overstretched. I know that they're doing some fantastic research over there, but to actually get assistance at home, I don't think that would have happened. Participant 34

Oh, I think Medicare's fantastic. Having a Health Care Card, having … I've seen a lot of specialists, and they're hundreds of dollars, and it's all added up to thousands of dollars, and I just don't have any more

> ***now that I'm not working. It's fantastic that- ... Medicare covers a lot of things, and Health Care Card helps with the travel costs and stuff like that. Participant 36***

Other aspects of the health system that participants spoke about being grateful for were subsidised diagnostic tests (n=6, 12.00%), government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services) (n=6, 12.00%) and the quality of specialist expertise in Australia (n=5, 10.00%).

In relation to sub-group variations, participants from rural areas (45.00%) described being grateful for Medicare (Access to specialists) more frequently than the general population (34.00%). Participants with a university education (45.83%), those with high physical function (54.55%), and those with high general health (50.00%) reported being grateful for the compassion and support shown by healthcare professionals more frequently than the general population (32.00%), while those with low physical function (17.86%) reported this less frequently. Participants from rural areas (25.00%), those with a hearing impairment (25.00%) and those with low physical function (25.00%) described being grateful for their healthcare card and the financial relief it provides, more frequently than the general population (14.00%), while there we no participants with high physical function (0.00%) that reported this.

Table 9.6: Aspects of the Australian health system that participants are grateful for

Aspects of the Australian health system that patients are grateful for	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant describes being grateful for Medicare (Access to specialists)	17	34.00	8	26.67	9	**45.00**	7	25.93	10	43.48
Participant describes being grateful for the compassion and support shown by healthcare professionals	16	32.00	11	36.67	6	30.00	9	33.33	8	34.78
Participant describes being grateful for Medicare (Access to allied health professionals)	10	20.00	4	13.33	6	30.00	3	11.11	7	**30.43**
Participant describes being grateful for their healthcare card and the financial relief it provides	7	14.00	2	6.67	5	**25.00**	3	11.11	4	17.39
Participant describes being grateful for subsidised diagnostic tests	6	12.00	4	13.33	2	10.00	5	18.52	1	4.35
Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)	6	12.00	3	10.00	3	15.00	5	18.52	1	4.35
Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care	5	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant describes frustration at the lack of services tailored towards mitochondria disease	5	10.00	4	13.33	1	5.00	4	14.81	1	4.35
Participant describes being grateful for the quality of specialist expertise in Australia	5	10.00	5	16.67	0	0.00	3	11.11	2	8.70

Aspects of the Australian health system that patients are grateful for	**All participants**		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant describes being grateful for Medicare (Access to specialists)	17	34.00	7	26.92	10	41.67	10	41.67	10	29.41
Participant describes being grateful for the compassion and support shown by healthcare professionals	16	32.00	6	23.08	11	45.83	9	37.50	10	29.41
Participant describes being grateful for Medicare (Access to allied health professionals)	10	20.00	4	15.38	6	25.00	5	20.83	8	23.53
Participant describes being grateful for their healthcare card and the financial relief it provides	7	14.00	2	7.69	5	20.83	6	25.00	4	11.76
Participant describes being grateful for subsidised diagnostic tests	6	12.00	4	15.38	2	8.33	3	12.50	4	11.76
Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)	6	12.00	5	19.23	1	4.17	4	16.67	6	17.65
Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care	5	10.00	3	11.54	2	8.33	1	4.17	2	5.88
Participant describes frustration at the lack of services tailored towards mitochondria disease	5	10.00	2	7.69	3	12.50	3	12.50	2	5.88
Participant describes being grateful for the quality of specialist expertise in Australia	5	10.00	1	3.85	4	16.67	1	4.17	3	8.82

Aspects of the Australian health system that patients are grateful for	**All participants**		**Physical function (High)**		**Physical function (Low)**		**Emotional well-being (High)**		**Emotional well-being (Low)**	
	n=50	**%**	**n=22**	**%**	**n=28**	**%**	**n=26**	**%**	**n=24**	**%**
Participant describes being grateful for Medicare (Access to specialists)	17	34.00	6	27.27	11	39.29	10	38.46	7	29.17
Participant describes being grateful for the compassion and support shown by healthcare professionals	16	32.00	12	54.55	5	17.86	8	30.77	9	37.50
Participant describes being grateful for Medicare (Access to allied health professionals)	10	20.00	3	13.64	7	25.00	6	23.08	4	16.67
Participant describes being grateful for their healthcare card and the financial relief it provides	7	14.00	0	0.00	7	25.00	3	11.54	4	16.67
Participant describes being grateful for subsidised diagnostic tests	6	12.00	5	22.73	1	3.57	5	19.23	1	4.17
Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)	6	12.00	2	9.09	4	14.29	4	15.38	2	8.33
Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care	5	10.00	0	0.00	5	17.86	1	3.85	4	16.67
Participant describes frustration at the lack of services tailored towards mitochondria disease	5	10.00	3	13.64	2	7.14	2	7.69	3	12.50
Participant describes being grateful for the quality of specialist expertise in Australia	5	10.00	3	13.64	2	7.14	3	11.54	2	8.33

Aspects of the Australian health system that patients are grateful for	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant describes being grateful for Medicare (Access to specialists)	17	34.00	6	30.00	11	36.67	6	27.27	11	39.29
Participant describes being grateful for the compassion and support shown by healthcare professionals	16	32.00	6	30.00	11	36.67	11	50.00	6	21.43
Participant describes being grateful for Medicare (Access to allied health professionals)	10	20.00	5	25.00	5	16.67	4	18.18	6	21.43
Participant describes being grateful for their healthcare card and the financial relief it provides	7	14.00	0	0.00	7	23.33	2	9.09	5	17.86
Participant describes being grateful for subsidised diagnostic tests	6	12.00	5	25.00	1	3.33	4	18.18	2	7.14
Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)	6	12.00	3	15.00	3	10.00	1	4.55	5	17.86
Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care	5	10.00	1	5.00	4	13.33	2	9.09	3	10.71
Participant describes frustration at the lack of services tailored towards mitochondria disease	5	10.00	2	10.00	3	10.00	4	18.18	1	3.57
Participant describes being grateful for the quality of specialist expertise in Australia	5	10.00	2	10.00	3	10.00	2	9.09	3	10.71

Aspects of the Australian health system that patients are grateful for	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant describes being grateful for Medicare (Access to specialists)	17	34.00	2	33.33	7	50.00	1	11.11	4	36.36	3	30.00
Participant describes being grateful for the compassion and support shown by healthcare professionals	16	32.00	4	66.67	5	35.71	1	11.11	4	36.36	3	30.00
Participant describes being grateful for Medicare (Access to allied health professionals)	10	20.00	2	33.33	3	21.43	1	11.11	2	18.18	2	20.00
Participant describes being grateful for their healthcare card and the financial relief it provides	7	14.00	1	16.67	1	7.14	0	0.00	3	27.27	2	20.00
Participant describes being grateful for subsidised diagnostic tests	6	12.00	0	0.00	3	21.43	1	11.11	1	9.09	1	10.00
Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)	6	12.00	2	33.33	0	0.00	2	22.22	1	9.09	1	10.00
Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care	5	10.00	0	0.00	0	0.00	0	0.00	1	9.09	4	40.00
Participant describes frustration at the lack of services tailored towards mitochondria disease	5	10.00	0	0.00	0	0.00	2	22.22	1	9.09	2	20.00
Participant describes being grateful for the quality of specialist expertise in Australia	5	10.00	1	16.67	2	14.29	0	0.00	2	18.18	0	0.00

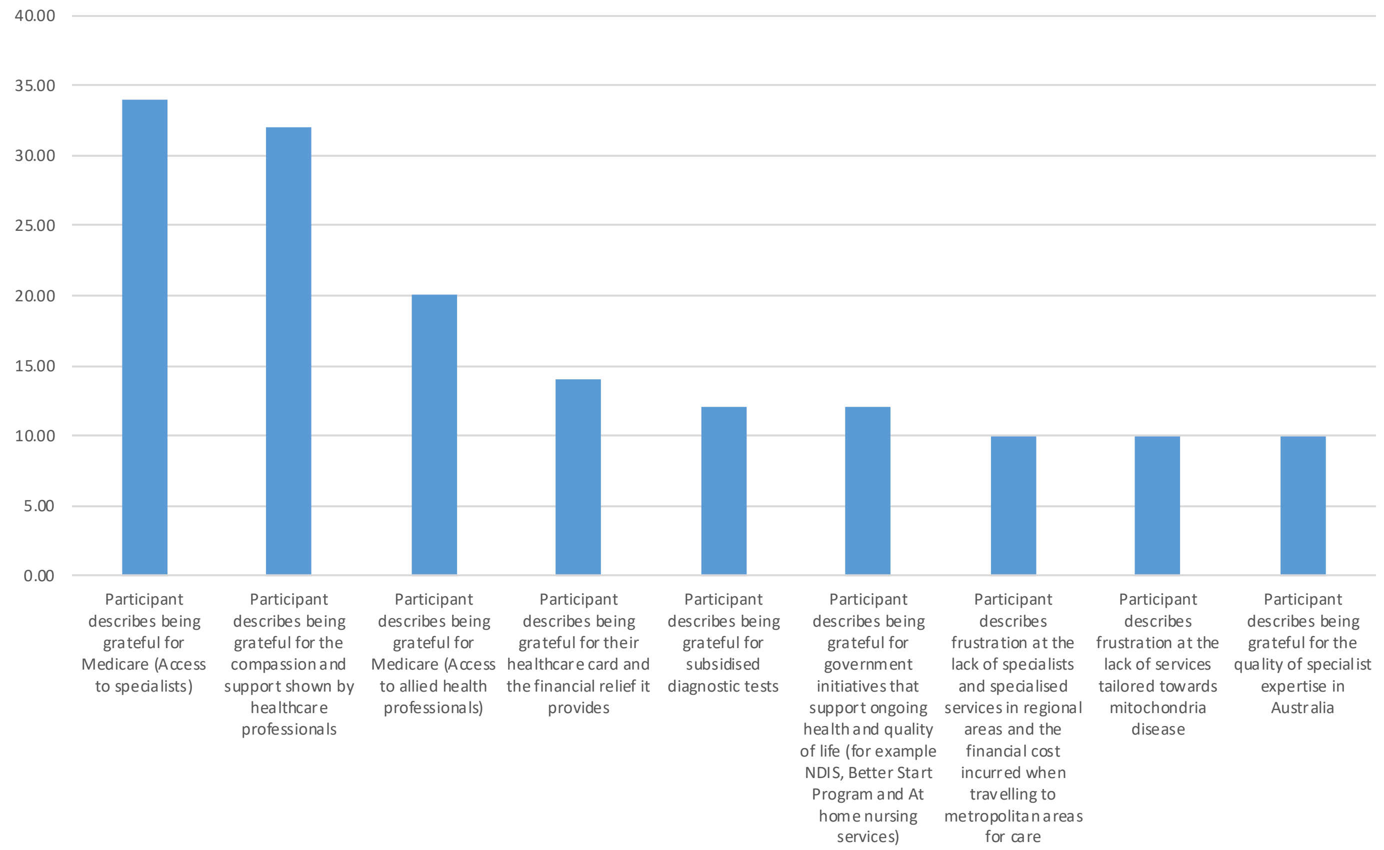

Figure 9.36: Aspects of the Australian health system that participants are grateful for

Messages to decision-makers about the treatment and care that people affected by mitochondrial disease

Participants were asked what their message to people who make decisions about their condition would be. The most common message is to support more research (n=20, 40.00%), however this was a general statement with no specific area noted.

Participant's message is to support more research (General - no specific area)

Just in general, give us some research money. That's the biggest thing. Research and awareness. We're not going to get anywhere without research. Participant 10

More money into research and more involvement in the people with mitochondria in the research. What are the subjects, what are the standards. Give us confidence that they will be able to solve the problems as essential to the treatment, so that they have better treatment and more success. Participant 17

Well, I'd say it's too scarce. They'd need to put money into research but then, how many things do the poor people have to research? Must be millions. Well, you just take the mitochondrial, the different kinds there are and how different everybody is affected. I'd just probably say to him, "Just throw a bit more money into research to try and help." I'm at the end of my life. As I said, it just doesn't bother me but you can imagine a child with something like this if it is diagnosed when they're a child. It would be pretty devastating and the research is needed. Participant 31

The next most common theme was to provide more education to the healthcare professionals, particularly education about managing the condition (n=15, 30.00%), and this was followed by the message to increase awareness of mitochondrial disease among the community (n=12, 24.00%).

Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)

Definitely educating doctors, GPs and things like that. If they knew more about it…I know when aren't convincing. I've seen my main GP, but I also see it, medical things could have been easier. Sometimes you can't get an appointment. When they ask you know what…they want my background and I told them what I have got, a couple of them were like oh, my God. I'm going to research this. That's good for them, to research it, but it's like a general knowledge of mitochondria would be better too. I think a lot of it--they don't know if. Participant 1

Health minister, while we acknowledge the work of you, minister, in improving hospital care, there is certainly room for improvement. Employing education programmes for GPs and healthcare workers, and particularly implementing a full-time position for a counsellor as a wraparound service to help improve the emotional and physical needs of these people would be extremely economically beneficial. Participant 7

Further education for Doctors, put mitochondrial on the Doctor's training curriculum. Something about social workers or genetic counsellors, or some other arm needs to be attached to just the physical diagnosis, because there's so many other bits that need like all the things I've talked about. The equipment, the test forms, the continence aids, the social … putting a will in place, advanced are directives, all that sort of stuff I know about because I'm a nurse, and I've dealt with palliative health and I know all of those things. But for somebody who doesn't know anything about what's wrong with them, it would be a really hard thing to deal with, and certainly nobody's done any of the things that have helped me, or set my place up. I've had to do it myself, so there's a gap somewhere between the diagnosis, and your investigations, and somebody acting on what you need. Participant 36

Participant's message is increase awareness of mitochondrial disease among the community

Good question. To conduct more research for the cure mito. To make the community more aware of the condition. Participant 6

Maybe raise awareness of it because I would say a good 90% of the people that I talked to have never heard about it before. Which makes sense because it is a fairly rare disease but it might make it easier on a lot of people if everyone knew even just a little bit about it. Participant 11

More babies die of Mitochondrial conditions than die of all the childhood cancers combined. Did you know that? And yet people have never heard about Mitochondrial conditions. So again, it comes back to education. Participant 24

My message would be educate people. Because it's a minority, and it's not diabetes, it's just as bad. Participant 40

To get it out in the public system of what it is and I know people with it are a lot worse than I am, to helping any way they can. Participant 41

There were 12 participants (24.00%) whose message is to provide more holistic and multidisciplinary/allied health care, and eight participants (16.00%) whose message is to improve treatments by following the example of other countries that have more advanced systems.

Participant's message is to provide more holistic and multidisciplinary/allied health care

Then I'd also say there's got to be a support function after you've been diagnosed, like where people can go and get proper information, but also being updated with what can help and also where you can actually have health professionals or specialists in the area given more research to try and combat it. Also, to set up a proper after-care support department, not a department, but somewhere that ... Yeah, somewhere that you can go and talk to and you've got all the right information rather than, you know, trying to find the information off the internet or that sort of thing. That would be my main thing. Participant 15

I think we need a large central clinic with a lot of multidiscipline things that it should be lodged five days a week, but it should also be able to move around the country. It should move. The people in the country should be able to access it and in the outer suburbs so that it could move around. That'll be one week in the city, because everyone should be able to access it no matter where they live without having to do multiple large amount of traveling. Sounds like Eutopia, doesn't it? Participant 21

Yeah, it's not really covered. I go to somebody a long way away, and they've referred me back to somebody else, but nothing happens. [Interviewer: You feel it's up to you to follow it up, and if you don't do it, then no ones going to be checking that you're okay?] Yeah, well they change it too, like I was referred from LOCATION A to particular ... I think it was a physiotherapist, or a rehab clinic at LOCATION B, but then my GP changed it, and just stuck me in LOCATION C for a couple of days, and people looked at me, but nobody really ... I didn't see one Doctor in the whole time I was there. I think the rehab people came once and stuck their head in, but I never saw ... I didn't really see a social worker or anybody. Participant 36

People with mitochondrial disease don't just need medication. They also need physical therapies. I would like occupational therapy and physiotherapy. I would really love more affordable access to that. [pause] If you get a healthcare plan, you get five free visits with the physio in a year. Five isn't enough. Yes, more affordable physical therapies please. Participant 4

Participant's message is to improve treatments by following the example of other countries that have more advanced systems

...we can be investing more money into preventions and treatments; we can be helping people with mito have a better quality of life. Australia is behind in its approach to mitochondrial disease. The UK has legalised the first known preventative measure and yet we're still fighting for clinical trials, yet alone for the disease to be heard of. We can do better. Participant 8

There is absolutely nothing as far as treatment goes for my son and hundreds of other people in Australia for mitochondrial disease. All we have is vitamin supplements to treat a whole complicated area of health conditions associated with mitochondrial disease and that something needs to be done about it. Participant 50

In relation to sub-group variations, participants from rural areas (55.00%) called for more research more frequently than the general population (40.00%). Participants with a hearing impairment (41.67%) had the message to provide more education to the healthcare professionals, more frequently than the general population (30.00%). Participants with a university education (12.50%) called for more awareness less frequently than the general population (24.00%). Participants with a university education (33.33%) and those with a hearing impairment (37.50%) had the message to support more funding (in general), more frequently than the general population (22.00%), while those with a high school or trade education reported this less frequently (11.54%). Participants with high physical function (13.64%) had the message to provide more holistic and multidisciplinary/allied health care less frequently than the general population (24.00%).

Table 9.7: Messages to decision-makers

Aspects of the Australian health system that	**All participants**		**Metropolitan**		**Rural**		**SEIFA (High)**		**SEIFA (Low)**	
	n=50	**%**	**n=30**	**%**	**n=20**	**%**	**n=27**	**%**	**n=23**	**%**
Participant's message is to support more research (General - no specific area)	20	40.00	9	30.00	11	**55.00**	11	40.74	9	39.13
Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)	15	30.00	8	26.67	7	35.00	7	25.93	8	34.78
Participant's message is increase awareness of mitochondrial disease among the community	12	24.00	8	26.67	4	20.00	6	22.22	6	26.09
Participant's message is to provide more holistic and multidisciplinary/allied health care	12	24.00	7	23.33	5	25.00	5	18.52	7	30.43
Participant's message is to support more funding (General - no specific area)	11	22.00	8	26.67	3	15.00	7	25.93	4	17.39
Participant's message is to improve treatments by following the example of other countries that have more advanced systems	8	16.00	5	16.67	4	20.00	6	22.22	3	13.04

	All participants		**High school or trade**		**University**		**Hearing impairment**		**Eye or visual impairment**	
	n=50	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=34**	**%**
Participant's message is to support more research (General - no specific area)	20	40.00	9	34.62	11	45.83	9	37.50	12	35.29
Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)	15	30.00	8	30.77	7	29.17	10	**41.67**	9	26.47
Participant's message is increase awareness of mitochondrial disease among the community	12	24.00	9	34.62	3	**12.50**	7	29.17	10	29.41
Participant's message is to provide more holistic and multidisciplinary/allied health care	12	24.00	5	19.23	7	29.17	6	25.00	9	26.47
Participant's message is to support more funding (General - no specific area)	11	22.00	3	**11.54**	8	**33.33**	9	**37.50**	7	20.59
Participant's message is to improve treatments by following the example of other countries that have more advanced systems	8	16.00	4	15.38	5	20.83	4	16.67	5	14.71

	All participants		**Physical function (High)**		**Physical function (Low)**		**Emotional well-being (High)**		**Emotional well-being (Low)**	
	n=50	**%**	**n=22**	**%**	**n=28**	**%**	**n=26**	**%**	**n=24**	**%**
Participant's message is to support more research (General - no specific area)	20	40.00	9	40.91	11	39.29	11	42.31	9	37.50
Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)	15	30.00	5	22.73	10	35.71	6	23.08	9	37.50
Participant's message is increase awareness of mitochondrial disease among the community	12	24.00	7	31.82	5	17.86	8	30.77	4	16.67
Participant's message is to provide more holistic and multidisciplinary/allied health care	12	24.00	3	**13.64**	9	32.14	5	19.23	7	29.17
Participant's message is to support more funding (General - no specific area)	11	22.00	6	27.27	5	17.86	6	23.08	5	20.83
Participant's message is to improve treatments by following the example of other countries that have more advanced systems	8	16.00	4	18.18	5	17.86	4	15.38	5	20.83

	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant's message is to support more research (General - no specific area)	20	40.00	10	50.00	10	33.33	10	45.45	10	35.71
Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)	15	30.00	4	20.00	11	36.67	4	18.18	11	39.29
Participant's message is increase awareness of mitochondrial disease among the community	12	24.00	5	25.00	7	23.33	5	22.73	7	25.00
Participant's message is to provide more holistic and multidisciplinary/allied health care	12	24.00	4	20.00	8	26.67	4	18.18	8	28.57
Participant's message is to support more funding (General - no specific area)	11	22.00	6	30.00	5	16.67	5	22.73	6	21.43
Participant's message is to improve treatments by following the example of other countries that have more advanced systems	8	16.00	2	10.00	7	23.33	5	22.73	4	14.29

	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant's message is to support more research (General - no specific area)	20	40.00	1	16.67	5	35.71	5	55.56	5	45.45	4	40.00
Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition)	15	30.00	1	16.67	3	21.43	5	55.56	3	27.27	3	30.00
Participant's message is increase awareness of mitochondrial disease among the community	12	24.00	2	33.33	5	35.71	3	33.33	0	0.00	2	20.00
Participant's message is to provide more holistic and multidisciplinary/allied health care	12	24.00	1	16.67	3	21.43	2	22.22	4	36.36	2	20.00
Participant's message is to support more funding (General - no specific area)	11	22.00	1	16.67	4	28.57	2	22.22	3	27.27	1	10.00
Participant's message is to improve treatments by following the example of other countries that have more advanced systems	8	16.00	2	33.33	1	7.14	1	11.11	2	18.18	3	30.00

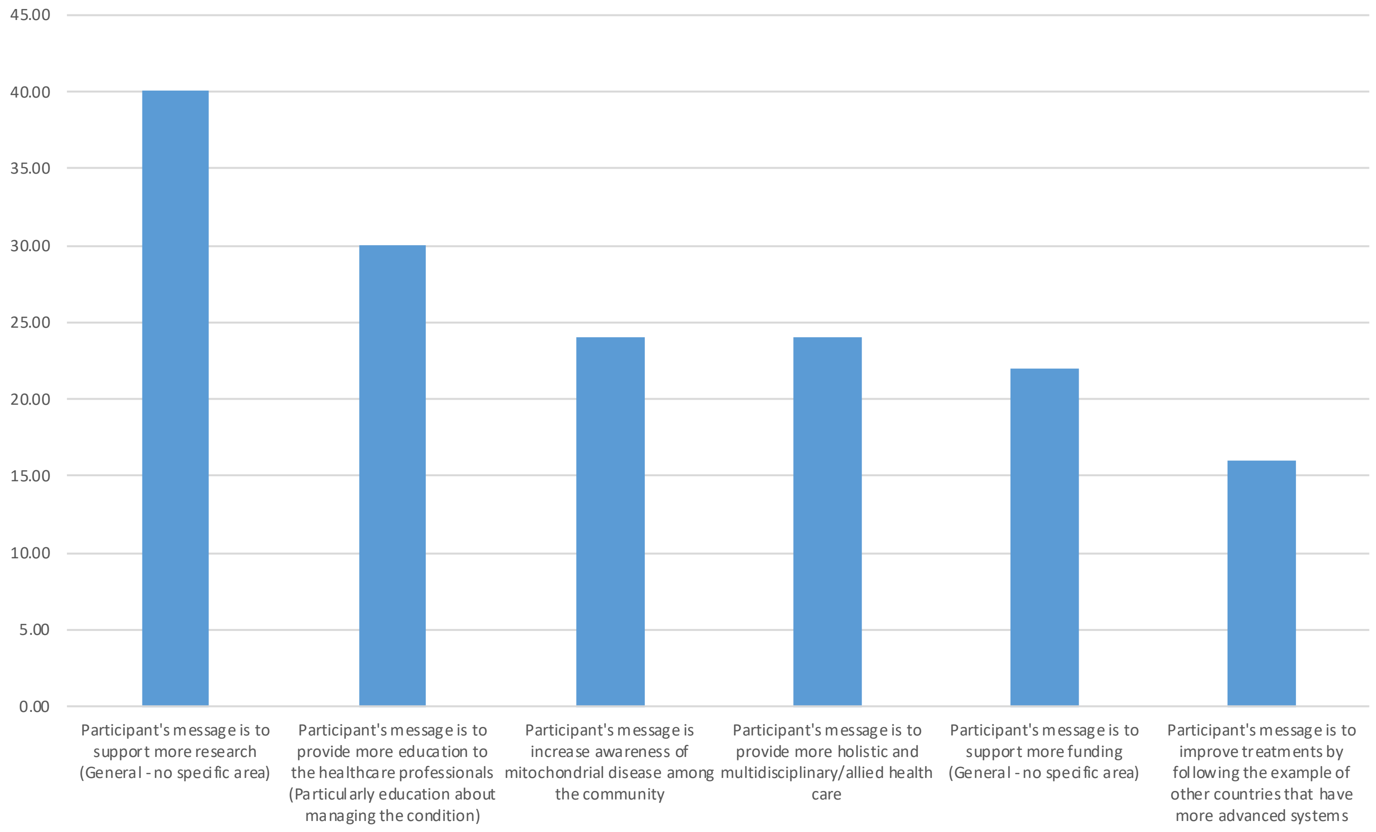

Figure 9.37: Messages to decision-makers (% of all participants)