Section 6 Information and communication

Section 6: Information and communication

Access to information

- The most common response from over half of all participants was accessing information from the Australian Mitochondrial Disease Foundation (n=32, 64.00%). The next most common theme was accessing information via the internet (n=25, 50.00%). There were 14 participants (28.00%) that described accessing information from medical journals and peer reviewed papers and 13 participants (26.00%) that described accessing information from online forums including Facebook.
- In relation to sub-group variations, participants from rural areas (75.00%), participants with a high school or trade education (76.92), participants with low physical functioning (75.00%) and low general health (75.00%) reported accessing information from the Australian Mitochondrial Disease Foundation more frequently than the general population (64.00%), while participants with a university education (50.00%) and high physical functioning reported this less frequently. Participants from rural areas (65.00%) and those with high physical function (68.18%) reported accessing information from the internet more frequently than the general population (50.00%), while those from low socio-economic areas (37.04%) and those with low physical functioning (35.71%) reported this less frequently. Participants from rural areas (15.00%) reported accessing medical journals less frequently than the general population (28.00%).

Information that was helpful

- There was a range of information that participants found particularly helpful including information from the AMDF (n=9, 18.00%) research papers (n=7, 14.00%), communicating with others with mitochondrial disease (n=7, 14.00%) and information from clinical teams (n=5, 10.00%).

Information that was not helpful

- The most common theme described by 22 participant (44.00%) was that no information was unhelpful. There were no other themes noted by more than five participants, however where participants made a comment about information that was not helpful, this included stories about other patients (n=3, 6.00%), lack of concise yet comprehensive information (n=3, 6.00%), and information that is too general (n=2, 4.00%) or too scientific (n=2, 4.00%).

Information preferences

- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common theme was talking to someone (n=25, 50.00%) of which, five participants specified a preference for talking to someone face-to-face. The next most common theme was a preference for information online (n=21, 42.00%) and a preference for information in a written format such as a booklet (n=7, 14.00%).
- In relation to sub-group variations, participants with a hearing impairment (29.12%) described a preference for online information less frequently than the general population (42.00%), while participants with low physical functioning (53.57%) and low general health (53.57%) reported this preference more frequently. Participants with a hearing impairment (25.00%) reported a preference for accessing written information more frequently than the general population (14.00%)

Timing of information

- The most common time that participants described being receptive to receiving information was at the time of diagnosis (n=18, 36.00%) and this was followed by participants describing that there was not a specific time that they were most receptive and that it is an ongoing process (n=10, 20.00%). There were also six participants (12.00%) that described there not being a specific time when they were most receptive - depends on their emotional state and level of interest.
- In relation to sub-group variations, participants with low general health (46.43%) described being most receptive to information at diagnosis, more frequently than the general population (36.00%)

Health professional communication

- Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described most healthcare professionals not knowing about mitochondrial disease (n=11, 22.00%). This was followed by participants being satisfied with health professional communication (n=10, 20.00%). The next most common themes were participants describing excellent communication (n=7, 14.00%), having minimal communication with healthcare professionals (n=6, 12.00%) and mostly good experiences, however there is a general lack of understanding of mitochondrial disease (n=6, 12.00%).
- In relation to sub-group variations, participants from low socio-economic areas (34.78%) described being satisfied with health professional communication more frequently than the general population (20.00%). Participants with high physical function (9.09%) and high general health (4.55%) described most healthcare professionals not knowing about mitochondrial disease less frequently than the general population (22.00%) while those with low physical functioning (32.14%) and low general health (35.71%) described this more frequently. Participants with high social functioning (25.00%) described excellent communication with their specialists more frequently than the general population (14.00%).

Knowledge and confidence

- The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, coping, recognition and management of symptoms, and adherence to treatment. A higher score denotes a better understanding and knowledge of disease.

Partners in health – overall score

- Overall, the participants scored in the top quintile for adherence to treatment indicating very good adherence to treatment. The scores for knowledge, recognition and management of symptoms, and total score were in the second highest quintile indicating good understanding and knowledge of disease. The score for coping was in the middle of the range of scores for this scale.

Partners in health - by general health

- Participants with higher general health had a statistically significant, better outcome for the coping subscale compared those with lower general health.

Partners in health – by physical functioning

- Participants with higher physical functioning had a statistically significant, better outcomes for the coping, adherence to treatment, and total score compared those with lower physical functioning.

Partners in health – by emotional well-being

- Participants with higher emotional well-being had a statistically significant, better outcomes for the coping, adherence to treatment, and total score compared those with lower emotional well-being.

Partners in health – by social functioning

- Participants with higher social functioning had a statistically significant, better outcomes for the coping, and total score compared those with social functioning.

Partners in health – by hearing problems

- No differences were observed between those with no hearing problems and those with hearing problems for any PIH subscale.

Partners in health – by eye problems

- Participants with no eye problems had significantly higher scores for the PIH knowledge, adherence to treatment and total score compared to those with eye problems.

Partners in health – by location

- Participants living in regional or rural areas had had a statistically significant, worse outcomes for the total score subscales compared those living in metropolitan areas.

Partners in health – by education

- No differences were observed between those with university education and those with high school or trade qualifications for any PIH subscale.

Partners in health – by SEIFA

- No differences were observed between those that lived in a higher SEIFA area compared to those that lived in an area with lower SEIFA scores for any PIH subscale.

Information given by health care professionals

- Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently:
- Information about disease cause (50.00%), treatment options (38.00%), and disease management (38.00%) were most frequently given to participants by healthcare professionals.
- Information about clinical trials (14.00%), interpreting test results (14.00%) and complementary therapies (16.00%) were give least often.
- Eight participants (16.00%) indicated that they received no information at all from health professionals about mitochondrial disease.

Information searched for independently

- Participants were asked about what type of information they searched for after receiving information from healthcare professionals:
- Information about treatment options (63.27%), disease management (59.18%), and disease cause (57.14%) were most frequently given to searched for independently.
- Information about interpreting test results (28.57%), hereditary, genes and biomarkers (28.57%) and psychological support (30.61%) were give least often.

Gaps in Information obtained

- The largest gaps in information, where information was neither given to patients nor searched for independently were how to interpret test results (62.00%), and psychological/social support (56.00%).
- Participants were given most information either from healthcare professionals or independently for treatment options (78.00%) and disease cause (78.00%).
- Clinical trials (42.00%) was the topic that was most searched for independently following no information from health professionals.

Most trusted information sources

- Across all participants, information from the participants' hospital or clinic and from the non-profit or charitable organisations was near equal and was most trusted. Information from pharmaceutical companies was least trusted. This order of preference was the same for all sub-groups.

Access to information

Participants were asked what information they had accessed in relation to their condition. The most common response from over half of all participants was accessing information from the Australian Mitochondrial Disease Foundation (n=32, 64.00%). The next most common theme was accessing information via the internet (n=25, 50.00%).

Participant describes accessing information from the Australian Mitochondrial Disease Foundation

Most of it's been on the AMDF website or phoning them. They've been very beneficial to me. Participant 6

Well, so once again, the foundation website is amazing. Basically I've used that foundation website, and then I've breadcrumbed. Participant 7

The AMDF has been very good. They've produce booklets, and of course there's what's online as well. Participant 34

The Australian Mitochondrial Disease Foundation actually sponsored me to go to an information day where I learned quite a bit, and spoke to other people that had similar or worse situations, and children with the disease, and became more aware of all the different forms that it can take. Participant 36

…the AMDF have had a lot more information on their website. They do an information session once a year and they publish a booklet that you can give to your GP. That's quite informative. Probably the Mitochondrial Disease Foundation provide the most information. Participant 43

Participant describes accessing information from the internet (general searching e.g. google)

So far as information that I've been able to get them myself is basically Dr. Google who's been the other source. It makes a severely dire reading. Participant 2

Internet's wonderful, just Mr. Google. Participant 4

Well, just most of it's been through the Internet. I'd say just about all of it's been through the Internet really. Participant 13

What I read on Google and the books they were sending out to me when I was first diagnosed, doing a lot of researching mitochondria. Participant 17

Really, what I can find on Google. Participant 18

I would say, most of it, we've actually done ourselves through Google. Participant 50

There were 14 participants (28.00%) that described accessing information from medical journals and peer reviewed papers and 13 participants (26.00%) that described accessing information from online forums including Facebook.

Participant describes accessing medical journals, peer reviewed papers

I have access to a lot of information. I've done a lot of research online looking at various published journal articles, looking at resources from the NPS website. Participant 8

If something interesting pops up or something new pops up or every now and then, I'll just look through the databases about some new research that's going on with mitochondrial disease. I have like quite a lot of information. Participant 11

Written public scientific publications. Anyone who's done things in that area, I have tried to keep up to date with...I also get articles from Pubmed and a few other places out to me most days. It's mainly literature and speakers in the area. Participant 27

Medical journals, medical textbooks, internet – I look for high quality published materials. Participant 30

I tried through Elsevier that you can get. I had the Lancet coming as email every week. Participant 32

So it's quite a information out then there's a number research papers on mitochondria and you can get in and do research on mitochondrial disease and other things and there's a lot of research papers you can read up on. Participant 42

Participant describes accessing information from online forums for mitochondrial disease (including Facebook)

...one of the most useful things is the Facebook groups with people who are -- There's one called Mito Café and just one for adults with Mitochondrial disease. There's a lot of people on that one, but often you'll post about something or ask a question and people will have their own experience that they can contribute. Participant 5

There are online forums which I've taken part of and also try and speak to other people who have been affected by this. Participant 8

I think the most information I've ever been able to find has come through a lady that I found out about on the internet via Facebook. Participant 28

In relation to sub-group variations, participants from rural areas (75.00%), participants with a high school or trade education (76.92), participants with low physical functioning (75.00%) and low general health (75.00%) reported accessing information from the Australian Mitochondrial Disease Foundation more frequently than the general population (64.00%), while participants with a university education (50.00%) and high physical functioning reported this less frequently. Participants from rural areas (65.00%) and those with high physical function (68.18%) reported accessing information from the internet more frequently than the general population (50.00%), while those from low socio-economic areas (37.04%) and those with low physical functioning (35.71%) reported this less frequently. Participants from rural areas (15.00%) reported accessing medical journals less frequently than the general population (28.00%).

Table 6.1: Access to information

Information accessed	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes accessing information from the Australian Mitochondrial Disease Foundation	**32**	64.00	17	56.67	15	**75.00**	16	59.26	16	69.57
Participant describes accessing information from the internet (general searching e.g. google)	**25**	50.00	12	40.00	13	**65.00**	10	**37.04**	15	65.22
Participant describes accessing medical journals, peer reviewed papers	**14**	28.00	11	36.67	3	**15.00**	9	33.33	5	21.74
Participant describes accessing information from their clinician	**13**	26.00	9	30.00	4	20.00	9	33.33	4	17.39
Participant describes accessing information from online forums for mitochondrial disease (including Facebook)	**7**	14.00	4	13.33	3	15.00	1	**3.70**	6	26.09
Participant describes accessing information from mitochondrial foundations websites	**6**	12.00	4	13.33	2	10.00	3	11.11	3	13.04

Information accessed	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 accessing information from the Australian Mitochondrial Disease Foundation	**32**	64.00	20	**76.92**	12	**50.00**	16	66.67	24	70.59
Participant describes accessing information from the internet (general searching e.g. google)	**25**	50.00	14	53.85	11	45.83	13	54.17	20	58.82
Participant describes accessing medical journals, peer reviewed papers	**14**	28.00	6	23.08	8	33.33	6	25.00	7	20.59
Participant describes accessing information from their clinician	**13**	26.00	6	23.08	7	29.17	6	25.00	7	20.59
Participant describes accessing information from online forums for mitochondrial disease (including Facebook)	**7**	14.00	3	11.54	4	16.67	3	12.50	6	17.65
Participant describes accessing information from mitochondrial foundations websites	**6**	12.00	3	11.54	3	12.50	2	8.33	5	14.71

Information accessed	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 accessing information from the Australian Mitochondrial Disease Foundation	**32**	64.00	11	**50.00**	21	**75.00**	14	53.85	18	**75.00**
Participant describes accessing information from the internet (general searching e.g. google)	**25**	50.00	15	**68.18**	10	**35.71**	12	46.15	13	54.17
Participant describes accessing medical journals, peer reviewed papers	**14**	28.00	4	18.18	10	35.71	6	23.08	8	33.33
Participant describes accessing information from their clinician	**13**	26.00	5	22.73	8	28.57	8	30.77	5	20.83
Participant describes accessing information from online forums for mitochondrial disease (including Facebook)	**7**	14.00	5	22.73	2	7.14	4	15.38	3	12.50
Participant describes accessing information from mitochondrial foundations websites	**6**	12.00	2	9.09	4	14.29	2	7.69	4	16.67

Information accessed	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 accessing information from the Australian Mitochondrial Disease Foundation	**32**	64.00	12	60.00	20	66.67	11	50.00	21	**75.00**
Participant describes accessing information from the internet (general searching e.g. google)	**25**	50.00	11	55.00	14	46.67	13	59.09	12	42.86
Participant describes accessing medical journals, peer reviewed papers	**14**	28.00	4	20.00	10	33.33	4	18.18	10	35.71
Participant describes accessing information from their clinician	**13**	26.00	6	30.00	7	23.33	7	31.82	6	21.43
Participant describes accessing information from online forums for mitochondrial disease (including Facebook)	**7**	14.00	4	20.00	3	10.00	3	13.64	4	14.29
Participant describes accessing information from mitochondrial foundations websites	**6**	12.00	4	20.00	2	6.67	1	4.55	5	17.86

Information accessed	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 accessing information from the Australian Mitochondrial Disease Foundation	**32**	64.00	5	83.33	5	35.71	7	77.78	6	54.55	9	90.00
Participant describes accessing information from the internet (general searching e.g. google)	**25**	50.00	1	16.67	8	57.14	5	55.56	8	72.73	3	30.00
Participant describes accessing medical journals, peer reviewed papers	**14**	28.00	2	33.33	6	42.86	1	11.11	3	27.27	2	20.00
Participant describes accessing information from their clinician	**13**	26.00	2	33.33	4	28.57	2	22.22	2	18.18	3	30.00
Participant describes accessing information from online forums for mitochondrial disease (including Facebook)	**7**	14.00	0	0.00	5	35.71	1	11.11	1	9.09	0	0.00
Participant describes accessing information from mitochondrial foundations websites	**6**	12.00	0	0.00	1	7.14	2	22.22	1	9.09	2	20.00

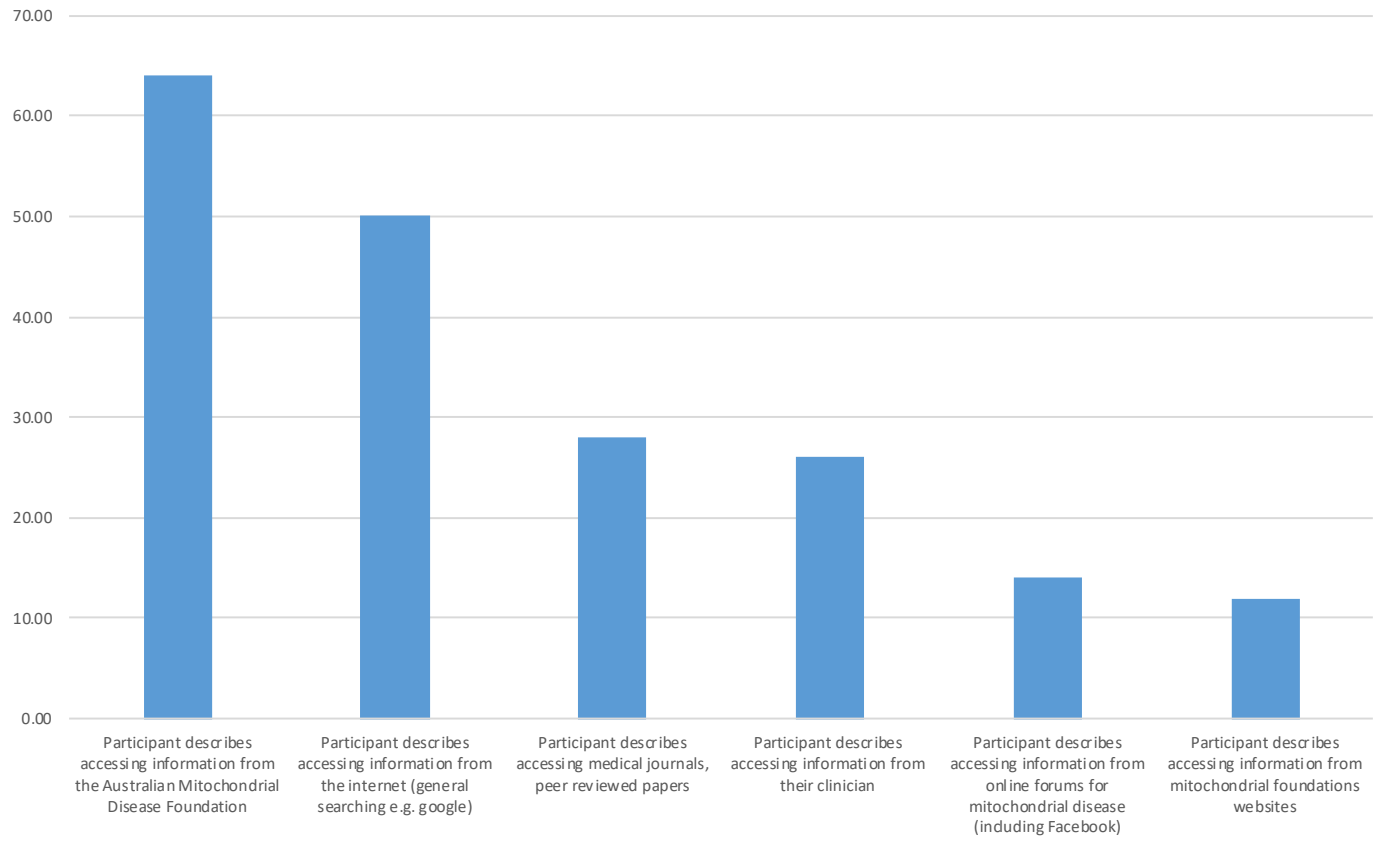


Figure 6.1: Access to information (% of all participants)

Information that was helpful

After talking about all of the information that participants had received, they were then asked what information had been helpful. There was a range of information that participants found particularly helpful including information from the AMDF (n=9, 18.00%) research papers (n=7, 14.00%), communicating with others with mitochondrial disease (n=7, 14.00%) and information from clinical teams (n=5, 10.00%).

Participant describes the AMDF as being helpful

The AMDF is really great for information. Participant 10

I have to say the AMDF focus has been possibly the most useful document, not just for me. I've been able to give that to my GP who herself, she didn't know what ALS was until I came along. I don't know whether she's read it or not. [Interviewer: you've given it to her?] I've given it to her and various other physicians that I was dealing with or friends, my mother. That was a really useful, eye-opening document for me. Also for me, being able to tell other people or show other people or let them know what it was. Participant 20

One lady, NAME from the AMDF was exceptionally useful. She was really helpful on a personal level. I had contacted her a couple times which was really, really good. Participant 26

Definitely, the mitochondrial disease foundation . Participant 43

Participant describes no information being specifically helpful

There's no information that's really helpful. A lot of it's interesting. There's nothing helpful. Participant 21

It's hard for me because I've already studied that. It's the same stuff as what I've already studied. I find it a bit repetitive also when you go through one website and then you go through another. Even one in America or something, they're all sort of similar in one sense or another. That's what I find. Participant 22

Well, there's none. None has been helpful at all really because it'd be the way you read if you would know if you've had anything to do with it. It's always CoQ_{10} is always mentioned which I have taken since 2000. None. Nothing. No. Participant 31

Participant describes current research papers as being helpful

There's a fantastic published article which talks about the different variations of LHON and percentage of prevalence between males and females, percentages of affectation within people, and also percentage of recovery because some types actually lead towards some recovery. It's a little bit tricky. I tend to look for different types of research at different times so it's hard to say which one is the best. Participant 8

I guess information that has some science base to it, some information where there is some-- they make it clear how many people they have looked at to make this out in their conclusions or something. Because often, you'll read an article and find out it was only one person, there were two people that we're talking about, just the sample size really isn't big enough to be sure that's right. Participant 13

Probably the written published articles as well if there's a specialist who has something that said something that's new to me then I would certainly listen to them and then go and try and research it. Participant 27

I don't know. I'd have to say more in the trials, new research, that kind of stuff probably. Participant 45

Participant describes communicating with others with mitochondrial disease as helpful

There's Facebook. It's very good because people will share resources and experiences. And there are international Facebook pages and that's better than Australia. Australia is just so far behind everybody else from what I can see. In terms of trials and things like that and the mitochondrial association networks. Those ones are probably the main ones and my own in the...When people put mitochondrial news bulletin in published recent studies and then I follow the studies and take it from there. Participant 3

Just individual people's stories is quite reassure-- It's very upsetting, but it can be reassuring too that you think, "Well, I'm not mad." This is what's been happening to me", the sort of thing. Participant 34

The most helpful one was actually finding that group, which my doctor absolutely had no idea. He didn't even know ... He knows what mitochondrial is, but very vague and basic to the point that he even prescribed me something that I went, "Hey, is that from this or that group of drug?" Participant 40

Participant describes information form clinical team as being helpful

I think, first off, when I got it, I actually talked to a GP that specialised in it just to have an idea about maybe some of the things you can do.... One of the things, you know, you see other, what do you call it, I call it peptides, but probably other, you know, you think, oh, should I take it? I wouldn't take it without...well, without a specialist, ... Telling me, "Yeah, that's okay.",or "That's not okay.", as far as you don't know, whether it's, you know, bogus information or not. Participant 15

Probably the written published articles as well if there's a specialist who has something that said something that's new to me then I would certainly listen to them and then go and try and research it. Participant 27

Receiving the information, what was the most helpful? I suppose some of the things that the neurologist just said to us where she has actually probably had some clients that she has seen that are in their teens and early 20s. Well, I guess helpful probably would be more that it's being more easing on our minds, that's positive information from her that she's had clients that are older than NAME, in their late teens and doing really well and they've continued to thrive regardless of having Leigh's disease. Participant 50

Table 6.2: Information that was helpful

Information that has been helpful	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes the AMDF as being helpful	9	18.00	5	16.67	4	20.00	4	14.81	5	21.74
Participant describes no information being specifically helpful	8	16.00	4	13.33	4	20.00	3	11.11	5	21.74
Participant describes current research papers as being helpful	7	14.00	5	16.67	2	10.00	5	18.52	2	8.70
Participant describes communicating with others with mitochondrial disease as most useful	7	14.00	4	13.33	3	15.00	3	11.11	4	17.39
Participant describes information form clinical team as being helpful	5	10.00	4	13.33	1	5.00	4	14.81	1	4.35

Information that has been helpful	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 the AMDF as being helpful	9	18.00	3	11.54	6	25.00	5	20.83	7	20.59
Participant describes no information being specifically helpful	8	16.00	6	23.08	2	8.33	4	16.67	5	14.71
Participant describes current research papers as being helpful	7	14.00	3	11.54	4	16.67	2	8.33	5	14.71
Participant describes communicating with others with mitochondrial disease as most useful	7	14.00	4	15.38	3	12.50	2	8.33	5	14.71
Participant describes information form clinical team as being helpful	5	10.00	2	7.69	3	12.50	2	8.33	2	5.88

Information that has been helpful	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 the AMDF as being helpful	9	18.00	5	22.73	4	14.29	5	19.23	4	16.67
Participant describes no information being specifically helpful	8	16.00	4	18.18	4	14.29	3	11.54	5	20.83
Participant describes current research papers as being helpful	7	14.00	3	13.64	4	14.29	6	23.08	1	4.17
Participant describes communicating with others with mitochondrial disease as most useful	7	14.00	3	13.64	4	14.29	4	15.38	3	12.50
Participant describes information form clinical team as being helpful	5	10.00	4	18.18	1	3.57	3	11.54	2	8.33

Information that has been helpful	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 the AMDF as being helpful	9	18.00	5	25.00	4	13.33	4	18.18	5	17.86
Participant describes no information being specifically helpful	8	16.00	3	15.00	5	16.67	4	18.18	4	14.29
Participant describes current research papers as being helpful	7	14.00	3	15.00	4	13.33	3	13.64	4	14.29
Participant describes communicating with others with mitochondrial disease as most useful	7	14.00	3	15.00	4	13.33	2	9.09	5	17.86
Participant describes information form clinical team as being helpful	5	10.00	3	15.00	2	6.67	4	18.18	1	3.57

Information that has been helpful	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 the AMDF as being helpful	9	18.00	0	0.00	5	35.71	1	11.11	2	18.18	1	10.00
Participant describes no information being specifically helpful	8	16.00	1	16.67	1	7.14	2	22.22	2	18.18	2	20.00
Participant describes current research papers as being helpful	7	14.00	1	16.67	3	21.43	2	22.22	1	9.09	0	0.00
Participant describes communicating with others with mitochondrial disease as most useful	7	14.00	2	33.33	2	14.29	1	11.11	2	18.18	0	0.00
Participant describes information form clinical team as being helpful	5	10.00	1	16.67	0	0.00	1	11.11	1	9.09	2	20.00

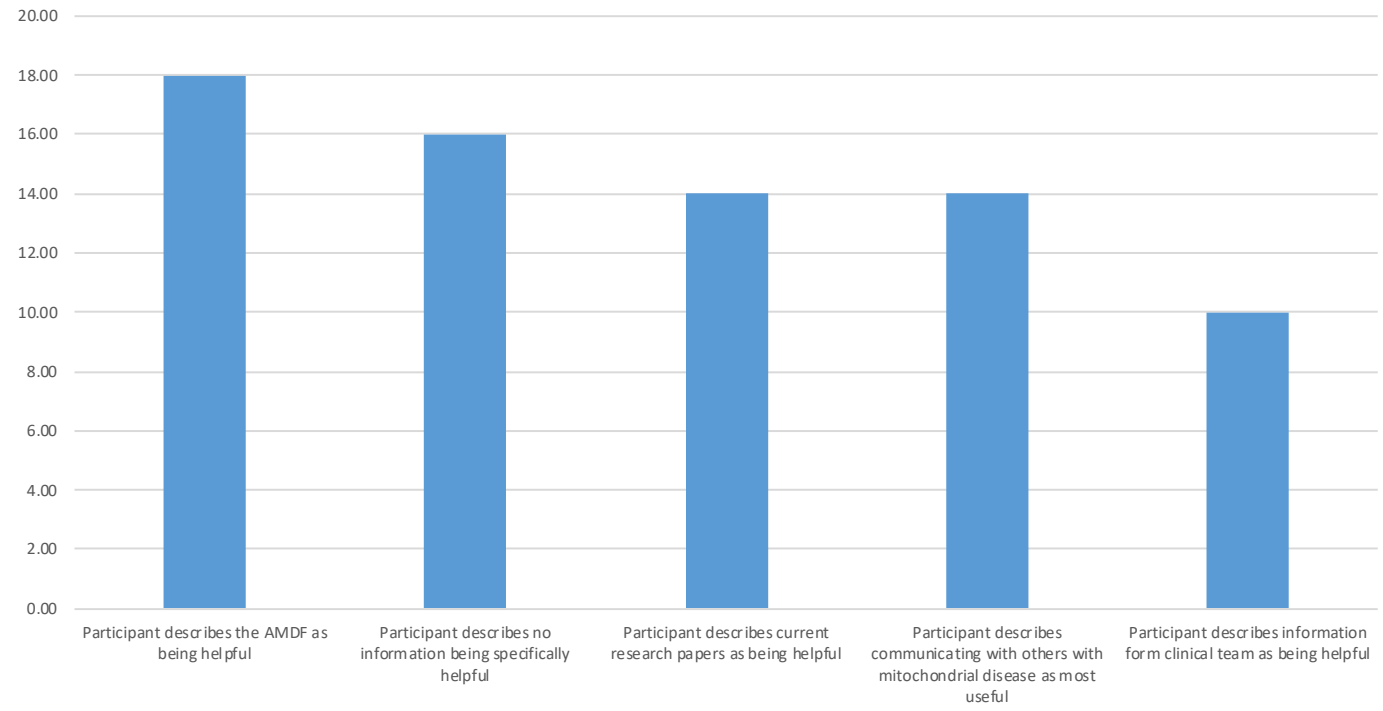


Figure 6.2: Information that was helpful

Information that was not helpful

Participants were asked whether there was any information they had come across that was not helpful. The most common theme described by 22 participant s(44.00%) was that no information was unhelpful:

Participant describes no information as being unhelpful

Not really because I find that altogether it paints a picture. I think it would be quite useful to have it all in one spot if possible and I know that that's something that the foundation has been working towards…but it is also tricky because there are so many different types of mito. It's hard to have a definitive resource library on each. Participant 8

No, it's all relevant to what's going on and it's helpful in a way that it takes you up with what I'm doing now with HOSPITAL that came from AMDF. I wouldn't have gone down that track if I didn't have any of the literature or anything from the AMDF. Participant 35

No, I haven't come across anything that's a bit weird or whacky or anything like that. Participant 42

There were no other themes noted by more than five participants, however where participants made a comment about information that was not helpful, this included stories about other patients (n=3, 6.00%), lack of concise yet comprehensive information (n=3, 6.00%), and information that is too general (n=2, 4.00%) or too scientific (n=2, 4.00%).

Table 6.3: Information that was not helpful

Information that has not been helpful	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes no information as being unhelpful	22	44.00	13	43.33	9	45.00	10	37.04	12	52.17
Participant describes the stories about other patients as unhelpful	3	6.00	1	3.33	2	10.00	2	7.41	1	4.35
Participant describes the lack of concise and comprehensive information as unhelpful	3	6.00	1	3.33	2	10.00	1	3.70	2	8.70
Participant describes not knowing if information is helpful or unhelpful	2	4.00	2	6.67	0	0.00	2	7.41	0	0.00
Participant describes information that is too general (not specific to their type of disease) as unhelpful	2	4.00	1	3.33	1	5.00	1	3.70	1	4.35
Participant describes information that is too scientific as unhelpful	2	4.00	0	0.00	2	10.00	1	3.70	1	4.35
Participant describes health professionals that do not take a holistic approach as unhelpful	2	4.00	2	6.67	0	0.00	1	3.70	1	4.35

Information that has not been helpful	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 no information as being unhelpful	22	44.00	14	53.85	8	33.33	10	41.67	16	47.06
Participant describes the stories about other patients as unhelpful	3	6.00	2	7.69	1	4.17	2	8.33	1	2.94
Participant describes the lack of concise and comprehensive information as unhelpful	3	6.00	0	0.00	3	12.50	2	8.33	3	8.82
Participant describes not knowing if information is helpful or unhelpful	2	4.00	2	7.69	0	0.00	1	4.17	2	5.88
Participant describes information that is too general (not specific to their type of disease) as unhelpful	2	4.00	0	0.00	2	8.33	2	8.33	0	0.00
Participant describes information that is too scientific as unhelpful	2	4.00	1	3.85	1	4.17	2	8.33	2	5.88
Participant describes health professionals that do not take a holistic approach as unhelpful	2	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Information that has not been helpful	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 no information as being unhelpful	22	44.00	10	45.45	12	42.86	12	46.15	10	41.67
Participant describes the stories about other patients as unhelpful	3	6.00	1	4.55	2	7.14	3	11.54	0	0.00
Participant describes the lack of concise and comprehensive information as unhelpful	3	6.00	1	4.55	2	7.14	1	3.85	2	8.33
Participant describes not knowing if information is helpful or unhelpful	2	4.00	1	4.55	1	3.57	1	3.85	1	4.17
Participant describes information that is too general (not specific to their type of disease) as unhelpful	2	4.00	2	9.09	0	0.00	1	3.85	1	4.17
Participant describes information that is too scientific as unhelpful	2	4.00	1	4.55	1	3.57	1	3.85	1	4.17
Participant describes health professionals that do not take a holistic approach as unhelpful	2	4.00	0	0.00	2	7.14	1	3.85	1	4.17

Information that has not been helpful	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 no information as being unhelpful	22	44.00	8	40.00	14	46.67	10	45.45	12	42.86
Participant describes the stories about other patients as unhelpful	3	6.00	1	5.00	2	6.67	2	9.09	1	3.57
Participant describes the lack of concise and comprehensive information as unhelpful	3	6.00	2	10.00	1	3.33	1	4.55	2	7.14
Participant describes not knowing if information is helpful or unhelpful	2	4.00	1	5.00	1	3.33	1	4.55	1	3.57
Participant describes information that is too general (not specific to their type of disease) as unhelpful	2	4.00	0	0.00	2	6.67	1	4.55	1	3.57
Participant describes information that is too scientific as unhelpful	2	4.00	1	5.00	1	3.33	0	0.00	2	7.14
Participant describes health professionals that do not take a holistic approach as unhelpful	2	4.00	0	0.00	2	6.67	0	0.00	2	7.14

Information that has not been helpful	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 no information as being unhelpful	22	44.00	4	66.67	5	35.71	6	66.67	2	18.18	5	50.00
Participant describes the stories about other patients as unhelpful	3	6.00	1	16.67	0	0.00	0	0.00	1	9.09	1	10.00
Participant describes the lack of concise and comprehensive information as unhelpful	3	6.00	0	0.00	2	14.29	0	0.00	0	0.00	1	10.00
Participant describes not knowing if information is helpful or unhelpful	2	4.00	0	0.00	1	7.14	1	11.11	0	0.00	0	0.00
Participant describes information that is too general (not specific to their type of disease) as unhelpful	2	4.00	0	0.00	1	7.14	0	0.00	1	9.09	0	0.00
Participant describes information that is too scientific as unhelpful	2	4.00	0	0.00	0	0.00	0	0.00	2	18.18	0	0.00
Participant describes health professionals that do not take a holistic approach as unhelpful	2	4.00	0	0.00	2	14.29	0	0.00	0	0.00	0	0.00

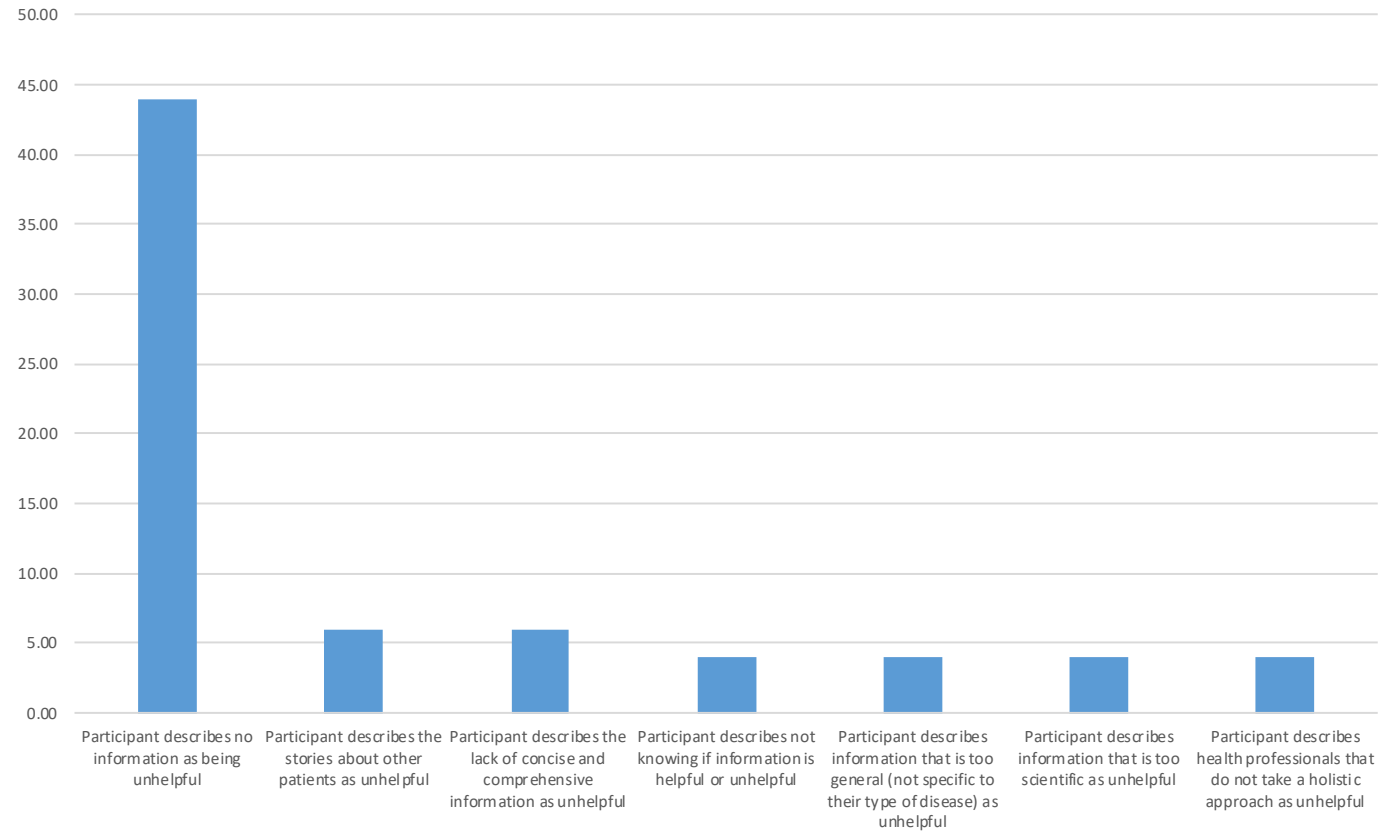


Figure 6.3: Information that was not helpful (% of all participants)

Information preferences (Format of information)

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common theme was talking to someone (n=25, 50.00%) of which, five participants specified a preference for talking to someone face-to-face.

Participant describes preferring to talk to someone

I suppose my preference, it would be getting the information and then talking through it. Yes, that's sort of. Then, that's a good thing that my daughter comes to the appointment because she understands it a lot more, having a medical background. Then we can talk about through that. Participant 1

I tend to prefer, I'm fortunately not a millennial, but I tend to prefer to talk to someone because then generally the information that's given then become very specific to you rather then the online thing where it's just, sort of, it can become specific, but it's, what's the word, yeah, so I prefer to talk to someone about it rather because I figure rightly or wrongly you get a better understanding…Yes. Tell it to you rather than, sort of, this is general. Participant 15

Participant describes preferring to talk to someone (face-to-face)

I prefer to speak to someone face to face …Because I got cataracts in my eyes from my immune-suppressants hormone they've developed. I can't read too well. I'm using a magnifying glass at present [laughs]. Participant 6

Probably because of the way I learn, so I like to hear something, I like to have a discussion, and I like to read, so having something that's audio-visual and face-to-face would be my preferred option. Participant 7

Most of my questions, every time I go, it's quite a long consultation with Doctor NAME, she's quite thorough and everything, she just goes over anything that's happened to me with all my medical conditions. Participant 16

The next most common theme was a preference for information online (n=21, 42.00%) and a preference for information in a written format such as a booklet (n=7, 14.00%).

Participant describes preferring information online

I prefer it online because I like to be able to read it and digest it on my own time. I think one of the hard parts about having something like Mito is, the doctor will will speak at you, but you have no record, you can't go, what was it that they said and what was that word that they used again. Although I like people usually talking something through with me. I think reading it online is the most useful, then you can Google all the words if you don't know them or something. It just means you can digest it in your own time. Participant 5

I think with my experiences so far, online information has been more effective than talking to people. Mainly because a lot of people that I talk to don't really know how to help. Also, a lot of people that I talk to have dozens of other patients as well. I feel like sometimes they don't spend enough time with all their patients. Participant 11

I think online is the most accessible. You can always review it over and over again. If you have a conversation with someone, you sometimes miss some of that information or sometimes it's just too much for you. I think having it online is really useful. Participant 26

Participant describes preferring information in a written format like a booklet

Also, just sometimes it's a quickness and for each information can be a lot easier in terms of booklet from…No, sorry. I just thought I think know in terms of booklet, that one is quite handy. I like being able to hold onto something and can look at it but if I move quite a bit, it's a bit tricky to always access them or keep them. Participant 8

I like to try a more…it's just by an invitation in reading and thinking, I suppose. I was very pleased to get the booklets from AMDF. Participant 17

On paper is good, so I can keep it and think about it. Participant 24

In relation to sub-group variations, participants with a hearing impairment (29.12%) described a preference for online information less frequently than the general population (42.00%), while participants with low physical functioning (53.57%) and low general health (53.57%) reported this preference more frequently. Participants with a hearing impairment (25.00%) reported a preference for accessing written information more frequently than the general population (14.00%).

Table 6.4: Information preferences (Format)

Information preferences	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes preferring to talk to someone	20	40.00	12	40.00	8	40.00	12	44.44	8	34.78
Participant describes preferring to talk to someone (face-to-face)	5	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant describes preferring information online	21	42.00	13	43.33	9	45.00	10	37.04	12	52.17
Participant describes preferring information in a written format like a booklet	7	14.00	5	16.67	2	10.00	4	14.81	3	13.04
Participant describes not having a preferred information format and/or various modes are acceptable	6	12.00	5	16.67	1	5.00	6	22.22	0	0.00
Participant describes preferring information from their specialist	5	10.00	4	13.33	1	5.00	2	7.41	3	13.04

Information preferences	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 preferring to talk to someone	20	40.00	11	42.31	9	37.50	13	54.17	11	32.35
Participant describes preferring to talk to someone (face-to-face)	5	10.00	2	7.69	3	12.50	2	8.33	3	8.82
Participant describes preferring information online	21	42.00	12	46.15	10	41.67	7	29.17	16	47.06
Participant describes preferring information in a written format like a booklet	7	14.00	2	7.69	5	20.83	6	25.00	3	8.82
Participant describes not having a preferred information format and/or various modes are acceptable	6	12.00	4	15.38	2	8.33	4	16.67	3	8.82
Participant describes preferring information from their specialist	5	10.00	4	15.38	1	4.17	1	4.17	5	14.71

Information preferences	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 preferring to talk to someone	20	40.00	11	50.00	9	32.14	12	46.15	8	33.33
Participant describes preferring to talk to someone (face-to-face)	5	10.00	2	9.09	3	10.71	2	7.69	3	12.50
Participant describes preferring information online	21	42.00	7	31.82	15	53.57	12	46.15	10	41.67
Participant describes preferring information in a written format like a booklet	7	14.00	3	13.64	4	14.29	5	19.23	2	8.33
Participant describes not having a preferred information format and/or various modes are acceptable	6	12.00	3	13.64	3	10.71	3	11.54	3	12.50
Participant describes preferring information from their specialist	5	10.00	2	9.09	3	10.71	3	11.54	2	8.33

Information preferences	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 preferring to talk to someone	20	40.00	6	30.00	14	46.67	10	45.45	10	35.71
Participant describes preferring to talk to someone (face-to-face)	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14
Participant describes preferring information online	21	42.00	9	45.00	13	43.33	7	31.82	15	53.57
Participant describes preferring information in a written format like a booklet	7	14.00	2	10.00	5	16.67	5	22.73	2	7.14
Participant describes not having a preferred information format and/or various modes are acceptable	6	12.00	3	15.00	3	10.00	3	13.64	3	10.71
Participant describes preferring information from their specialist	5	10.00	2	10.00	3	10.00	2	9.09	3	10.71

Information preferences	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 preferring to talk to someone	**20**	40.00	2	33.33	5	35.71	4	44.44	4	36.36	5	50.00
Participant describes preferring to talk to someone (face-to-face)	**5**	10.00	0	0.00	0	0.00	2	22.22	1	9.09	2	20.00
Participant describes preferring information online	**21**	42.00	4	66.67	9	64.29	2	22.22	4	36.36	3	30.00
Participant describes preferring information in a written format like a booklet	**7**	14.00	1	16.67	2	14.29	0	0.00	2	18.18	2	20.00
Participant describes not having a preferred information format and/or various modes are acceptable	**6**	12.00	0	0.00	1	7.14	1	11.11	2	18.18	2	20.00
Participant describes preferring information from their specialist	**5**	10.00	1	16.67	1	7.14	1	11.11	1	9.09	1	10.00

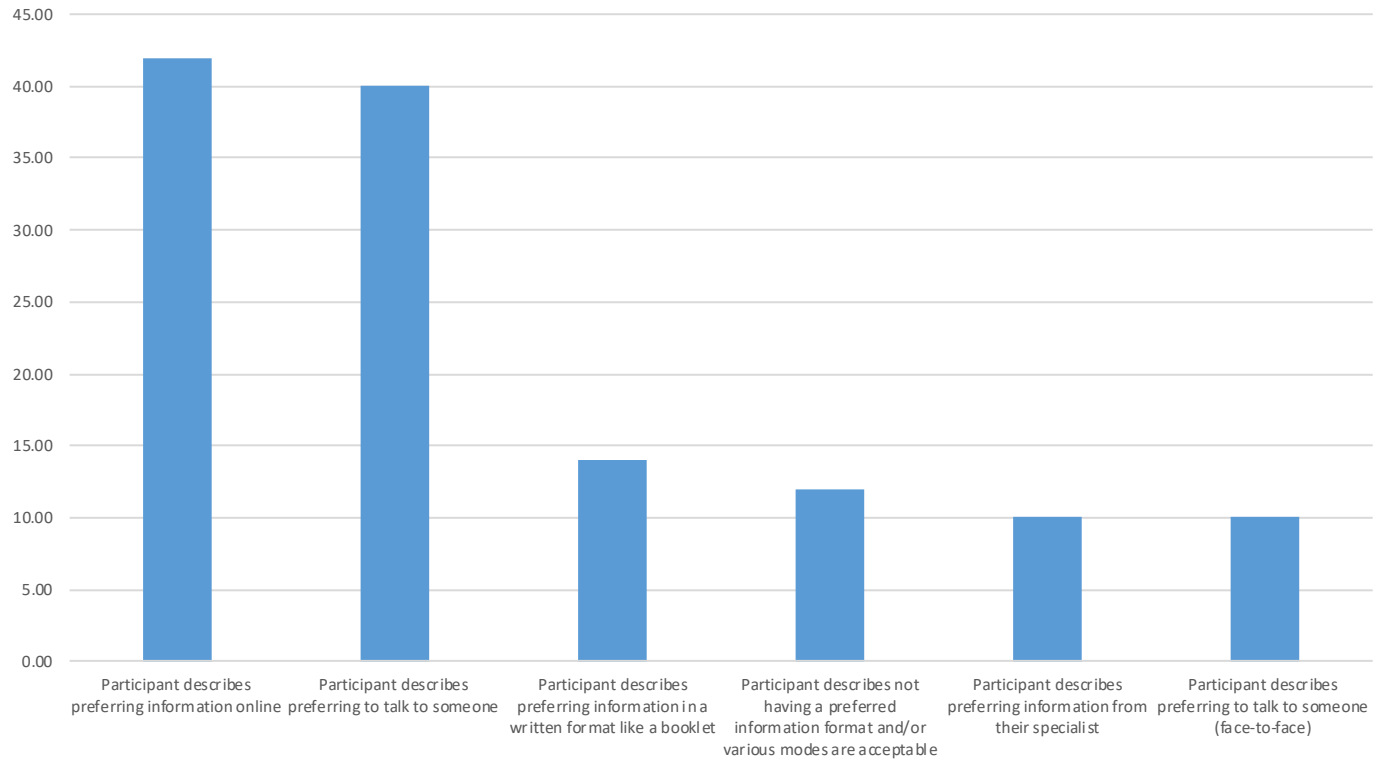


Figure 6.4: Information preferences – Format
(% of all participants)

Information preferences (Timing of information)

Participants were asked to reflect on their experience and think about when they were most receptive to receiving information, not when they actually received the information, but when they felt they could take it all in. The most common time that participants described being receptive to receiving information was at the time of diagnosis (n=18, 36.00%).

Participant describes being most receptive when they were first diagnosed (beginning)

I think the most, because I wanted to know, was at the very beginning when I had never heard of it and just wasn't being talked about. I wanted to be aware and informed and that's why I actually sorted out a lot of information so I could find it out for myself and help my family with that. Participant 8

Yes, at first because I knew about the mitochondrial. In humans, in all cases, I wanted to learn more about it and to understand it a bit more. I knew what's going on. It's like if you say to someone, "I've got cancer," they understand. They know what's going to happen. Where will I say, "Okay. We've got mitochondrial disease." "MELAS huh, what's that?" They still don't grasp it. I'd like to teach that person as much as I can as well to pass that information on. Participant 22

Yes. I think around the diagnosing process and around when we're doing the muscle biopsies and things like that. I was pretty keen on trying to understand what I could do and now I sort of got an understanding that I'm very limited in what I can do. Participant 49

The next most common theme was participants describing that there was not a specific time that they were most receptive and that it is an ongoing process (n=10, 20.00%).

Participant describes there not being a specific time when they were most receptive - an ongoing process

Not really. I think when you're…I think that's the time when you're like, "Tell me everything. I want to know. I want to know. I want to know", but you don't take it in. It's later on that you can have time to sit back and go through things a little bit more then it all starts to sink in. There's not really a time as such. It's on-going. Participant 10

That's overwhelming, anything after that doesn't matter. Is there a time that's most receptive to receiving information? No, I would say to people if you've had the tests and you're now going to get the results for potentially a diagnosis. Take someone with you that can take notes. Because your brain becomes paralysed. And you're overwhelmed with information that you don't understand, in most cases. And even though the doctor's trying to explain it to you, you kind of stop thinking. It's hard to explain. Yeah, your brain stops listening. The brain stops listening and it starts thinking about all sorts of possibility. So you don't absorb. So you need somebody else there with you. Well to take notes preferably, yeah to take notes. Participant 24

That's a hard one. Yeah, we always knew it wasn't going to be what we wanted to hear, so yeah. No, there would have never been a better time. Participant 46

There were also six participants (12.00%) that described there not being a specific time when they were most receptive - depends on their emotional state and level of interest.

Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest

Look, I think at any time, because I think if I receive the information, and I'm not up to looking at it, or reading it, or dealing with it, I'll just put it into a folder and come back to it later, so at any time, really. Participant 7

You really needed somebody to guide you then, and there wasn't anyone. You just have to do it, you can't drop your bundle. Participant 28

When will I be most receptive? Probably when I'm in a good mood. [laughs] Does that make sense, if I'm not depressed and feeling blue. Participant 42

In relation to sub-group variations, participants with low general health (46.43%) described being most receptive to information at diagnosis, more frequently than the general population (36.00%)

Table 6.5: Information preferences (Timing)

Timing of information	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes being most receptive when they were first diagnosed (beginning)	**18**	36.00	13	43.33	5	25.00	11	40.74	7	30.43
Participant describes there not being a specific time when they were most receptive - an ongoing process	**10**	20.00	5	16.67	5	25.00	7	25.93	3	13.04
Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest	**6**	12.00	3	10.00	3	15.00	2	7.41	4	17.39
Participant describes not being receptive during diagnosis but being more receptive post diagnosis	**3**	6.00	1	3.33	2	10.00	1	3.70	2	8.70
Participant describes being always receptive to receiving information	**2**	4.00	1	3.33	1	5.00	1	3.70	1	4.35
Participant describes being most receptive a year(s) after diagnosis	**2**	4.00	1	3.33	1	5.00	0	0.00	2	8.70
Participant describes being more receptive now once learning more about the disease, compared to the beginning	**2**	4.00	1	3.33	1	5.00	1	3.70	1	4.35

Timing of 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 most receptive when they were first diagnosed (beginning)	**18**	36.00	11	42.31	7	29.17	7	29.17	13	38.24
Participant describes there not being a specific time when they were most receptive - an ongoing process	**10**	20.00	6	23.08	4	16.67	5	20.83	7	20.59
Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest	**6**	12.00	2	7.69	4	16.67	5	20.83	5	14.71
Participant describes not being receptive during diagnosis but being more receptive post diagnosis	**3**	6.00	3	11.54	0	0.00	1	4.17	3	8.82
Participant describes being always receptive to receiving information	**2**	4.00	1	3.85	1	4.17	1	4.17	1	2.94
Participant describes being most receptive a year(s) after diagnosis	**2**	4.00	0	0.00	2	8.33	1	4.17	1	2.94
Participant describes being more receptive now once learning more about the disease, compared to the beginning	**2**	4.00	1	3.85	1	4.17	1	4.17	2	5.88

Timing of 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 most receptive when they were first diagnosed (beginning)	**18**	36.00	8	36.36	10	35.71	10	38.46	8	33.33
Participant describes there not being a specific time when they were most receptive - an ongoing process	**10**	20.00	3	13.64	7	25.00	7	26.92	3	12.50
Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest	**6**	12.00	3	13.64	3	10.71	3	11.54	3	12.50
Participant describes not being receptive during diagnosis but being more receptive post diagnosis	**3**	6.00	1	4.55	2	7.14	1	3.85	2	8.33
Participant describes being always receptive to receiving information	**2**	4.00	0	0.00	2	7.14	0	0.00	2	8.33
Participant describes being most receptive a year(s) after diagnosis	**2**	4.00	1	4.55	1	3.57	1	3.85	1	4.17
Participant describes being more receptive now once learning more about the disease, compared to the beginning	**2**	4.00	1	4.55	1	3.57	2	7.69	0	0.00

Timing of 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 most receptive when they were first diagnosed (beginning)	**18**	36.00	5	25.00	13	43.33	5	22.73	13	**46.43**
Participant describes there not being a specific time when they were most receptive - an ongoing process	**10**	20.00	6	30.00	4	13.33	5	22.73	5	17.86
Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest	**6**	12.00	3	15.00	3	10.00	3	13.64	3	10.71
Participant describes not being receptive during diagnosis but being more receptive post diagnosis	**3**	6.00	1	5.00	2	6.67	1	4.55	2	7.14
Participant describes being always receptive to receiving information	**2**	4.00	0	0.00	2	6.67	1	4.55	1	3.57
Participant describes being most receptive a year(s) after diagnosis	**2**	4.00	1	5.00	1	3.33	1	4.55	1	3.57
Participant describes being more receptive now once learning more about the disease, compared to the beginning	**2**	4.00	1	5.00	1	3.33	1	4.55	1	3.57

Timing of 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 most receptive when they were first diagnosed (beginning)	**18**	36.00	2	33.33	5	35.71	5	55.56	4	36.36	2	20.00
Participant describes there not being a specific time when they were most receptive - an ongoing process	**10**	20.00	2	33.33	2	14.29	0	0.00	3	27.27	3	30.00
Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest	**6**	12.00	0	0.00	3	21.43	1	11.11	1	9.09	1	10.00
Participant describes not being receptive during diagnosis but being more receptive post diagnosis	**3**	6.00	0	0.00	0	0.00	1	11.11	1	9.09	1	10.00
Participant describes being always receptive to receiving information	**2**	4.00	1	16.67	0	0.00	0	0.00	0	0.00	1	10.00
Participant describes being most receptive a year(s) after diagnosis	**2**	4.00	0	0.00	1	7.14	1	11.11	0	0.00	0	0.00
Participant describes being more receptive now once learning more about the disease, compared to the beginning	**2**	4.00	0	0.00	1	7.14	0	0.00	1	9.09	0	0.00

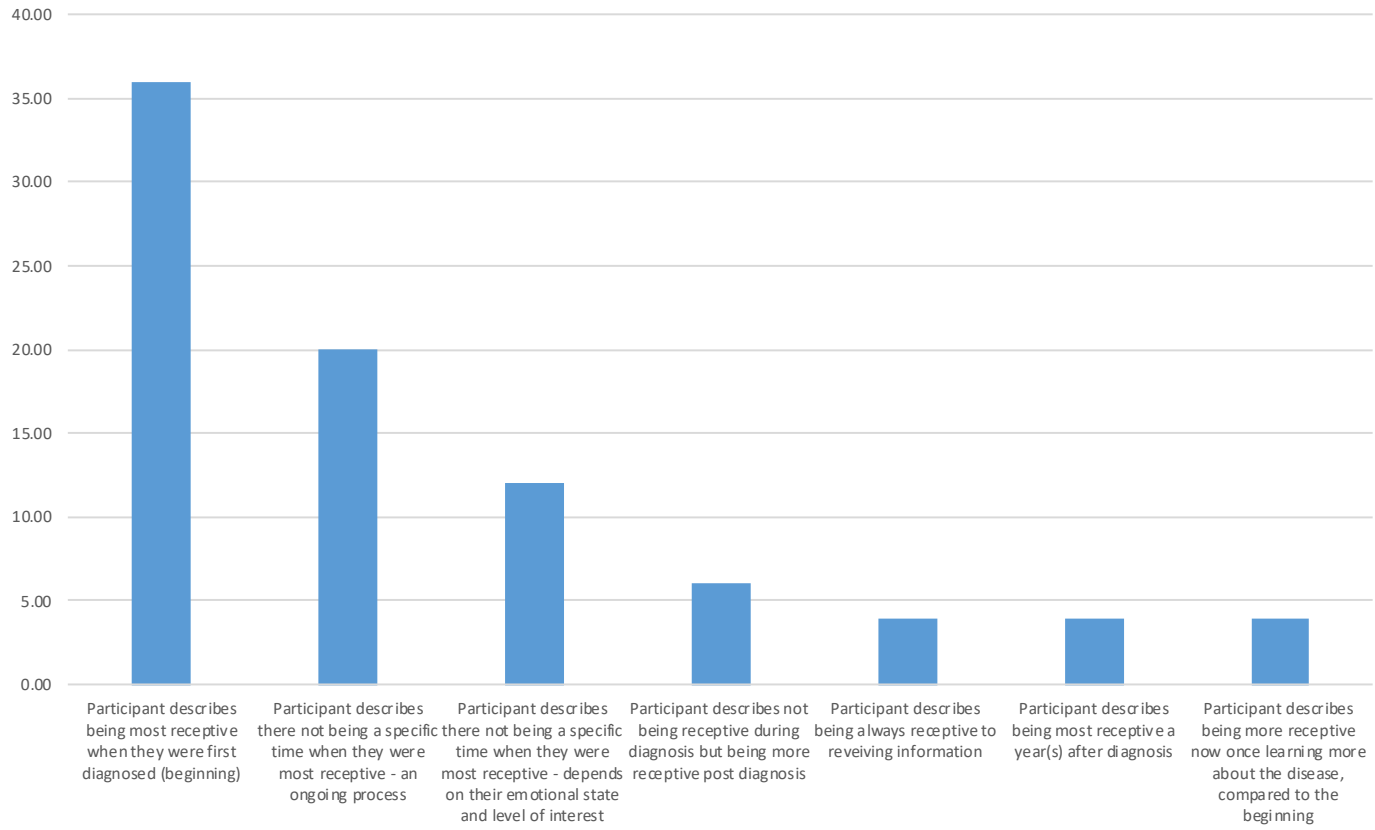


Figure 6.5: Information preferences – Timing
(% of all participants)

Communication with health professionals

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described most healthcare professionals not knowing about mitochondrial disease (n=11, 22.00%). This was followed by participants being satisfied with health professional communication (n=10, 20.00%).

Participant describes most healthcare professionals not knowing about mitochondrial disease

I'm always educating people wherever I go like the other day I had to go and see a urologist and they want to know about the Mitochondrial myopathy. Again, I just seem to forever educating people about it…No, it's not a common thing like the cold. Participant 16

My GP is useless. [laughs] Upon saying that, she's lovely. She knows nothing about it and has no interest even though she has a patient with it, knowing just in finding anything out. Even when I had to have the colonoscopy, they hadn't heard of it. None of these medical professionals that I've dealt with seems to have even heard of it. As I said, because I don't look like I'm ill, unless I'm having a really bad day and got a really bad link which does happen, I think it's all taken with a grain of salt by the medical profession. Participant 18

Difficult. I am usually the Mito educator, explaining the disease process to them and why certain treatments are not suitable or contraindicated. They will also not speak to each other, or read each other's notes, so I have to give a "potted history" of everything that has happened since I last saw them. Participant 30

Participant describes being satisfied with health professional communication

My GP is excellent. Of course, he's young. He's done courses or whatever you study. He's studied on it as well, so he's very good with it. I might go to him with a problem and he will say, "Okay. Maybe it's from the MELAS, maybe it's not, so we'll go and get it tested." Participant 22

It's been fine. They've all been on top on top of everything. Participant 35

I've mostly found my doctors to be to be very, informed and helpful. I would say there's not enough information, but I don't think that's the doctors' fault. Participant 43

The next most common themes were participants describing excellent communication (n=7, 14.00%), having minimal communication with healthcare professionals (n=6, 12.00%) and mostly good experiences, however there is a general lack of understanding of mitochondrial disease (n=6, 12.00%).

Participant describes excellent communication with their specialists

My GP is excellent. Of course, he's young. He's done courses or whatever you study. He's studied on it as well, so he's very good with it. I might go to him with a problem and he will say, "Okay. Maybe it's from the MELAS, maybe it's not, so we'll go and get it tested." Participant 22

Excellent. I'm very fortunate, not everybody has the same experience in this country or in others. I have a friend in Boston who's Facebooked me this morning. She's having major problems, and she can't get a doctor to tell her what's wrong. She has Mito, but she's also having these other problems where she falls, literally just drops. And they won't tell her. So yes, I'm very fortunate. Participant 24

So the metabolic specialist is brilliant. When you go outside of that into other areas of the hospital, you find that you inform them, more than the other way around, for sure. Participant 46

Participant describes having minimal communication with healthcare professionals

Virtually nil. Not many know or really…the hospital know nothing and now none of them know much about it. Participant 6

Pretty appalling. Look, I think it would be best described as non-existent. Because I don't think it's an appropriate response from a medical practitioner to say, "I don't know anything about it," and just basically leave it at that. Participant 7

Zero. Literally, zero. My doctor just looks at me like ... I think when I started having the B12 shots, and I started getting better, and he'd go, "Oh, that's great." But no questions, no "Oh, hang on a sec. Maybe the B12 has played a role here." Just basically push everything aside. "That's good. It's good. You sure you want to go back to work? Okay. That's good." … And I did ask my doctor, "What can I expect with this?" And he goes, "You'll probably lose your eyesight. Probably lose your hearing." That's what he told me on the phone, when I talked to him. And I literally went, "What the hell?" Is there something wrong with my brain? I'm going to lose my hearing. And I'd do something, I'm scared. Participant 40

In relation to sub-group variations, participants from low socio-economic areas (34.78%) described being satisfied with health professional communication more frequently than the general population (20.00%). Participants with high physical function (9.09%) and high general health (4.55%) described most healthcare professionals not knowing about mitochondrial disease less frequently than the general population (22.00%) while those with low physical functioning (32.14%) and low general health (35.71%) described this more frequently. Participants with high social functioning (25.00%) described excellent communication with their specialists more frequently than the general population (14.00%).

Table 6.6: Communication with health professionals

Health professional communication	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes most healthcare professionals not knowing about mitochondrial disease	11	22.00	5	16.67	6	30.00	5	18.52	6	26.09
Participant describes being satisfied with health professional communication	10	20.00	5	16.67	5	25.00	2	7.41	8	34.78
Participant describes excellent communication with their specialists	7	14.00	4	13.33	3	15.00	4	14.81	3	13.04
Participant describes having minimal communication with healthcare professionals	6	12.00	5	16.67	2	10.00	5	18.52	2	8.70
Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease	6	12.00	5	16.67	1	5.00	5	18.52	1	4.35
Participant describes a few poor experiences with general practitioners	4	8.00	3	10.00	1	5.00	3	11.11	1	4.35
Participant describes feeling as though time with specialists is too short (rushed)	4	8.00	3	10.00	1	5.00	3	11.11	1	4.35

Health professional communication	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes most healthcare professionals not knowing about mitochondrial disease	11	22.00	5	16.67	6	30.00	5	18.52	6	26.09
Participant describes being satisfied with health professional communication	10	20.00	5	16.67	5	25.00	2	7.41	8	34.78
Participant describes excellent communication with their specialists	7	14.00	4	13.33	3	15.00	4	14.81	3	13.04
Participant describes having minimal communication with healthcare professionals	6	12.00	5	16.67	2	10.00	5	18.52	2	8.70
Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease	6	12.00	5	16.67	1	5.00	5	18.52	1	4.35
Participant describes a few poor experiences with general practitioners	4	8.00	3	10.00	1	5.00	3	11.11	1	4.35
Participant describes feeling as though time with specialists is too short (rushed)	4	8.00	3	10.00	1	5.00	3	11.11	1	4.35

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 describes most healthcare professionals not knowing about mitochondrial disease	11	22.00	2	9.09	9	32.14	5	19.23	6	25.00
Participant describes being satisfied with health professional communication	10	20.00	5	22.73	5	17.86	4	15.38	6	25.00
Participant describes excellent communication with their specialists	7	14.00	3	13.64	4	14.29	6	23.08	1	4.17
Participant describes having minimal communication with healthcare professionals	6	12.00	3	13.64	4	14.29	2	7.69	5	20.83
Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease	6	12.00	2	9.09	4	14.29	4	15.38	2	8.33
Participant describes a few poor experiences with general practitioners	4	8.00	3	13.64	1	3.57	4	15.38	0	0.00
Participant describes feeling as though time with specialists is too short (rushed)	4	8.00	3	13.64	1	3.57	2	7.69	2	8.33

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 describes most healthcare professionals not knowing about mitochondrial disease	11	22.00	2	9.09	9	32.14	5	19.23	6	25.00
Participant describes being satisfied with health professional communication	10	20.00	5	22.73	5	17.86	4	15.38	6	25.00
Participant describes excellent communication with their specialists	7	14.00	3	13.64	4	14.29	6	23.08	1	4.17
Participant describes having minimal communication with healthcare professionals	6	12.00	3	13.64	4	14.29	2	7.69	5	20.83
Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease	6	12.00	2	9.09	4	14.29	4	15.38	2	8.33
Participant describes a few poor experiences with general practitioners	4	8.00	3	13.64	1	3.57	4	15.38	0	0.00
Participant describes feeling as though time with specialists is too short (rushed)	4	8.00	3	13.64	1	3.57	2	7.69	2	8.33

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 describes most healthcare professionals not knowing about mitochondrial disease	11	22.00	1	16.67	3	21.43	1	11.11	2	18.18	4	40.00
Participant describes being satisfied with health professional communication	10	20.00	0	0.00	3	21.43	3	33.33	2	18.18	2	20.00
Participant describes excellent communication with their specialists	7	14.00	1	16.67	1	7.14	1	11.11	1	9.09	3	30.00
Participant describes having minimal communication with healthcare professionals	6	12.00	1	16.67	1	7.14	3	33.33	2	18.18	0	0.00
Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease	6	12.00	1	16.67	3	21.43	1	11.11	0	0.00	1	10.00
Participant describes a few poor experiences with general practitioners	4	8.00	0	0.00	2	14.29	0	0.00	2	18.18	0	0.00
Participant describes feeling as though time with specialists is too short (rushed)	4	8.00	0	0.00	1	7.14	0	0.00	2	18.18	1	10.00

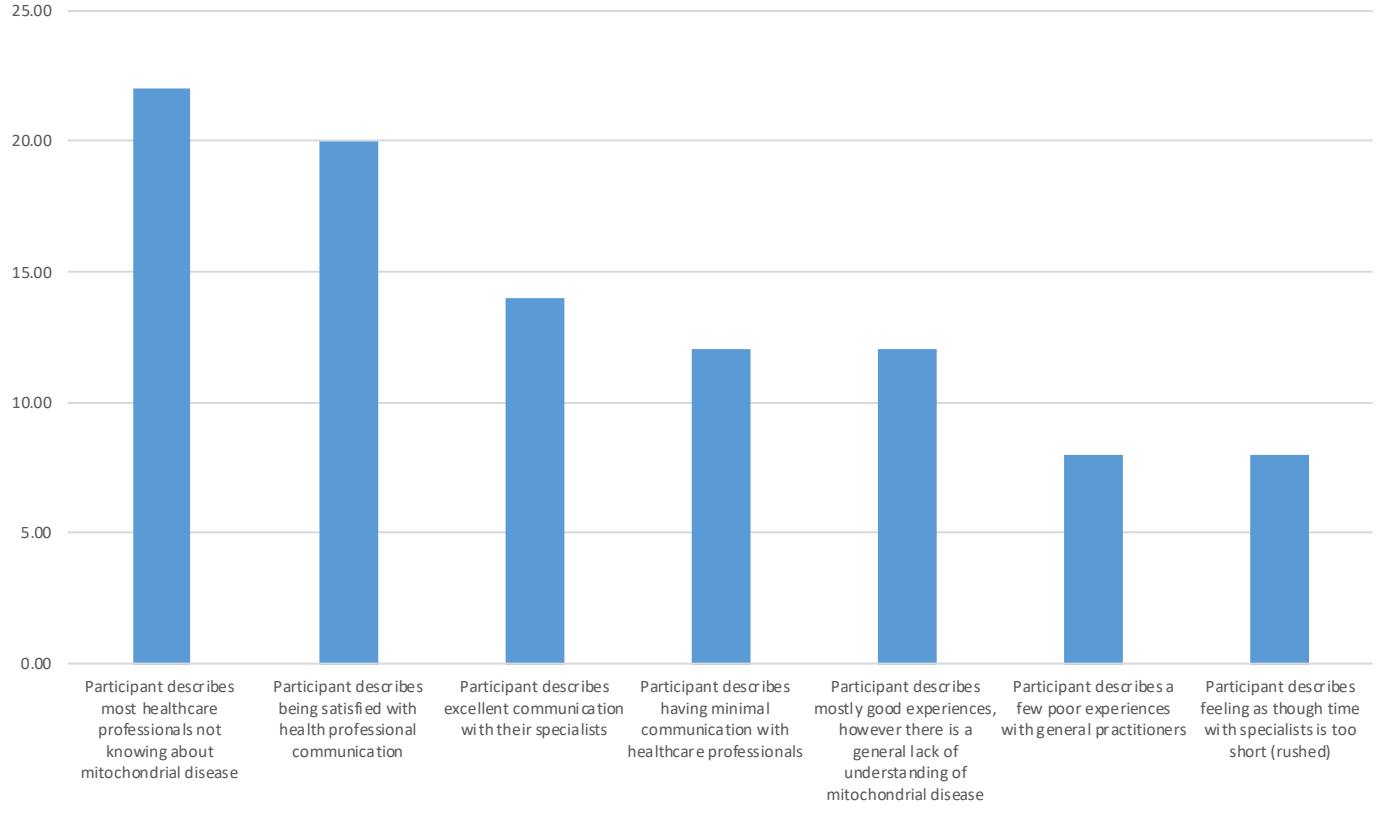


Figure 6.6: Communication with health professionals (% of all participants)

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.7. Overall, the participants scored in the top quintile for adherence to treatment (Median=14.00, IQR = 1.00) indicating very good adherence to treatment. The scores for knowledge (Median = 24.00, IQR = 3.00), recognition and management of symptoms (Mean = 18.76, SD = 2.89) and total score (Median=71.50, IQR = 12.75) were in the second highest quintile indicating good outcomes. The score for coping (Mean = 13.40, SD = 4.73),was in the middle of the range of scores for this scale.

Box plots display each of the Partners in Health sub-scales by general health, physical functioning, emotional well-being, social functioning, hearing problems status, eye problem status, location, education and SEIFA (Figures 6.7 – 6.51).

Comparisons of PIH global and sub scales have been made based on general health (Figures 6.7 to 6.11, Tables 6.8 to 6.9), physical functioning (Figures 6.12 to 6.16, Tables 6.10 to 6.11), emotional well-being (Figures 6.17 to 6.21, Tables 6.12 to 6.13), social functioning (Figures 6.22 to 6.26, Table 6.14 to 6.15), hearing problem status (Figures 6.27 to 6.31, Tables 6.16 to 6.17), eye problem status (Figures 6.32 to 6.36, Tables 6.18 to 6.19), location (Figures 6.37 to 6.41, Tables 6.20 to 6.21), education status (Figures 6.42 to 6.46, Tables 6.22 to 6.23), and SEIFA, (Figures 6.47 to 6.51, Tables 6.24 to 6.25).

Table 6.7: Summary statistics all participants Partners in Health

	Mean	SD	Median	IQR	Possible range
Knowledge	23.32	6.05	24.00	3.00	0-32
Coping*	13.40	4.73	13.00	3.00	0-24
Recognition and management of symptoms*	18.76	2.89	19.00	1.75	0-24
Adherence to treatment	13.18	3.26	14.00	1.00	0-16
Total score	68.66	12.75	71.50	4.25	0-96

*** Normal distribution use Mean and SD**

Comparisons of PIH sub scales by general health

Comparisons of PIH subscales were made general health, those that had a SF36 general health score above average for the group (Higher general health) were compared with those that had an average or lower score (Lower general health). Summary statistics are listed in Tables 6.11 and 6.12.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

A two sample t-test indicated no significant difference in the recognition and management of symptoms scale [t(48)= 0.41, p-=0.0.4786] with those with higher general health (Mean = 19.09, SD = 3.13) scoring similarlt to those with lower general health (Mean = 18.50, SD = 2.71).

A Wilcoxon rank sum test with continuity correction indicated a significant difference in the coping score [W=442.00, p=0.0088], those with higher general health (Median = 15.00, IQR = 5.75) scoring higher than those with lower general health (Median = 12.00, IQR = 4.25). No other statistically significant differences were observed between these two groups

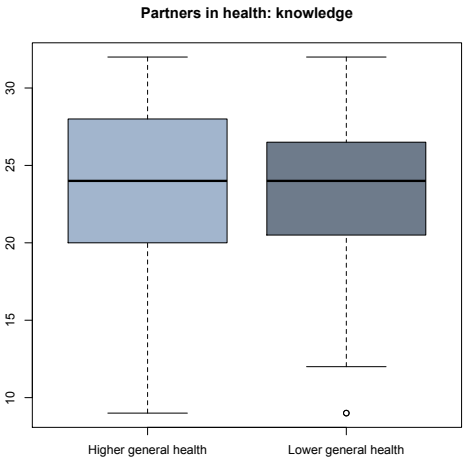


Figure 6.7: Boxplot of PIH knowledge by general health

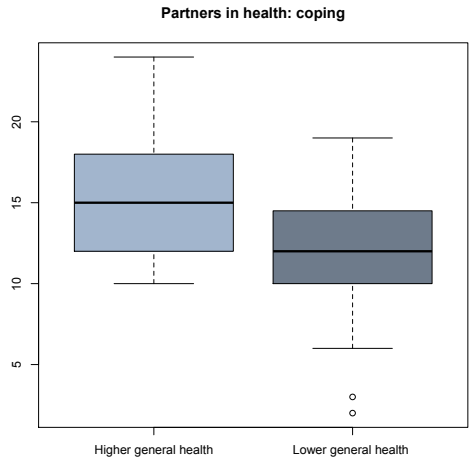


Figure 6.8: Boxplot of PIH coping by general health

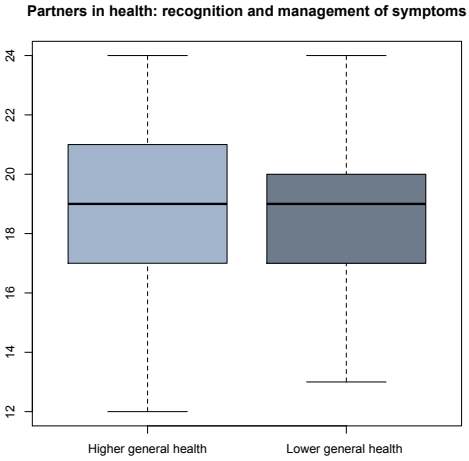


Figure 6.9: Boxplot of PIH recognition and management of symptoms by general health

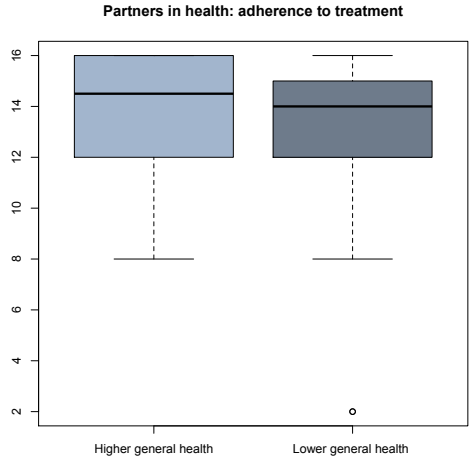


Figure 6.10: Boxplot of PIH adherence to treatment by general health

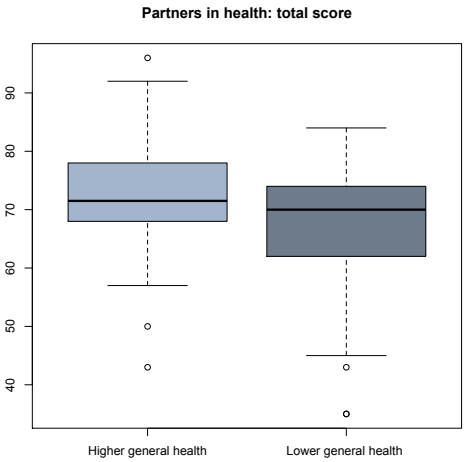


Figure 6.11: Boxplot of PIH total score by general health

Table 6.8: Summary statistics and t-test PIH scales by general health

Partners in health scale by general health	Group	Count	Mean	SD	Median	IQR	t	dF	p
Recognition and management of symptoms	Higher general health	22	19.09	3.13	19.00	3.75	0.71	48	0.4786
	Lower general health	28	18.50	2.71	19.00	3.00			

Table 6.9: Summary statistics and Wilcoxon rank sum test PIH scales by general health

Partners in health scale by general health	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	Higher general health	22	23.82	6.33	24.00	7.75	332.50	0.6371
	Lower general health	28	22.93	5.91	24.00	5.50		
Coping	Higher general health	22	15.59	4.39	15.00	5.75	442.00	0.0088*
	Lower general health	28	11.68	4.30	12.00	4.25		
Adherence to treatment	Higher general health	22	13.59	2.68	14.50	4.00	346.50	0.4504
	Lower general health	28	12.86	3.67	14.00	3.00		
Total score	Higher general health	22	72.09	12.28	71.50	9.75	384.00	0.1392
	Lower general health	28	65.96	12.68	70.00	11.50		

*Statistically significant at p<0.05

Comparisons of PIH sub scales by Physical function

Comparisons of PIH subscales were made physical functioning, those that had a SF36 physical functioning score above average for the group (Higher physical functioning) were compared with those that had an average or lower score (Lower physical functioning) . Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). A two sample t-test indicated a significant difference in the coping scale [t(48)= 2.27, p=0.275] those with a higher emotional well-being score (Mean = 15.05, SD = 4.21) scoring higher than those with a lower emotional well-being score (Mean = 12.11, SD = 4.77).

No other statistically significant differences were observed between these two groups for any other PIH sub scale (Tables 6.18).

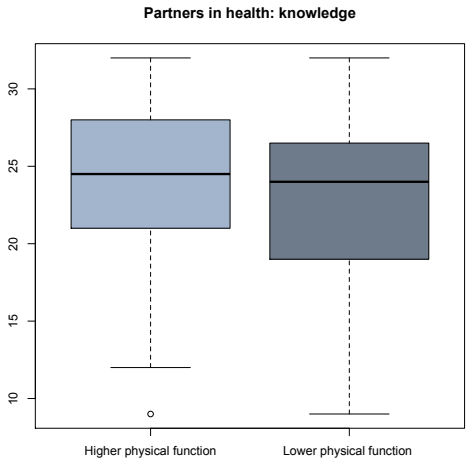


Figure 6.12: Boxplot of PIH knowledge by physical functioning

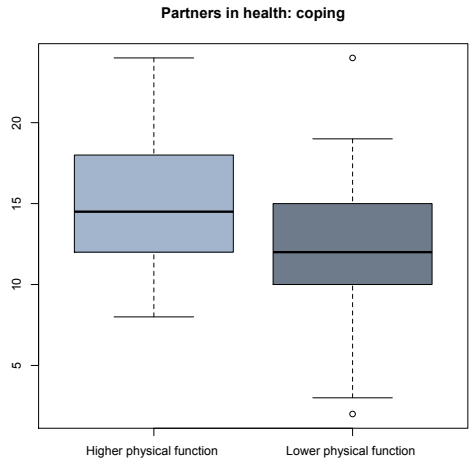


Figure 6.13: Boxplot of PIH coping by physical functioning

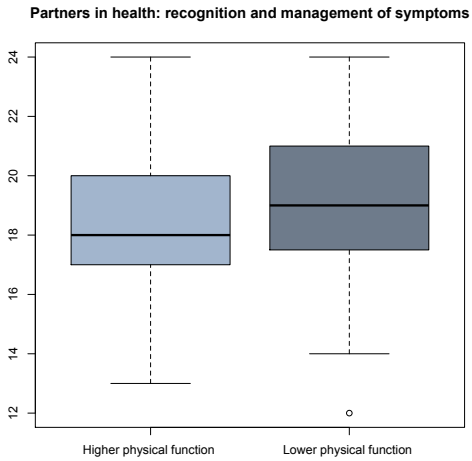


Figure 6.14: Boxplot of PIH recognition and management of symptoms by physical functioning

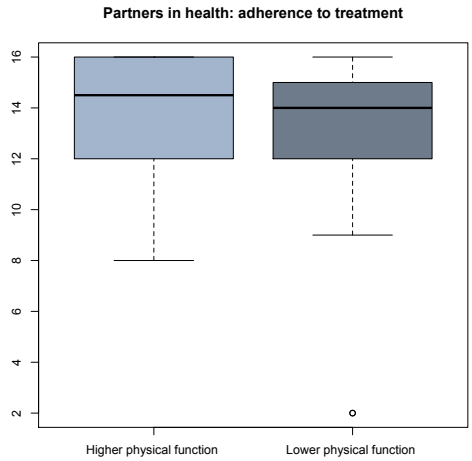


Figure 6.15: Boxplot of PIH aherence to treatment by physical functioning

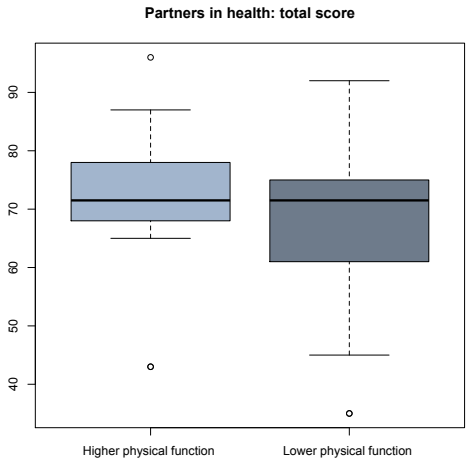


Figure 6.16: Boxplot of PIH total score by physical functioning

Table 6.10: Summary statistics and t-test PIH subscales by physical functioning

Partners in health scales by physical function	Group	Count	Mean	SD	t	dF	p
Coping	Higher physical function	22	15.05	4.21	2.27	48	0.0275*
	Lower physical function	28	12.11	4.77			
Recognition and management of symptoms	Higher physical function	22	18.45	2.67	-0.66	48	0.5132
	Lower physical function	28	19.00	3.08			

Table 6.11: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by physical functioning

Partners in health scales by physical function	Group	Count	Median	IQR	W	p
Knowledge	Higher physical function	22	24.50	6.75	334.00	0.6162
	Lower physical function	28	24.00	6.75		
Adherence to treatment	Higher physical function	22	14.50	4.00	342.50	0.4995
	Lower physical function	28	14.00	3.00		
Total score	Higher physical function	22	71.50	4.25	347.50	0.4450
	Lower physical function	28	71.50	13.50		

Comparisons of PIH sub scales by emotional well-being

Comparisons of PIH subscales were made by emotional well-being, those that had a SF36 emotional well-being score above average for the group (Higher emotional well-being) were compared with those that had an average or lower score (Lower emotional well-being) . Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). A two sample t-test indicated a significant difference in the coping scale [t(48)= 4.50, p<0.0001] those with a higher emotional well-being score (Mean = 15.85, SD = 4.12) scoring higher than those with a lower emotional well-being score (Mean = 10.75, SD = 3.87).

A Wilcoxon rank sum test with continuity correction indicated a significant difference in the adherence to treatment score [W=412.50, p=0.0485], those with higher emotional well-being (Median = 15.00, IQR = 2.75) scoring higher than those with lower emotional well-being (Median = 14.00, IQR = 5.50); and for the total score [W= 455.50, p = 0.0054], those with higher emotional well-being (Median = 72.50, IQR = 8.50) scoring higher than those with lower emotional well-being (Median = 68.00, IQR =18.75).

No other statistically significant differences were observed between these two groups

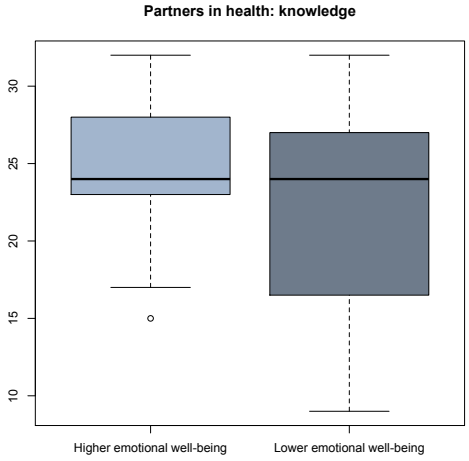


Figure 6.17: Boxplot of PIH knowledge by emotional well-being

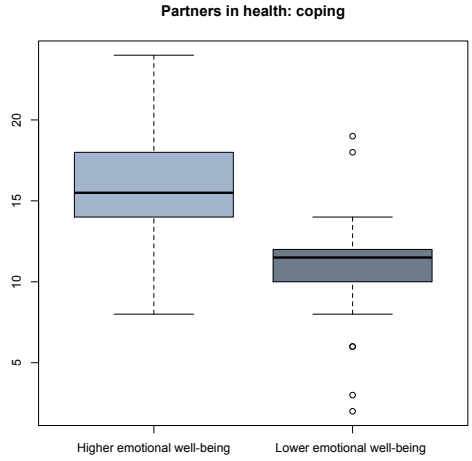


Figure 6.18: Boxplot of PIH coping by emotional well-being

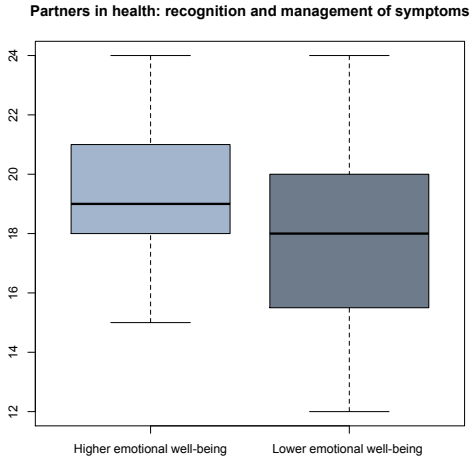


Figure 6.19: Boxplot of PIH recognition and management of symptoms by emotional well-being

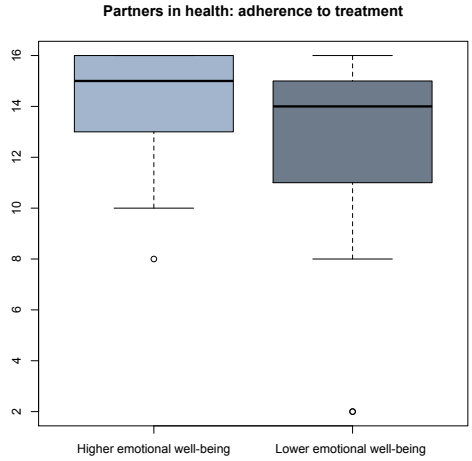


Figure 6.20: Boxplot of PIH adherence to treatment by emotional well-being

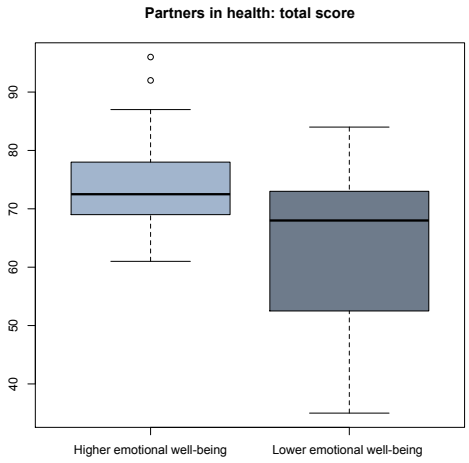


Figure 6.21: Boxplot of PIH total score by emotional well-being

Table 6.12: Summary statistics and two sample t-test PIH subscale by emotional well-being

Partners in health scales by emotional well-being	Group	Count	Mean	SD	Median	IQR	T	dF	p
Coping	Higher emotional well-being	26	15.85	4.12	15.50	3.75	4.50	48	<0.0001*
	Lower emotional well-being	24	10.75	3.87	11.50	2.00			
Recognition and management of symptoms	Higher emotional well-being	26	19.50	2.23	19.00	3.00	1.94	48	0.0586
	Lower emotional well-being	24	17.96	3.33	18.00	2.00			

* Statistically significant at p<0.05

Table 6.13: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by emotional well-being

Partners in health scales by emotional well-being	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	Higher emotional well-being	26	24.65	4.35	24.00	4.50	361.50	0.3386
	Lower emotional well-being	24	21.88	7.29	24.00	10.25		
Adherence to treatment	Higher emotional well-being	26	14.12	2.14	15.00	2.75	412.50	0.0485*
	Lower emotional well-being	24	12.17	3.95	14.00	3.50		
Total score	Higher emotional well-being	26	74.12	8.25	72.50	8.50	455.50	0.0054*
	Lower emotional well-being	24	62.75	14.23	68.00	18.75		

* Statistically significant at p<0.05

Comparisons of PIH sub scales by social functioning

Comparisons of PIH subscales were made by social functioning, those that had a social functioning score above average for the group (Higher social functioning) were compared with those that had an average or lower score (Lower social functioning) . Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). A two sample t-test indicated a significant difference in the coping scale [t(48)= 5.47, p<0.0001] those with a higher social functiong (Mean = 16.95, SD = 3.86) scoring higher than those with a lower social functioning score (Mean = 11.03, SD = 3.67).

A Wilcoxon rank sum test with continuity correction indicated a significant difference in the total score [W=426.50, p=0.0124], those with higher social functioning (Median = 74.00, IQR = 10.50) scoring higher than those with lower social functioning (Median = 70.00, IQR = 11.00).

No other statistically significant differences were observed between these two groups

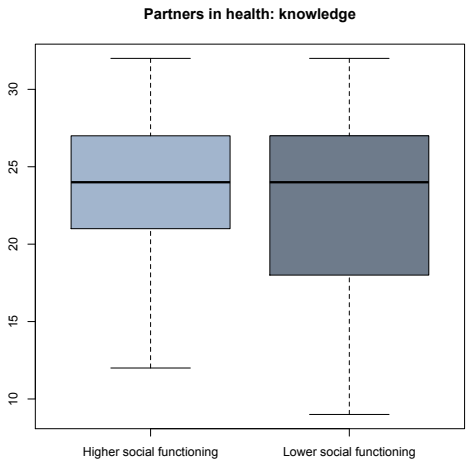


Figure 6.22: Boxplot of PIH knowledge by social functioning

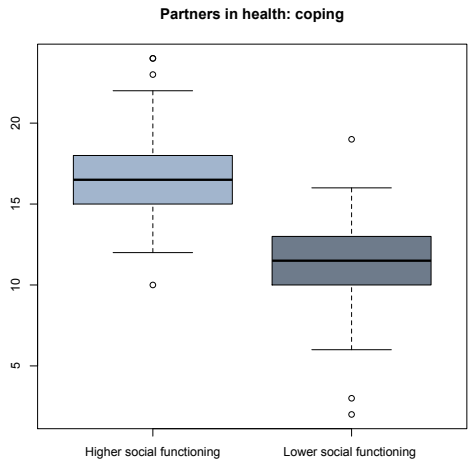


Figure 6.23: Boxplot of PIH coping by social functioning

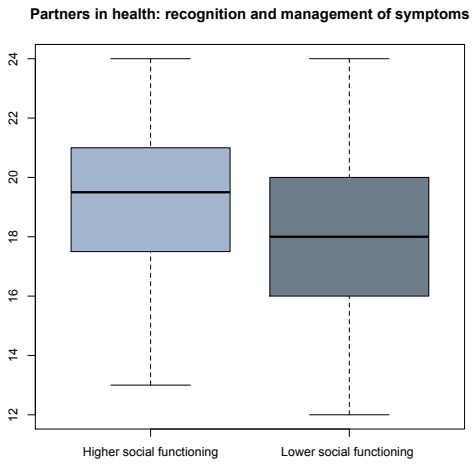


Figure 6.24: Boxplot of PIH recognition and management of symptoms by social functioning

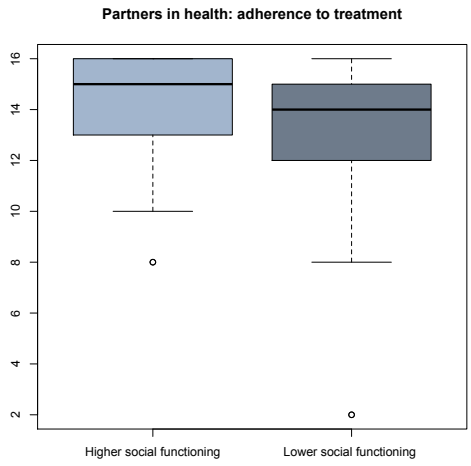


Figure 6.25: Boxplot of PIH adherence to treatment by social functioning

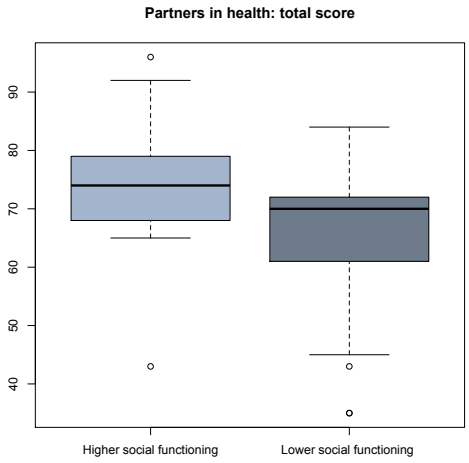


Figure 6.26: Boxplot of PIH total score by social functioning

Table 6.14: Summary statistics and two sample t-test PIH subscale by social functioning

Partners in health scales by social functioning	Group	Count	Mean	SD	Median	IQR	t	dF	p
Coping	Higher	20	16.95	3.86	16.50	3.00	5.47	48	<0.0001*
	Lower	30	11.03	3.67	11.50	2.75			
Recognition and management of symptoms	Higher	20	19.60	2.84	19.50	3.25	1.71	48	0.0935
	Lower	30	18.20	2.83	18.00	2.75			

*Statistically significant at p<0.05

Table 6.15: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by emotional well-being

Partners in health scales by social functioning	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	Higher	20	23.80	5.29	24.00	5.50	303.00	0.9603
	Lower	30	23.00	6.58	24.00	8.50		
Adherence to treatment	Higher	20	13.85	2.54	15.00	3.00	359.00	0.2391
	Lower	30	12.73	3.64	14.00	3.00		
Total score	Higher	20	74.20	11.30	74.00	10.50	426.50	0.0124*
	Lower	30	64.97	12.48	70.00	11.00		

*Statistically significant at p<0.05

Comparisons of PIH sub scales by hearing problem status

Comparisons of PIH subscales were made by those that had no hearing problems compared with those with hearing problems. Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No statistically significant differences were observed between these two groups

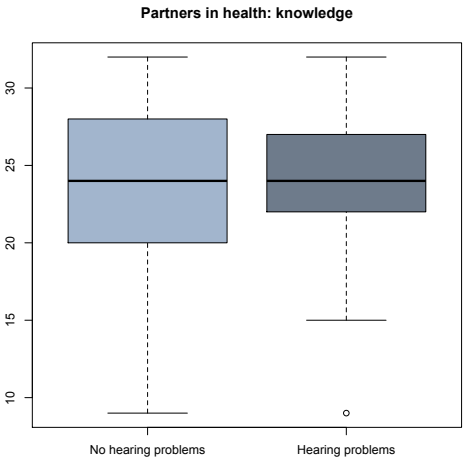


Figure 6.27: Boxplot of PIH knowledge by hearing problems

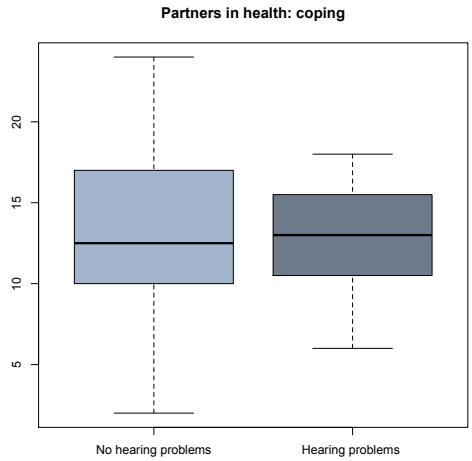


Figure 6.28: Boxplot of PIH coping by h

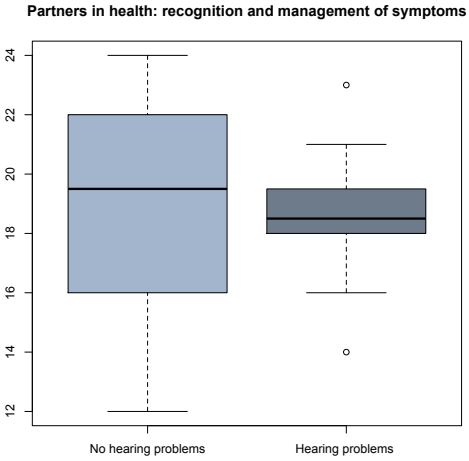


Figure 6.29: Boxplot of PIH recognition and management of symptoms by hearing problems

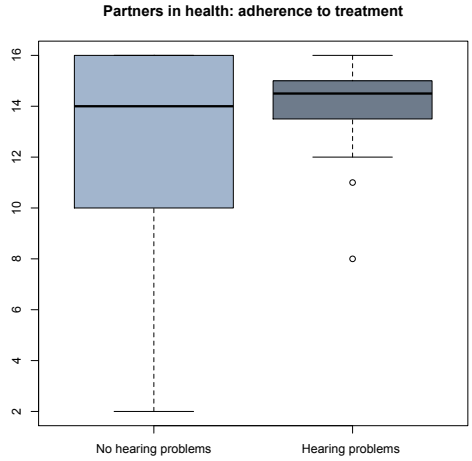


Figure 6.30: Boxplot of PIH adherence to treatment by h

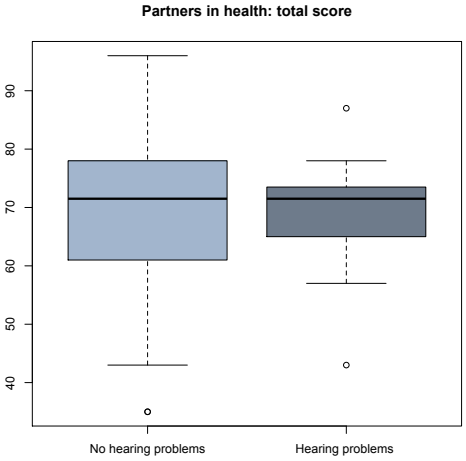


Figure 6.31: Boxplot of PIH total score by hearing problems

Table 6.16: Summary statistics and two sample t-test PIH subscale by hearing problems

Partners in health scales by hearing problems	Group	Count	Mean	SD	Median	IQR	t	dF	p
Knowledge	No hearing problems	26	23.08	6.52	24.00	7.75	-0.29	48	0.7708
	Hearing problems	24	23.58	5.63	24.00	4.50			

Table 6.17: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by hearing problems

Partners in health scales by hearing problems	Group	Count	Mean	SD	Median	IQR	W	p
Coping	No hearing problems	26	13.92	5.59	12.50	6.50	339.50	0.5983
	Hearing problems	24	12.83	3.61	13.00	4.50		
Recognition and management of symptoms	No hearing problems	26	18.88	3.63	19.50	5.75		
	Hearing problems	24	18.63	1.86	18.50	4.50	347.00	0.4999
Adherence to treatment	No hearing problems	26	12.38	4.01	14.00	5.50		
	Hearing problems	24	14.04	1.92	14.50	1.25	254.50	0.2607
Total score	No hearing problems	26	68.27	15.92	71.50	15.00	340.50	0.5859
	Hearing problems	24	69.08	8.40	71.50	8.25		

Comparisons of PIH sub scales by eye problem status

Comparisons of PIH subscales were made by eye problem status, those that had no eye problems were compared with those that eye problems. Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

A Wilcoxon rank sum test with continuity correction indicated a significant difference in the knowledge sub scale [W=399.50, p=0.0079], those with no eye problems (Median = 27.50, IQR = 7.00) scoring higher than those with eye problems (Median = 24.00, IQR = 7.50); a significant difference in the adherence to treatment sub scale [W=367.50, p=0.0447], those with no eye problems (Median = 15.00, IQR = 2.00) scoring higher than those with eye problems (Median = 14.00, IQR = 3.75); and a significant difference in the total score [W=383.50,
p=0.0207], those with no eye problems (Median = 74.00, IQR = 9.00) scoring higher than those with eye problems (Median = 68.50, IQR = 10.50).

No other statistically significant differences were observed between these two groups

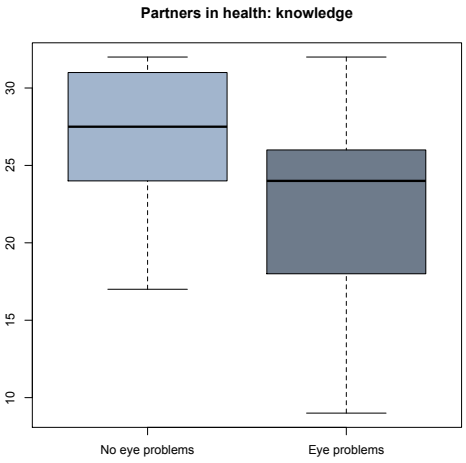


Figure 6.32: Boxplot of PIH knowledge by eye problems

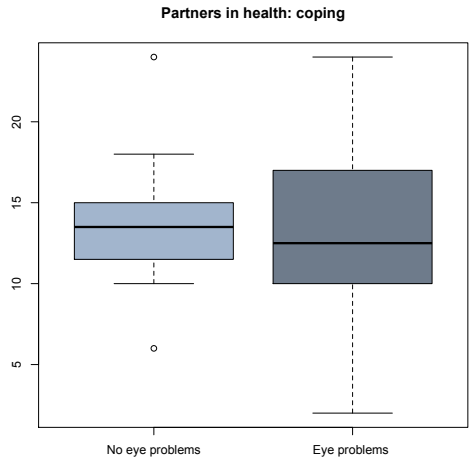


Figure 6.33: Boxplot of PIH coping by eye problems

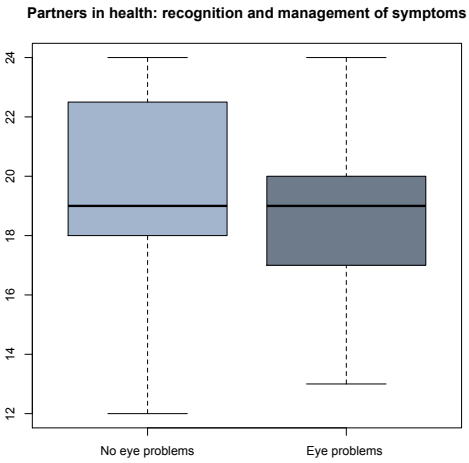


Figure 6.34: Boxplot of PIH recognition and management of symptoms by eye problems

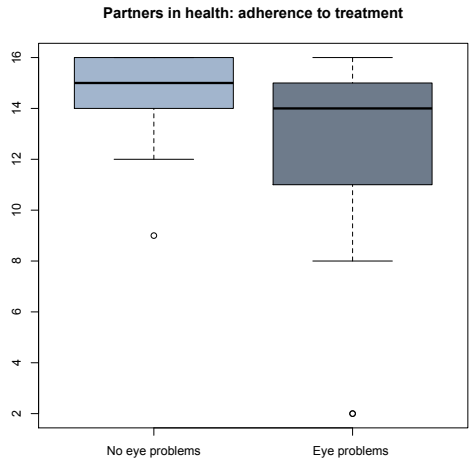


Figure 6.35: Boxplot of PIH adherence to treatment by eye problems

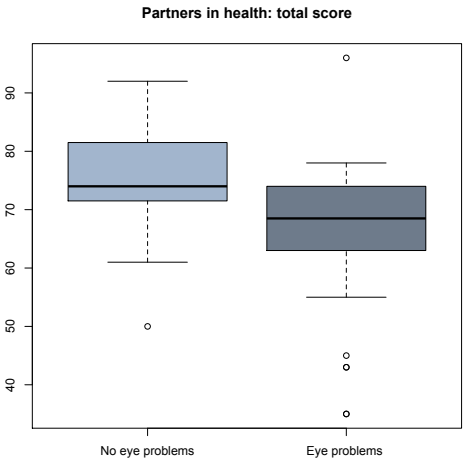


Figure 6.36: Boxplot of PIH total score by eye problems

Table 6.18: Summary statistics and two sample t-test PIH subscale by eye problems

Partners in health scales by eye problems	Group	Count	Mean	SD	Median	IQR	t	dF	p
Coping	No eye problems	16	13.56	3.92	13.50	3.25	0.17	48	0.8695
	Eye problems	34	13.32	5.12	12.50	6.75			
Recognition and management of symptoms	No eye problems	16	19.75	3.36	19.00	4.25	1.69	48	0.0969
	Eye problems	34	18.29	2.56	19.00	6.75			

Table 6.19: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by eye problems

Partners in health scales by eye problems	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	No eye problems	16	26.44	4.95	27.50	7.00	399.50	0.0079*
	Eye problems	34	21.85	6.02	24.00	7.50		
Adherence to treatment	No eye problems	16	14.50	1.83	15.00	2.00	367.50	0.0447*
	Eye problems	34	12.56	3.61	14.00	3.75		
Total score	No eye problems	16	74.25	10.20	74.00	9.00	383.50	0.0207*
	Eye problems	34	66.03	13.11	68.50	10.50		

*Statistically significant at p<0.05

Comparisons of PIH sub scales by location

Comparisons of PIH subscales were made by location, those that lived in a metropolitan area were compared with those that lived in a regional or rural location. Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

A Wilcoxon rank sum test with continuity correction indicated a significant difference in the total score [W=410.00, p=0.0298], those that lived in a metropolitan area (Median = 72.50, IQR = 8.75) scoring higher than those that lived in a regional or rural area (Median = 68.00, IQR = 12.00).

No other statistically significant differences were observed between these two groups

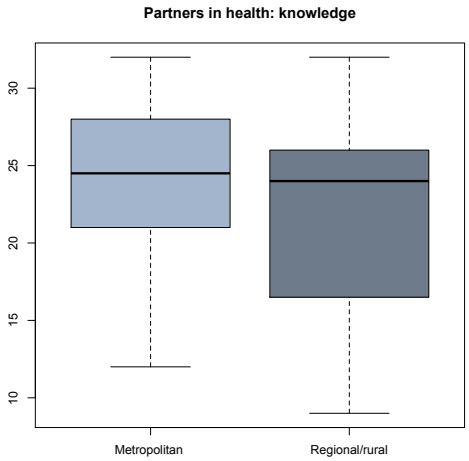


Figure 6.37: Boxplot of PIH knowledge by location

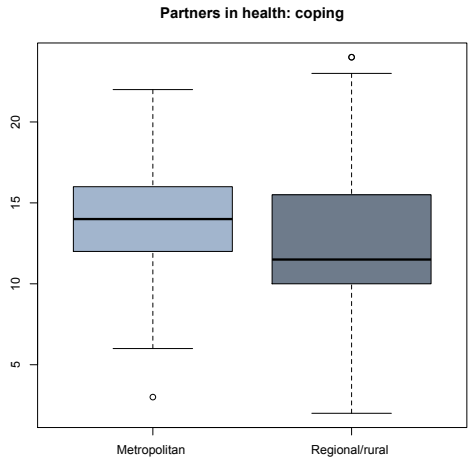


Figure 6.38: Boxplot of PIH coping by location

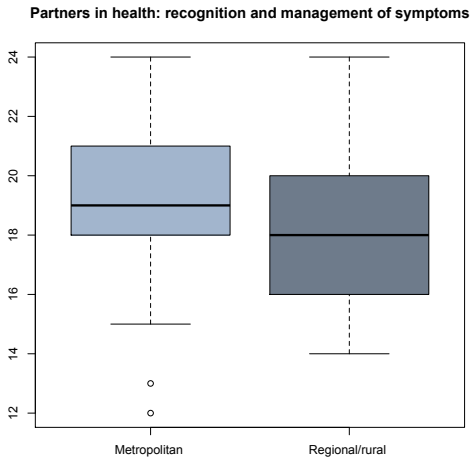


Figure 6.39: Boxplot of PIH recognition and management of symptoms by location

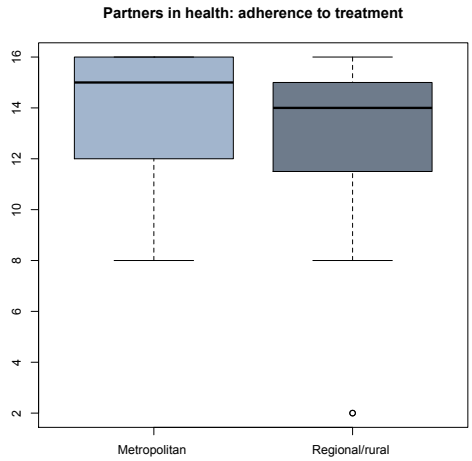


Figure 6.40: Boxplot of PIH adherence to treatment by location

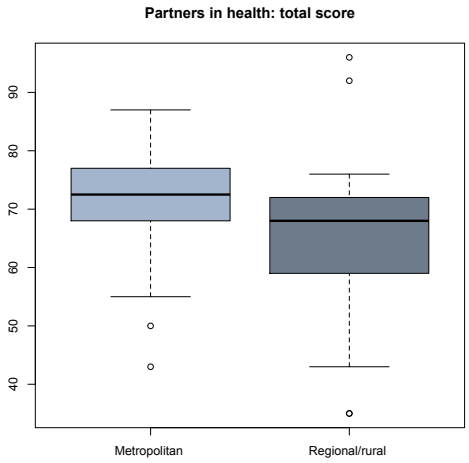


Figure 6.41: Boxplot of PIH total score by location

Table 6.20: Summary statistics and two sample t-test PIH subscale by social functioning

Partners in health scales by location	Group	Count	Mean	SD	Median	IQR	t	dF	P
Recognition and management of symptoms	Metropolitan	30	19.13	2.83	19.00	3.00	1.12	48	0.2675
	Regional/Rural	20	18.20	2.97	18.00	5.25			

Table 6.21: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by emotional well-being

Partners in health scales by location	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	Metropolitan	30	24.43	5.32	24.50	7.00	365.00	0.1989
	Regional/Rural	20	21.65	6.81	24.00	9.25		
Coping	Metropolitan	30	13.87	3.84	14.00	4.00	381.00	0.1092
	Regional/Rural	20	12.70	5.85	11.50	5.25		
Adherence to treatment	Metropolitan	30	13.83	2.31	15.00	3.50	369.00	0.1681
	Regional/Rural	20	12.20	4.20	14.00	3.25		
Total score	Metropolitan	30	71.27	9.50	72.50	8.75	410.00	0.0298*
	Regional/Rural	20	64.75	15.97	68.00	12.00		

*Statistically significant at p<0.05

Comparisons of PIH sub scales by education status
Comparisons of PIH subscales were made education, those that had a university qualification were compared with those that high school or trade qualifications. Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No statistically significant differences were observed between these two groups

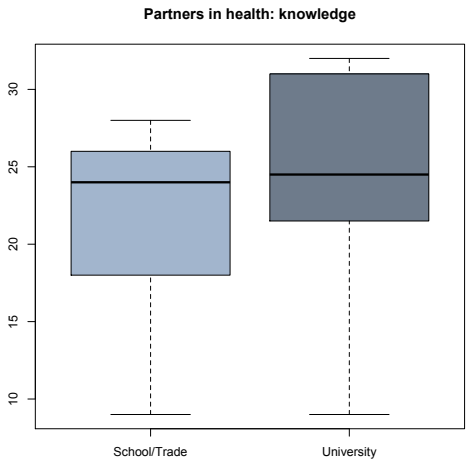


Figure 6.42: Boxplot of PIH knowledge by education

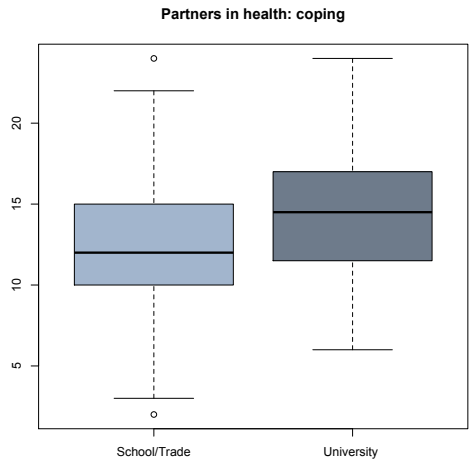


Figure 6.43: Boxplot of PIH coping by education

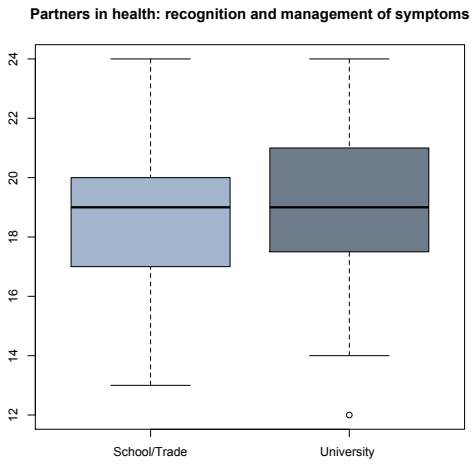


Figure 6.44: Boxplot of PIH recognition and management of symptoms by education

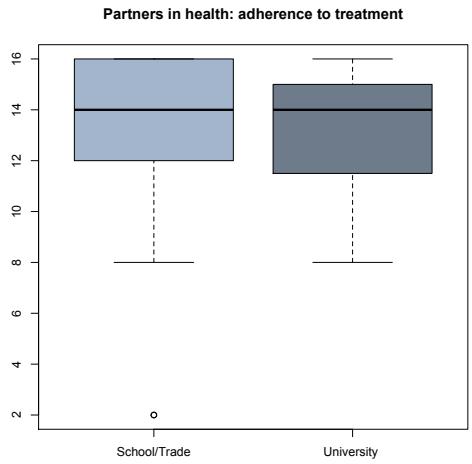


Figure 6.45: Boxplot of PIH adherence to treatment by education

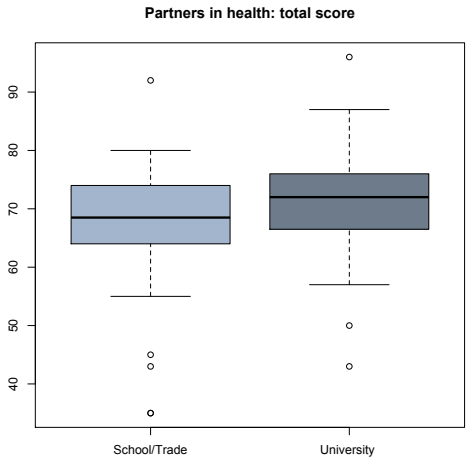


Figure 6.46: Boxplot of PIH total score by education

Table 6.22: Summary statistics and two sample t-test PIH subscale by education

Partners in health scales by education	Group	Count	Mean	SD	Median	IQR	T	dF	p
Coping	School/Trade	26	12.54	5.05	12.00	6.00	-1.35	48	0.1823
	University	24	14.33	4.25	14.50	5.25			
Recognition and management of symptoms	School/Trade	26	18.62	2.94	19.00	4.25	-0.37	48	0.7167
	University	24	18.92	2.89	19.00	5.25			

Table 6.23: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by education

Partners in health scales by education	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	School/Trade	26	22.08	5.86	24.00	7.75	249.00	0.2222
	University	24	24.67	6.08	24.50	9.25		
Adherence to treatment	School/Trade	26	13.12	3.84	14.00	3.25	337.50	0.6218
	University	24	13.25	2.57	14.00	3.25		
Total score	School/Trade	26	66.35	13.72	68.50	13.00	250.00	0.2314
	University	24	71.17	11.37	72.00	8.75		

Comparisons of PIH sub scales by SEIFA

Comparisons of PIH subscales were made by SEIFA, those that lived in an area with a SEIFA score of 7-10 (Higher SEIFA) were compared with those that lived in an area with a SEIFA score of 1-6 (Lower SEIFA) . Summary statistics are listed in Tables 6.11 and 6.14.

Two sample t-test was used when assumptions for normality and variance were met (Table 6.16). When assumptions normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No statistically significant differences were observed between these two groups

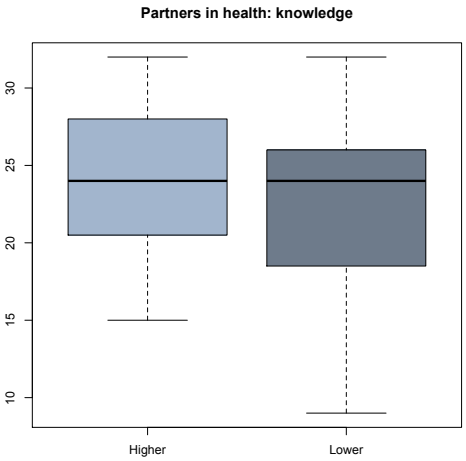


Figure 6.47: Boxplot of PIH knowledge by SEIFA

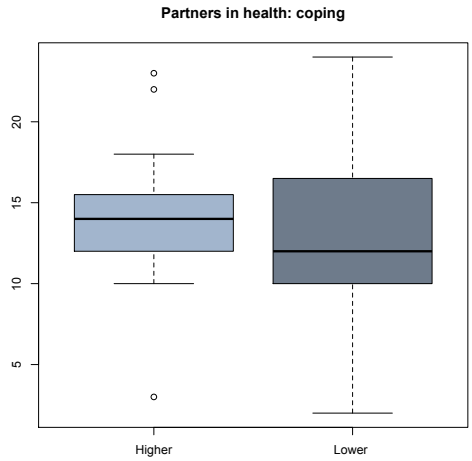


Figure 6.48: Boxplot of PIH coping by SEIFA

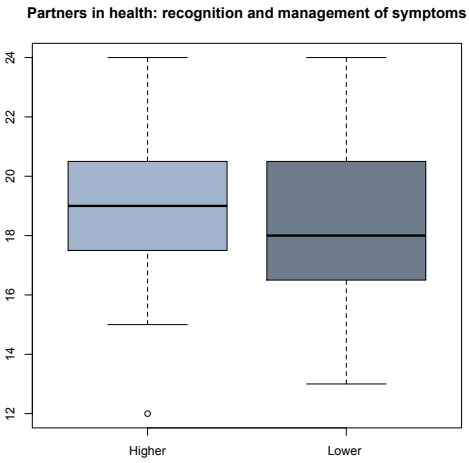


Figure 6.49: Boxplot of PIH recognition and management of symptoms by SEIFA

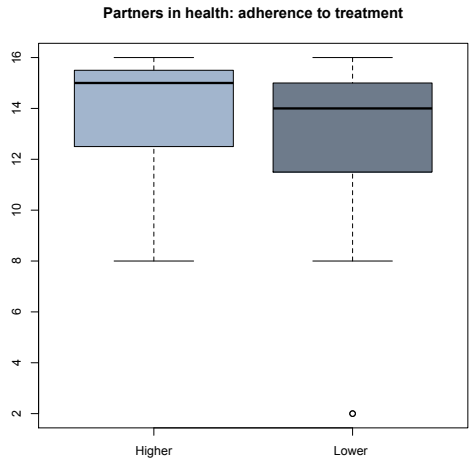


Figure 6.50: Boxplot of PIH adherence to treatment by SEIFA

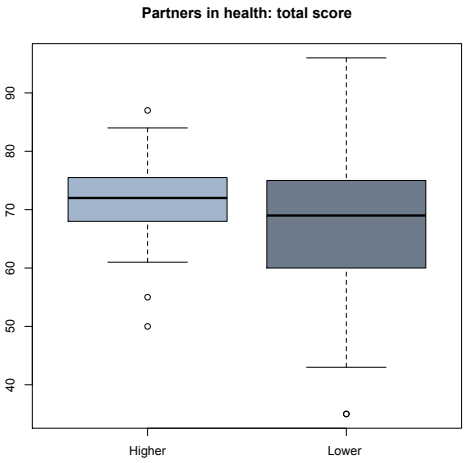


Figure 6.51: Boxplot of PIH total score by SEIFA

Table 6.24: Summary statistics and two sample t-test PIH subscale by SEIFA

Partners in Health scales by SEIFA	Group	Count	Mean	SD	Median	IQR	t	dF	p
Coping	Higher SEIFA	27	13.85	3.97	14.00	3.50	0.73	48	0.4695
	Lower SEIFA	23	12.87	5.53	12.00	6.50			
Recognition and management of symptoms	Higher SEIFA	27	19.04	2.68	19.00	3.00	0.73	48	0.4683
	Lower SEIFA	23	18.43	3.15	18.00	6.50			

Table 6.25: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by SEIFA

Partners in Health scales by SEIFA	Group	Count	Mean	SD	Median	IQR	W	p
Knowledge	Higher SEIFA	27	24.30	5.04	24.00	7.50	345.50	0.4994
	Lower SEIFA	23	22.17	7.00	24.00	7.50		
Adherence to treatment	Higher SEIFA	27	13.85	2.27	15.00	3.00	370.50	0.2392
	Lower SEIFA	23	12.39	4.05	14.00	3.50		
Total score	Higher SEIFA	27	71.04	8.31	72.00	7.50	363.50	0.3058
	Lower SEIFA	23	65.87	16.30	69.00	15.00		

*Statistically significant at $p<0.05$

Information given by healthcare professionals and searched for independently.

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about disease cause (50.00%), treatment options (38.00%), and disease management (38.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (14.00%), interpreting test results (14.00%) and complementary therapies (16.00%) were give least often (Figure 6.30). Eight participants (16.00%) indicated that they received no information at all from health professionals about mitochondrial disease.

Within subgroups, the types of information given differed, the most notable differences were observed for information: those with higher general health received more information about disease cause (68.18% compared to 37.17% for lower general health) and those with lower general health received more information about diet (39.29% compared to 13.64% for higher general health); those with higher physical functioning received more information disease cause (68.18%%) compared to those with lower physical functioning (35.71%) and hereditary, genes and biomarkers (45.5% compared to 25.00% for lower physical functioning); those with higher emotional well-being (46.15%) received information more often about disease management compared to those with lower emotional well-being (29.17%); those with no hearing problems (38.46%) received information about diet more often than those with hearing problems (16.67%); those that lived in regional or remote areas received more information about treatment options (55.00% compared with metropolitan 30%) and disease management (50.00% compared with metropolitan 30.00%) and hereditary, genes and biomarkers (50.00% compared with metropolitan 30.00%) those with a university education (62.50%) received information more often about disease cause compared to those with a high school or trade qualification (38.46%) and those that lived in an area with a higher SEIFA score (37.04%) received information about diet more often than those that lived in an area with a lower SEIFA score (17.39%).

Participants were asked about what type of information they searched for after receiving information from healthcare professionals. Information about treatment options (63.27%), disease management (59.18%), and disease cause (57.14%) were most frequently given to searched for independently, and information about interpreting test results (28.57%), hereditary, genes and biomarkers (28.57%) and psychological support (30.61%) were give least often (Figure 6.30). Two participants (4.08%) indicated that they did not search for any information.

Within subgroups, the types of information searched for differed, the most notable differences were observed for information: those with lower physical functioning health searched for more information about clinical trials (53.57% compared to 31.82% for higher physical functioning); those with lower social functioning searched for information more often about disease cause (68.97% compared to those with higher social functioning 40.00%), and those with information about disease management (72.41% compared to those with higher social functioning 40.00%); those with hearing problems searched for more often for information about disease cause (69.57% compared to those with no hearing problems 46.15%) and more often for clinical trials (61.54% compared to those with no hearing problems 26.09%); those with no eye problems searched for more often for information about disease management (81.25% compared to those with eye problems 48.48%) and those with eye problems searched for information more often about clinical trials (51.52%% compared to those with no eye problems 31.25%); those living in regional or rural locations searched for more information about clinical trials (63.16% compared to metropolitan 33.33%), interpreting test results (42.11% compared to metropolitan 20.00%), physical activity (57.89% compared to metropolitan 26.67%), and psychological/social support (47.37% compared to metropolitan 20.00%); those that lived in an area with a higher SEIFA score searched for more information about disease cause (66.67% compared to lower SEIFA 45.45%).

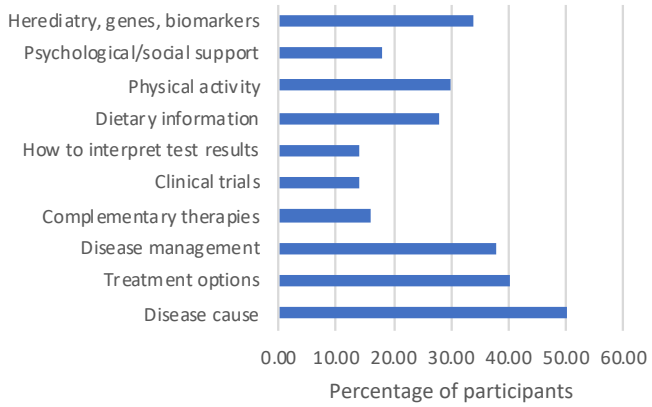


Figure 6.52: Information given by healthcare professionals: all participants

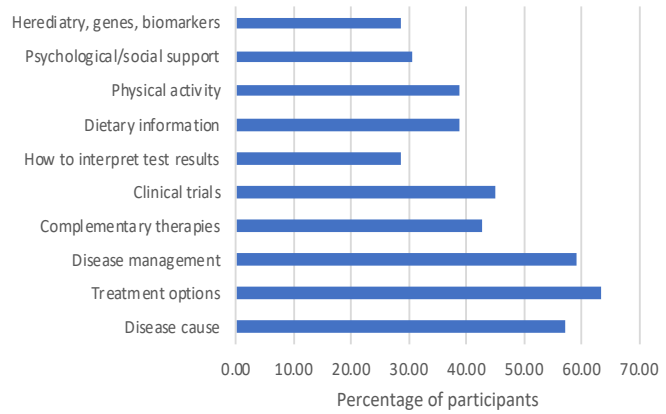


Figure 6.53: Information searched for independently: all participants

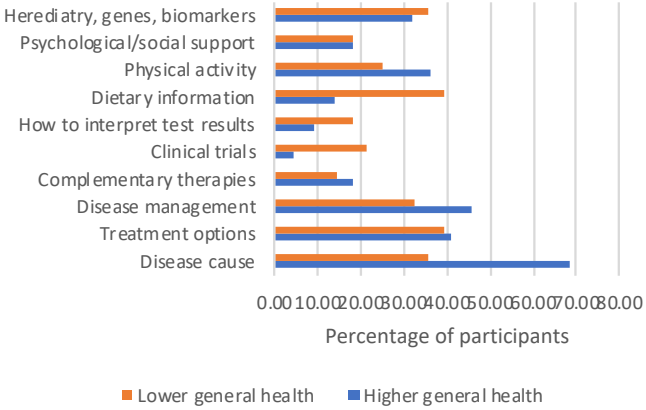


Figure 6.54: Information given by healthcare professionals by general health

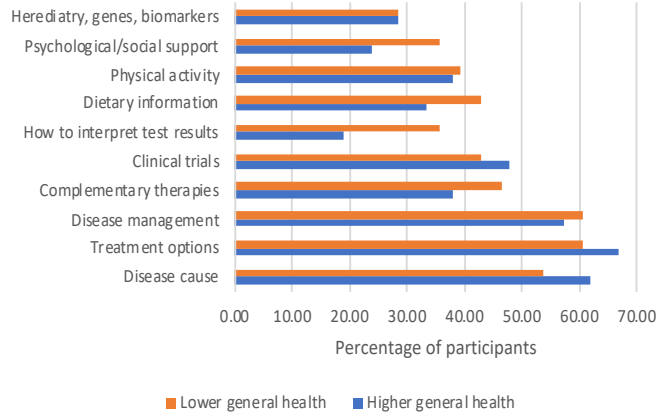


Figure 6.55: Information searched for independently by general health

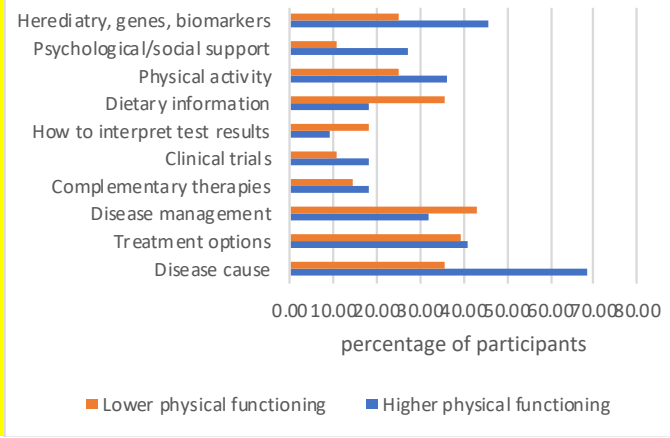


Figure 6.56: Information given by healthcare professionals by physical functioning

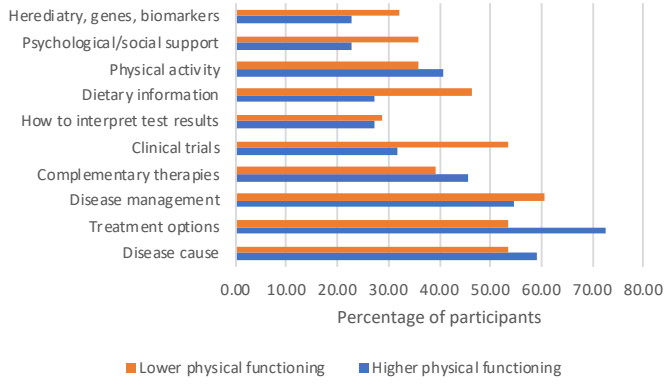


Figure 6.57: Information searched for independently by physical functioning

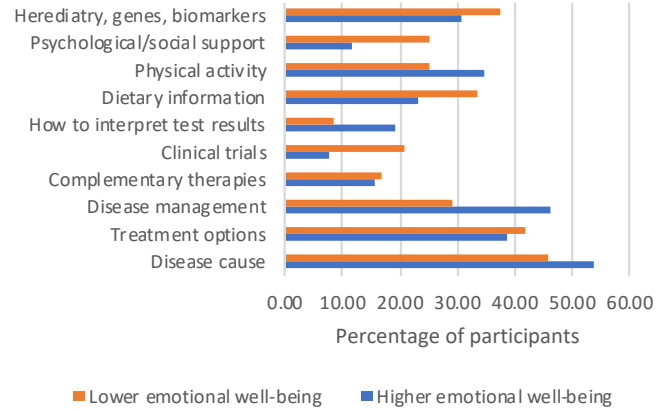


Figure 6.58: Information given by healthcare professionals by emotional well-being

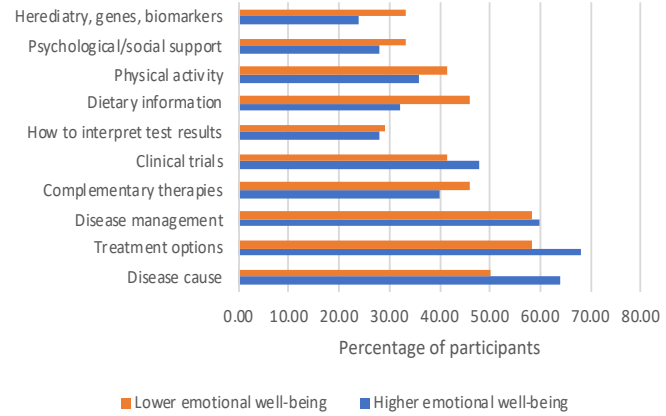


Figure 6.59: Information searched for independently by emotional well-being

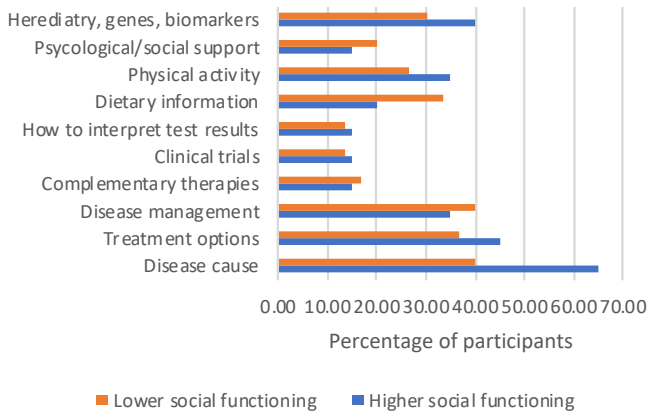


Figure 6.60: Information given by healthcare professionals by social functioning

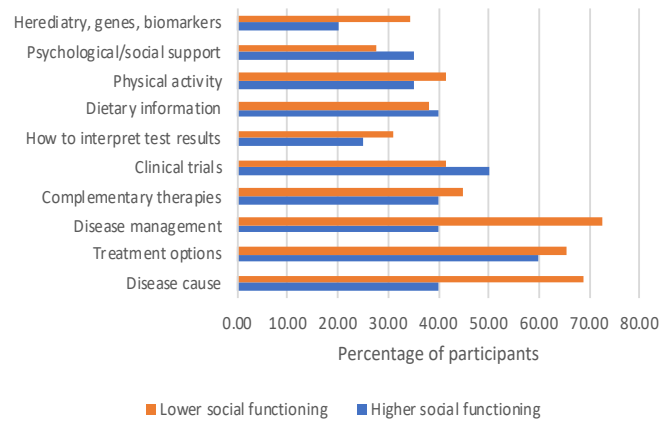


Figure 6.61: Information searched for independently by social functioning

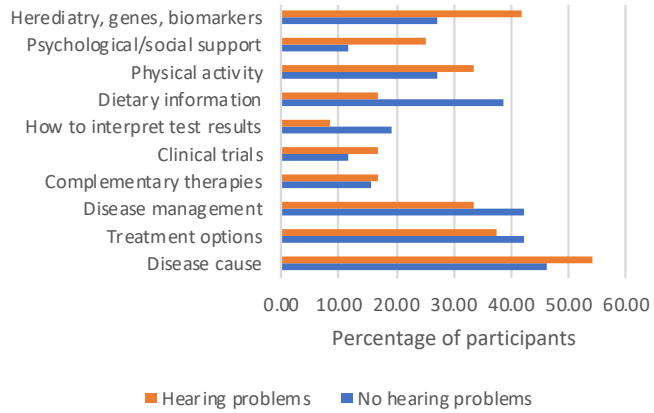


Figure 6.62: Information given by healthcare professionals by hearing problems

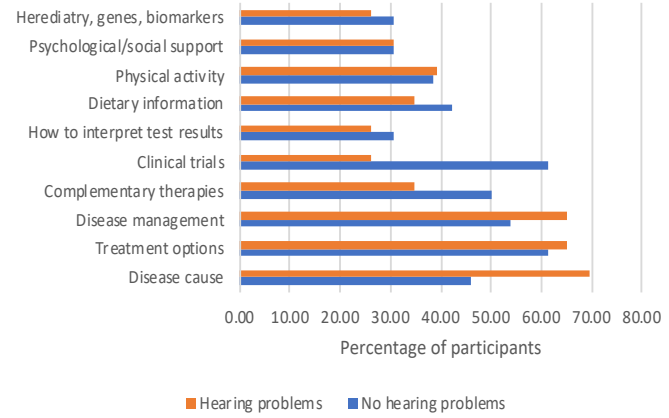


Figure 6.63: Information searched for independently by hearing problems

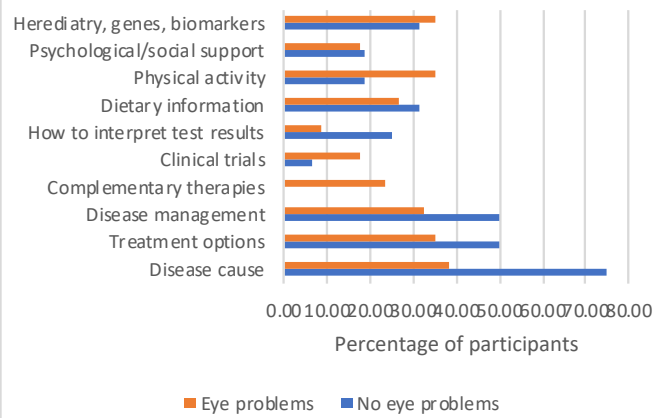


Figure 6.64: Information given by healthcare professionals by eye problems

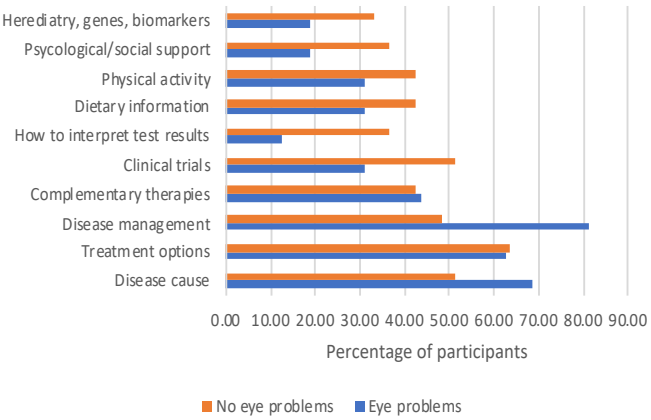
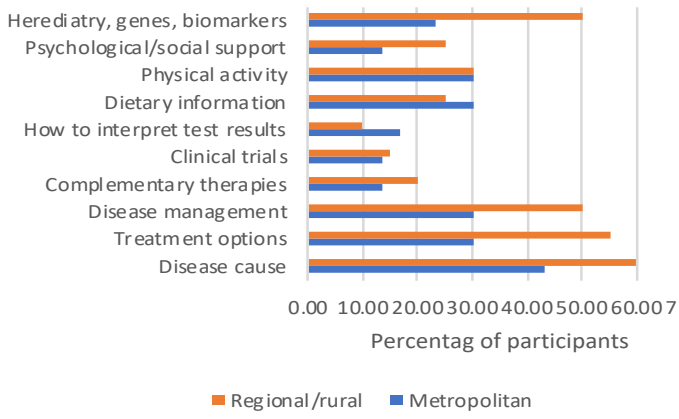


Figure 6.65: Information searched for independently by eye problems



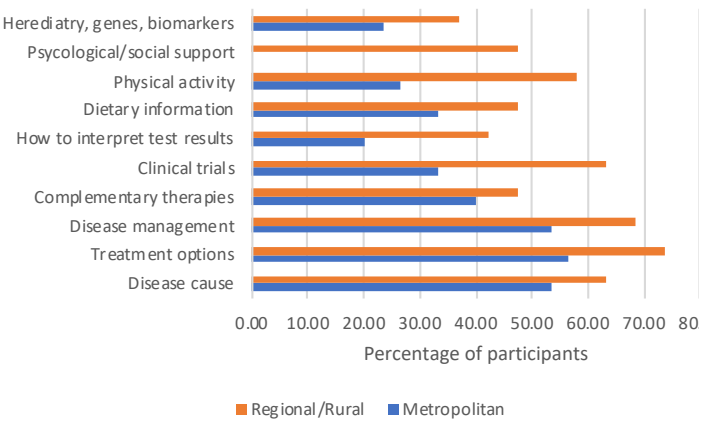


Figure 6.66: Information given by healthcare professionals by location

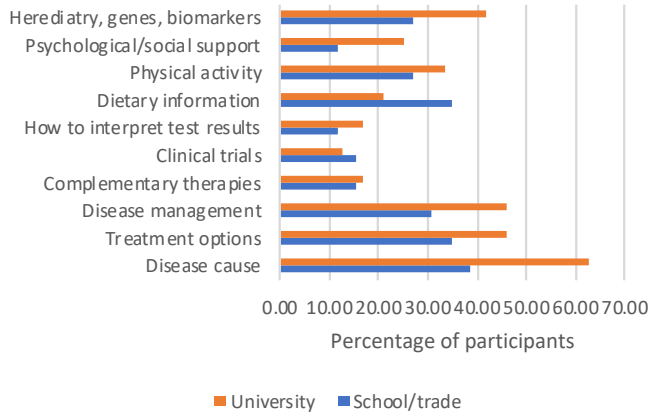


Figure 6.67: Information searched for independently by location

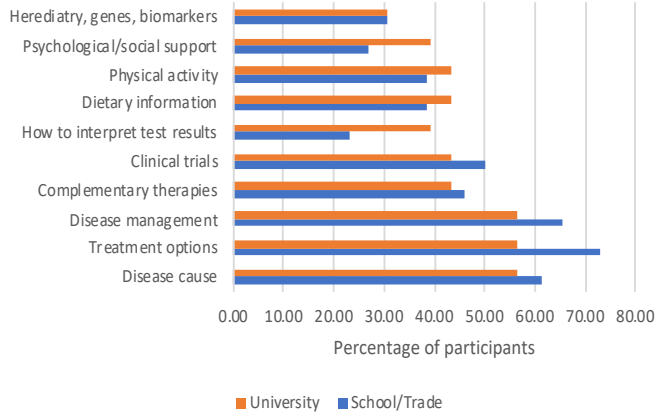


Figure 6.68: Information given by healthcare professionals by education

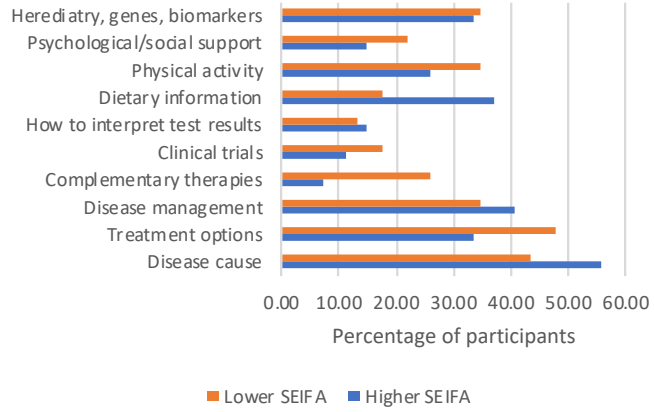


Figure 6.69: Information searched for independently by education

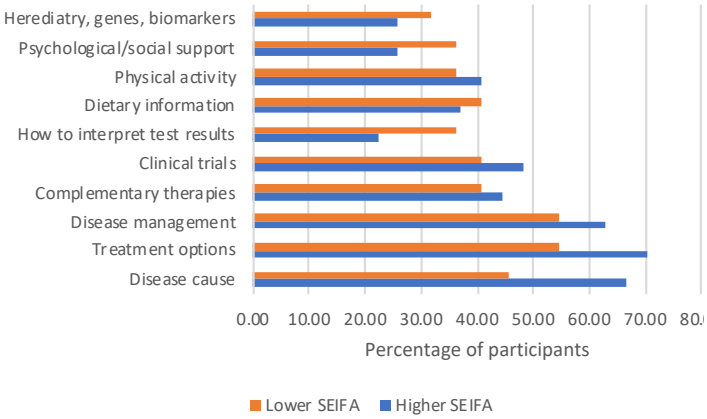


Figure 6.70: Information given by healthcare professionals by SEIFA

Figure 6.71: Information searched for independently by SEIFA

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were how to interpret test results (62.00%), and psychological/social support (56.00%) (Figure 6.72). Participants were given most information either from healthcare professionals or independently for treatment options (78.00%) and disease cause (78.00%) (Figure 6.72). Clinical trials (42.00%) was the topic that was most searched for independently following no information from health professionals (Figure 6.72).

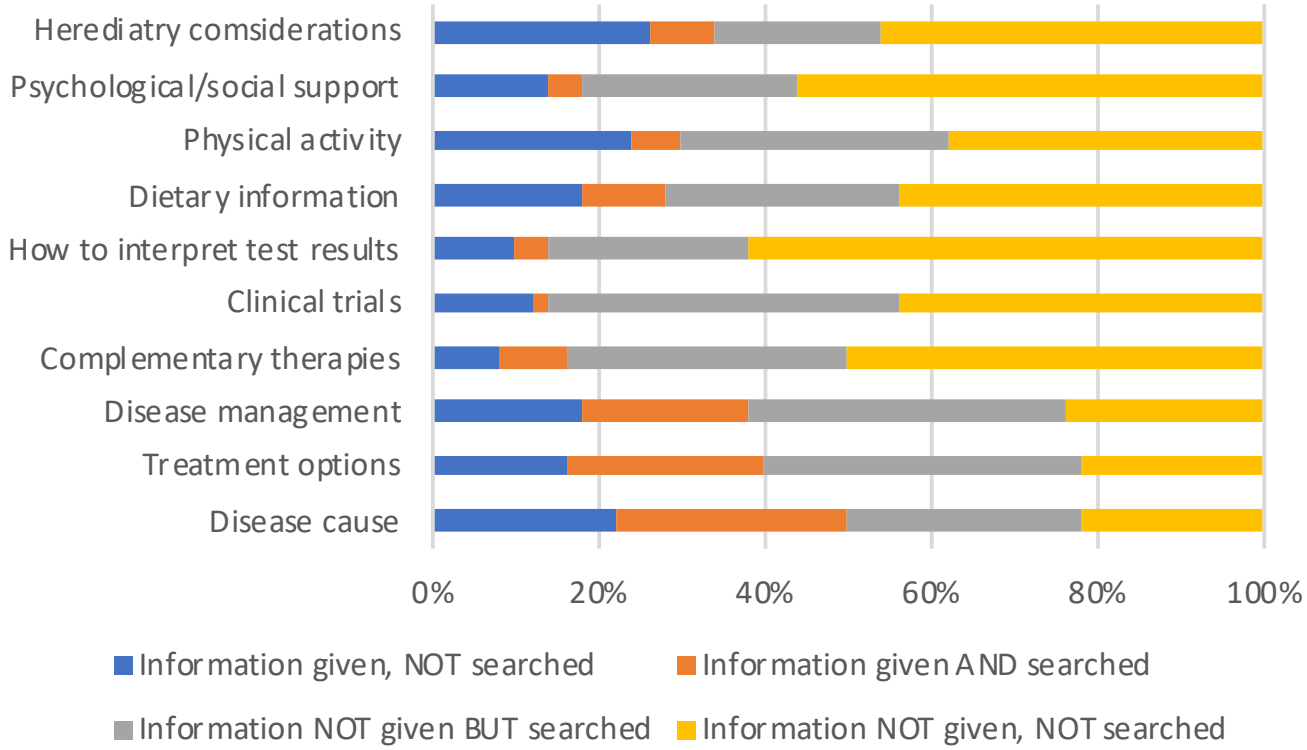


Figure 6.72: Proportion of information given by health care professionals and searched for independently.

Most trusted information sources

Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Figure 6.41. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from the participants' hospital or clinic and from the non-profit or charitable organisations was near equal and was most trusted. Information from pharmaceutical companies was least trusted. (Figure 6.73). This order of preference was the same for all sub-groups (Figures 6.74 – 6.82).

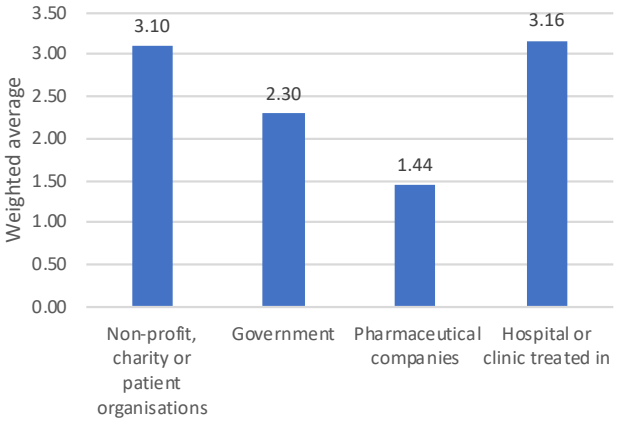


Figure 6.73: Most trusted information sources

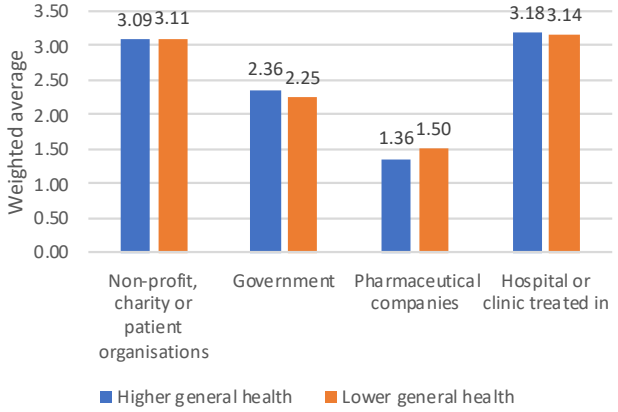


Figure 6.74: Most trusted information sources by general health

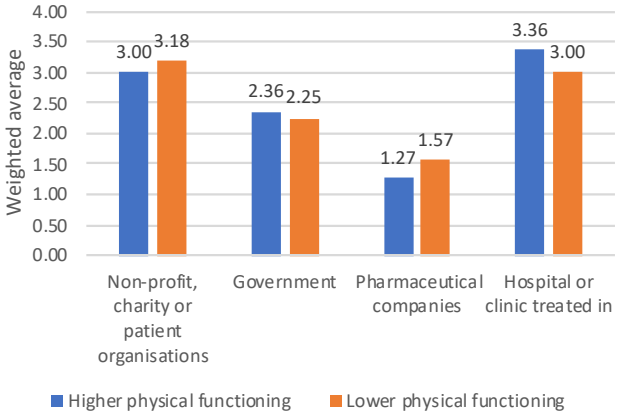


Figure 6.75: Most trusted information sources by physical functioning

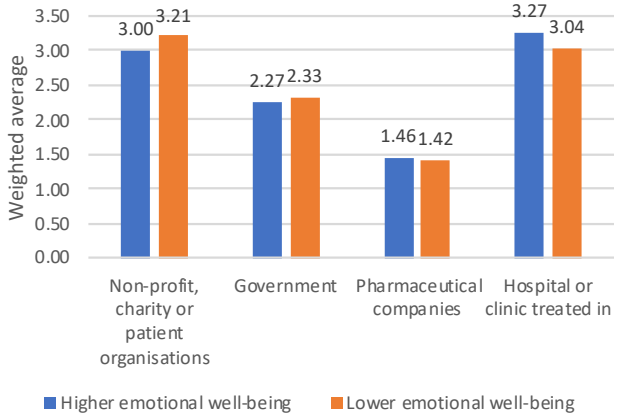


Figure 6.76: Most trusted information sources by emotional well-being

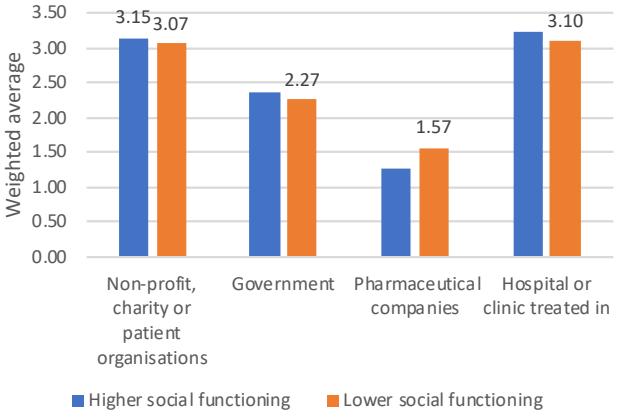


Figure 6.77: Most trusted information sources by social functioning

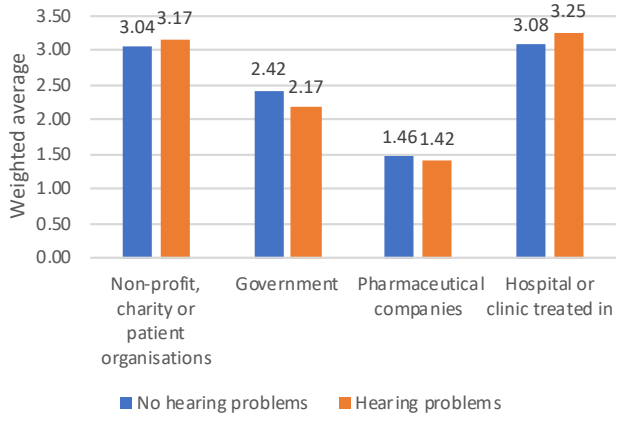


Figure 6.78: Most trusted information sources by hearing problems

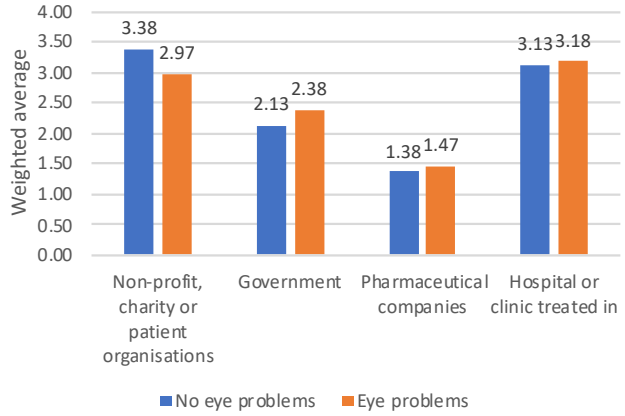


Figure 6.79: Most trusted information sources by eye problems

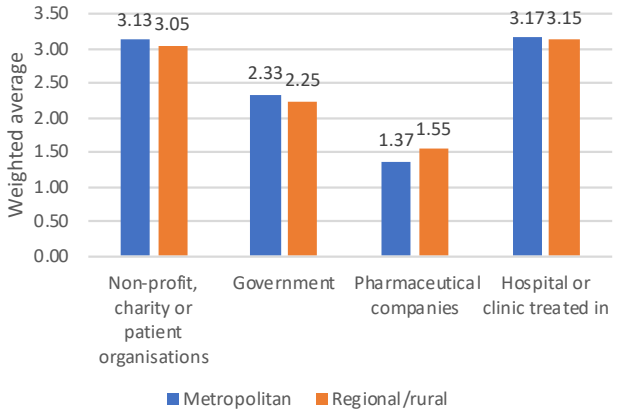


Figure 6.80: Most trusted information sources by location

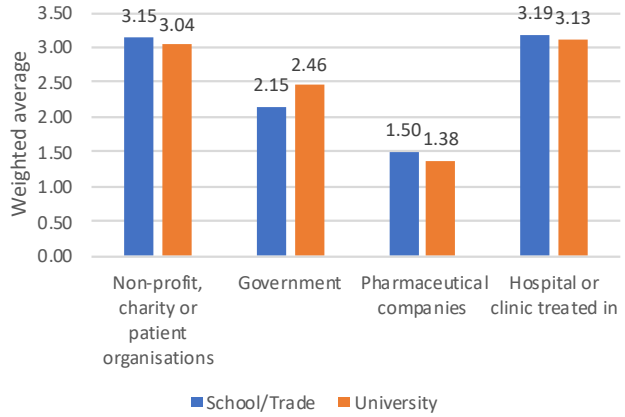


Figure 6.81: Most trusted information sources by education

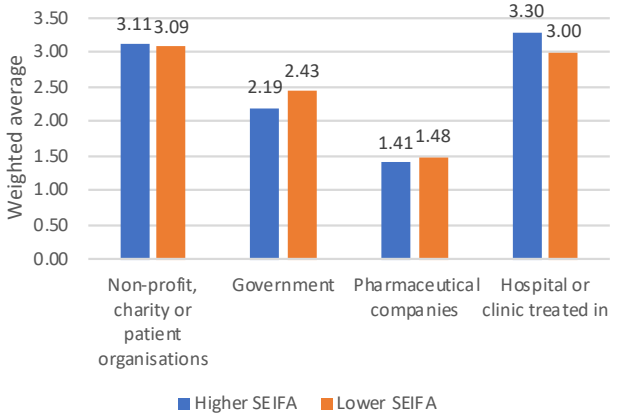


Figure 6.82: Most trusted information sources by SEIFA