Section 6

Information and communication

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Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (55.32%), their treating clinician (42.55%), and from a specific health charity (36.17 %). Other themes included information from other patient's experience (Including support groups) (31.91%), from journals (research articles) (25.53%), from books, pamphlets and newsletters (21.28%), from allied health professionals (8.51%), and from family members (8.51%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (25.53%), talking to a doctor or specialist or healthcare team (21.28%), and information from health charities (21.28 %). Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (19.15%), information about lifestyle changes and risk prevention (14.89%), medical or scientific information (8.51%), and information presented by webinar or video (8.51%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (42.55%), information given by their GP or specialist was not helpful (12.77%), sources that are not credible or not evidence-based were not helpful (12.77 %), information that not type specific or too general (10.64%), and information with too much medical jargon as unhelpful (8.51%). Others described being confident in deciding themselves if information was not helpful (8.51%).

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 responses were talking to someone (36.17%), talking to someone plus online information (27.66%), and written information (17.02 %). Other preferences included online information (14.89%), all forms (10.64%), and apps (2.13%).

The main reasons for a preference for talking to someone was being able to ask questions (21.28%), and the information was personalized and relevant (17.02%). Other reasons included that it was more supportive, and that body language helps with understanding (10.64%), and cognitive/sight problems make other forms not able to be used (6.38%).

The main reasons for a preference for online information were accessibility (21.28%), that you can can refer back to it and clarify information (17.02 %), and being able to digest information at their own pace (10.64%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (27.66%), and after the shock of diagnosis (14.89%). Other themes included continuously (12.77%), 12 months or more after diagnosis (12.77%),when medical emergency over (8.51%), after treatment (6.38%), and after test results or changes to condition (6.38%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Participants gave descriptions that communication as overall positive (34.04%), overall positive, with the exception of one or two occasions(34.04%), and overall negative (27.66 %).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because it was holistic with two way, supportive and comprehensive conversations (31.91%).

Participants that had negative communication, described the reasons for this were that communication was dismissive (One way conversation) (19.15 %), limited in multi-disciplinary communication and care coordination (10.64%), limited in relation health professionals not having a lot of time (8.51%), and limited in that they have not had a lot (6.38%).

Partners in health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=28, 56.00%), disease cause (n=19, 38.00%), disease management (n=18, 36.00%) and, dietary (n=18, 36.00%) were most frequently given to participants by healthcare professionals, and, information about hereditary considerations (n=4, 8.00%), and complementary therapies (n=2, 4.00%) were given least often. No participants (0.00%) were given information about clinical trials.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease cause (n=22, 44.00%), treatment options (n=19, 38.00%), disease management (n=19, 38.00%) and, how to interpret test results (n=17, 34.00%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=11, 22.00%), complementary therapies (n=10, 20.00%) and clinical trials (n=4, 8.00%) were searched for least often

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=46, 92.00%) and complementary therapies (n=39, 78.00%).

The topics that participants were given most information from healthcare professionals but not searched for independently for were treatment options (n=16, 32.00%) and physical activity (n=15, 30.00%).

The topics that participants searched for independently after receiving information from healthcare professionals were treatment options (n=12, 24.00%) and disease management (n=8, 16.00%)

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=15, 30.00%) and interpret test results (n=13, 26.00%).

Most accessed information

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 20 participants (40.00%) that had accessed My Health Record.

Of those that had accessed My Health Record, there were 8 participants (42.11%) who found it to be poor or very poor, 4 participants (21.05%) who found it acceptable, and 7 participants (36.84%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (55.32%), their treating clinician (42.55%), and from a specific health charity (36.17 %). Other themes included information from other patient's experience (Including support groups) (31.91%), from journals (research articles) (25.53%), from books, pamphlets and newsletters (21.28%), from allied health professionals (8.51%), and from family members (8.51%).

Participant describes accessing information through the internet in general

I got some information from the hospital. I think the doctors gave me some information and I did a bit of research online myself.
Participant 008_2023AUHBV

Yeah, sure. So I've done a lot of Googling. There's I mentioned earlier so I've I've had connections with Her Heart along the way and they they're a great resource to to connect with people and through them have come across a few groups. So I don't, you know, have got lots of information from those groups who do research in their own way. I suppose I'll look at the Victor Chang web site a little bit to see if there's any updates or what information they have... I'll go and look into whether that looks like something that they've mentioned in the research that they've published. And same with I can't think of what the research organization is, the Mayo Clinic in America is what it is. So I'll research there just to keep up to date with it if there's you know ways that I can one challenge perhaps my preventative treatment and to suggest other. There's not been much to suggest to be honest but you know things other people are doing like if I've been advised I can't run and then I see somebody else say I've been you know it's been suggested I could go back to doing things like I'll I use that as a bit of I use that information as a tool. But that's but they're the places I go and that's where I get most of my information from.
Participant 009_2023AUHBV

Ah, well, I'm a PROFESSION, so I went to the journals. I went to the, you know, the the Mayo Clinic to the Cleveland Clinic, to their websites. I went to the all the, all the evidence basis I could find, including the evidence basis for alternative options because I didn't want to have my chest cracked open if I didn't need to. Is there any way I can reverse this? Is there any, you know, kind of any inflammatory approach to nutrition I can take that might resolve it? You know, is there anything else I can do? So yes, I did. I did hours and hours and hours and hours and hours.
Participant 010_2023AUHBV

Participant describes primarily accessing information through treating clinician

I really probably have not even accessed it. I knew what I had and I dealt with it. And I had my doctor's support and my cardiologist, and I don't feel like I needed any. I needed to go there anymore.
Participant 005_2023AUHBV

So for me it's medical journals and stuff like that. I don't like doctor Google. It has to be like a peer reviewed thing or yeah, information that's credible. I've talked a lot with my GP…so we have quite good conversations about it, but sort of that's where it ends I suppose.
Participant 014_2023AUHBV

Yeah, I do a lot of research on Google with that. You know, anything like that concerns, you know, just for my own sake. All information I've received now is basically from being from my GPS, my specialist.
Participant 025_2023AUHBV

Participant describes accessing information from a specific health charity

Yeah, I as soon as I got the letter from the cardiologist, I basically copy and pasted it straight into Google just so I could understand what it was. Cuz when you're looking at a specialist's writing and diagnosis that it's all gobbledygook to me, I don't understand any of it. So I'm jumping onto the Heart Foundation website trying to understand, you know, what exactly this is and what it can cause for me. You know, like when they talk about blood pressure and all this other stuff like I have no idea what that means. Yeah, so yeah, I just start Googling everything that I know It's silly, but I mean that that's. Yeah, I just jumped straight to Google for it to start with.
Participant 028_2023AUHBV

The primary and most important source of information to me has been the Stroke Foundation. Everything I need to know comes from the Stroke Foundation. That's not only through their literature, but it's also through interaction with other people. It's a treasure of information. If the Stroke Foundation

was not there it would have been an extraordinary struggle for me.
Participant 045_2023AUHBV

Participant describes primarily accessing information through other patient's experience

A lot comes from online support groups, which I honestly find to be more beneficial than anything else because I'm talking to people who have had this longer than me and can answer my questions straight up and have that personal experience. So that's probably my #1 go to
Participant 019_2023AUHBV

I suppose because I'm a PROFESSION, I know what resources to look at. At first, when I was diagnosed, I didn't really want to know, because I didn't really, sort of put my head in a hole about it. But now I'm a lot more informed about what's going on. I use, the support group's really good and we have, I'm involved in a support group, and they will send out information on new research in the field and so on, and things to be aware of like clots. Be aware of these levels, blood levels, and make sure you're drinking lots and so on. I've found they have a really good, really great support, actually. I just, you know, there's some days, they're just fantastic. So you can, if you're having one of those really bad days, you can just email them, or you just hop on the Facebook site and people will provide encouragement or advice or whatever. So I just find that really, really helpful. I go to information sessions at HOSPITAL as well, and they're really, really good as well. My doctor's really well-informed, and the practise nurse there is really well-informed as well. Anything else that I'm concerned about, I'll look up on reputable websites and journals, yeah.
Participant 030_2023AUHBV

I've learnt a lot through meeting other people, and the information, their wealth of information. The internet, I usually just go to the Stroke Foundation's page to get the information. It's just a matter of talking to other stroke survivors and giving information. Doctors are really good nowadays with stroke things, but they weren't back in my day. No.
Participant 049_2023AUHBV

Participant describes accessing information primarily through journals (research articles)

I make informed choices about high cholesterol and on occasion if I have, if I have some doubts, I search in articles and now is excellent to have some now knowledge about that.
Participant 026_2023AUHBV

Most of the information I get is from stroke organisations and medical journals. Basically, I've done a lot of university degrees. I still had access to university library journals and that sort of thing. I've done a bit of reading there. To be honest, I haven't done any reading for probably 10 years because my symptoms are static. You can't make a dead piece of the brain not be dead. If I had symptoms that weren't static, then I would certainly be trying to stay on top of that sort of thing, and talking to my GP about it. For my particular situation, it's not really a thing anymore.
Participant 046_2023AUHBV

Participant describes receiving information from books, pamphlets and newsletters

So I've pretty much googled it because I haven't been given much officially from the doctor. A few printed handouts with some highlighted information about healthy levels and things. And you know the all the basics eat avocados and oats and and very general sort of stuff. But I haven't. I I spent a lot of more time just doing research on my own on the Internet.
Participant 020_2023AUHBV

I'm with Heart Care LOCATION STATE. They've got brochures on all different procedures and things, and my GP's pretty good with communicating and answering questions. I always go with a lot of questions in my head or written down, and I also find that I direct a lot of my questions to the technicians ... They are very, very clear and helpful, actually.
Participant 023_2023AUHBV

Yes. Like I said, I'm a researcher, so I'll go onto Heart Support Australia. All those information websites. I go on there and I use those. I do have some brochures about what it's like to live with atrial fibrillation, which is extremely informative. I go on social media, and there's a lot of support forums, and I'm involved with probably three or four of those, and I find that extremely helpful as well. Yeah, so it's print and social media, and also TV. There's quite a lot going on at the moment with the TV, as far as information about strokes and atrial fibrillation, et cetera. Yeah. So I do follow it quite well, because I'm always looking for new information about improvements in treatment and all that sort of thing. And it's up to me to do that. While it's good for the cardiologist -- well, the cardiologist has some brochures, but I find it's easier just for me to do the research myself. Because I love doing it.
Participant 031_2023AUHBV

Participant describes receiving information through allied health

When I left there, in the April or the May when I left, the physio, the whole lot. From there then I started doing the rehab after I had the clips done. I was seeing my now current cardiologist and as I said they refused me to do the heart study gym at the hospital after I was discharged. NAME go me into the normal gym and I got a lot of information from that. As I said, I was the only heart failure patient, which I found pretty frustrating. After I had an admittance at the hospital they put me under the heart failure gym at the hospital, so I've done another six weeks of heart failure gym, and information, and education,I've done both lots.
Participant 033_2023AUHBV

I've had a lot of information. I had a lot of information from cardiac rehab if since when I attended there, they had classes, they had lectures, they had everything. I actually seen private dieticians, that sort of thing. One of the women that tell me that I needed to eat healthy and do this and do that chair tucks up, arms hanging down onto the desk. You're telling me from and would have been at least about 130 kilos. And I thought you're telling me that I need what I need to be doing. Yeah. Right. OK. No, the dietitian was a young lady from came to cardiac rehab one day and while I was there I got talking to her about what was the correct foods and what was not and told her I was buying fruit and that sort of thing and what I was eating of it. And she said well that's wrong because they're for sugar and that sort of thing. So and you have just got early diabetes. She gave me. She said take this sheet, a four sheet. See on there, there foods you can have all day. They're all-day foods. They're part time foods. They're that's what you can have of that. It just immediately got me going where it was simply diagnosed. You can have these, these are as much as eat as much as this food all day long as you like this one. So this a bit with the meals once a day, you know what I'm saying? Like, so, yeah, She was just so much on the so much on to it, you know, in line with terms of where you need to be.
Participant 006_2023AUHBV

Participant describes accessing information from family members

I think it's just just growing up knowing other, you know, all our family members that, you know, going along to appointments with my dad, taking him to appointments and stuff like that and sitting in with him because he wanted me to, or just learning, you know, learning about it from a young age. Really. I haven't really thought about it since I've been on the medication.
Participant 016_2023AUHBV

In rehab, I asked them about stroke because one was talking to me about it. I was really getting myself a bit distressed about it so I asked them about the stroke and they gave me a booklet. In the booklet, there was a website for a stroke foundation I think it was. I joined it and they send out newsletters but I don't find any of that very helpful at all. Then I looked up, stroke on the internet, and found out some really horrifying statistics about survival rate which scared me. [laughs] Then I talked to my son about it and he's probably helped me the most.
Participant 041_2023AUHBV

Table 6.1: Access to information.

Access to information	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes accessing information through the internet in general	26	55.32	10	55.56	16	55.17	6	66.67	9	52.94	11	52.38	13	48.15	13	65.00
Participant describes primarily accessing information through treating clinician	20	42.55	10	55.56	10	34.48	4	44.44	6	35.29	10	47.62	13	48.15	7	35.00
Participant describes accessing information from a specific health charity	17	36.17	2	11.11	15	51.72	2	22.22	10	58.82	5	23.81	9	33.33	8	40.00
Participant describes primarily accessing information through other patient's experience	15	31.91	3	16.67	12	41.38	3	33.33	6	35.29	6	28.57	9	33.33	6	30.00
Participant describes accessing information primarily through journals (research articles)	12	25.53	4	22.22	8	27.59	3	33.33	5	29.41	4	19.05	7	25.93	5	25.00
Participant describes receiving information from books, pamphlets and newsletters	10	21.28	5	27.78	5	17.24	2	22.22	3	17.65	5	23.81	5	18.52	5	25.00
Participant describes receiving information through allied health	4	8.51	1	5.56	3	10.34	0	0.00	1	5.88	3	14.29	3	11.11	1	5.00
Participant describes accessing information from family members	4	8.51	1	5.56	3	10.34	2	22.22	1	5.88	1	4.76	1	3.70	3	15.00

Access to information	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes accessing information through the internet in general	26	55.32	18	69.23	8	38.10	12	50.00	14	60.87	10	66.67	16	50.00	13	52.00	13	59.09
Participant describes primarily accessing information through treating clinician	20	42.55	10	38.46	10	47.62	10	41.67	10	43.48	3	20.00	17	53.13	10	40.00	10	45.45
Participant describes accessing information from a specific health charity	17	36.17	10	38.46	7	33.33	8	33.33	9	39.13	7	46.67	10	31.25	9	36.00	8	36.36
Participant describes primarily accessing information through other patient's experience	15	31.91	7	26.92	8	38.10	6	25.00	9	39.13	5	33.33	10	31.25	6	24.00	9	40.91
Participant describes accessing information primarily through journals (research articles)	12	25.53	8	30.77	4	19.05	4	16.67	8	34.78	5	33.33	7	21.88	8	32.00	4	18.18
Participant describes receiving information from books, pamphlets and newsletters	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	3	20.00	7	21.88	3	12.00	7	31.82
Participant describes receiving information through allied health	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64
Participant describes accessing information from family members	4	8.51	2	7.69	2	9.52	4	16.67	0	0.00	0	0.00	4	12.50	1	4.00	3	13.64

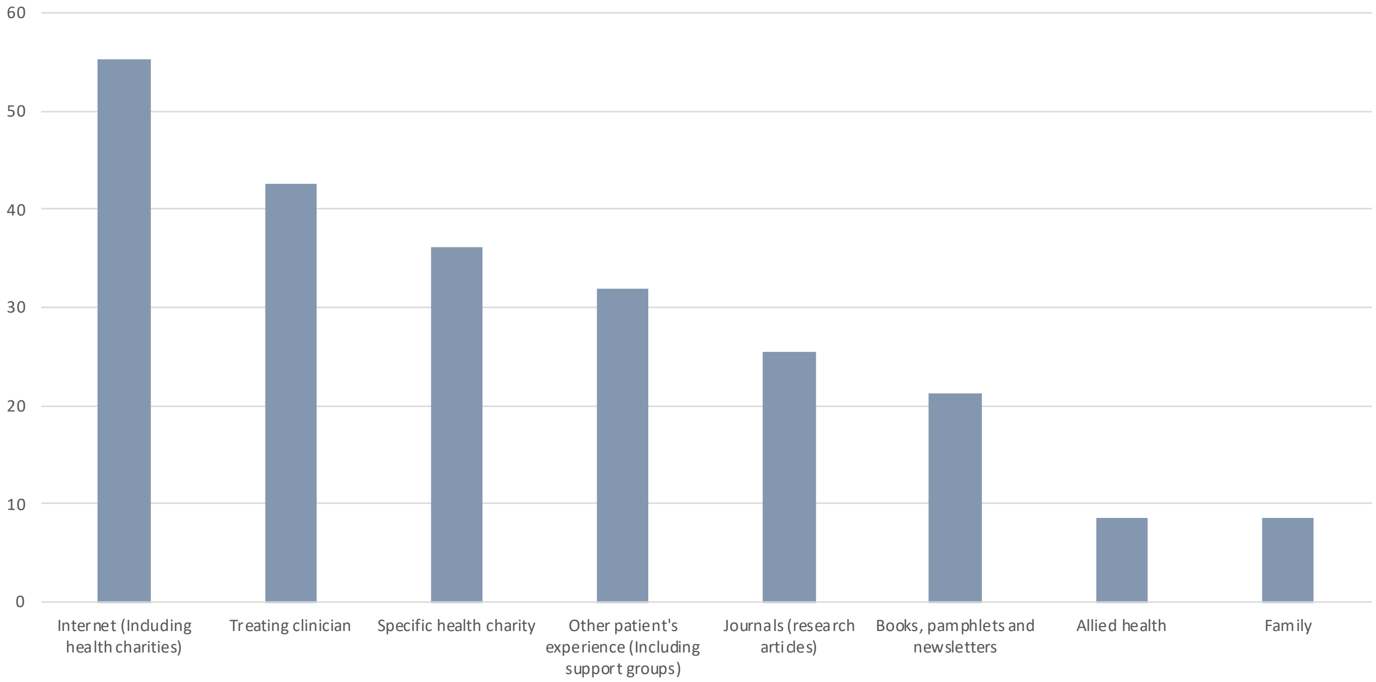

Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Male	High cholesterol under 50 years of age Female Regional or remote
Participant describes primarily accessing information through treating clinician	Regional or remote	Had LP(a) test Metropolitan
Participant describes accessing information from a specific health charity	Had LP(a) test High cholesterol under 50 years of age Heart conditions	Did not had LP(a) test Blood vessel conditions Regional or remote
Participant describes primarily accessing information through other patient's experience	Had LP(a) test	-
Participant describes receiving information from books, pamphlets and newsletters	-	Higher socioeconomic status
Participant describes accessing information from family members	-	High cholesterol under 50 years of age

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (25.53%), talking to a doctor or specialist or healthcare team (21.28%), and information from health charities (21.28 %). Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (19.15%), information about lifestyle changes and risk prevention (14.89%), medical or scientific information (8.51%), and information presented by webinar or video (8.51%).

Participant describes other people's experiences as helpful (Peer-to-peer)

I think to be honest, just knowing that there's lots of people all probably feeling the same way, not really sure what it all means to have had the doctor to have had a scab. So knowing that there are people asking the same questions that you're thinking in your head, you know, around lots of things you know they'll ask in a group, has anybody had a second one? How long between the years you know, how many years between? You know, just knowing that people are actually thinking, having similar thoughts and wondering the same things, I think that's the most useful thing I've taken away from it.
Participant 009_2023AUHBV

The online support group
Participant 019_2023AUHBV

To be honest, it's been more the parts that I'm not alone. There's other people out there that have strokes of all ages, even in the womb and that some are going to have really good effects with thrombolytics and all sorts of stuff and come out of their stroke with very little physical damage. Then others of us, are going to be well upstairs in the sense of have all their mental capacities but may have physical damage. Regardless, we're all in a tribe that's quite elite. For me, that's been the biggest thing, is that we're not alone. As much as we feel like we're alone because no stroke is ever the same, two strokes are never the same, it's just to remind us that we're not alone.
Participant 050_2023AUHBV

Participant describes talking to their doctor or specialist as helpful

most helpful would be, it's actually like completely non medical to be honest. Like the most helpful information I received the whole throughout my whole childhood, probably growing up, is that there are people with your condition or very similar sort of condition who are functioning day-to-day completely fine. You know, when I was a teenager, things were progressing quite quickly and probably the outlook wasn't great. So you're sort of get caught into a mindset of is this just going to be the progress forever until you get to a point where the decline is quite steep and quick and unfortunate I guess. But, you know, you hear stories or you speak to people or you just randomly come across these stories of people who have the same condition, Cardiomyopathy, It's pretty common, quite a lot of people do who are functioning in, you know, business or sport or, you know, whatever it is. Those were probably the most helpful pieces of information. And then you know your reassurances from your doctor that like things are actually going to be OK You know, you, you get a bunch of different forecasting from your doctors usually throughout and most of it was pretty positive in my sense. So I I think that was quite comforting. Participant 012_2023AUHBV

What information has been helpful? Well, I tend to -- because I follow a couple of support groups on Facebook, mostly, actually. People living with this, and that sort of thing, and I tend just to watch what's going on. Not really contribute, because I don't believe in sourcing my information like that. I like to just put my faith in someone that I trust, which is in my case my GP, and direct my questions there. Now, I know I had some questions before … this procedure now, and I find that he didn't actually call me back but one of the cardiac nurses did, and I actually found that really, really useful. Being able to chat to her. I tend to be quite focused on being specific on where I go to get my information. Participant 023_2023AUHBV

Participant describes health charities information as helpful

I guess the most helpful information was you know, I I, I love the Heart Foundation website it had a lot of great information there for me. But I guess the the main one was was knowing that the the blockage I've got in its current form isn't gonna kill me. Which gave me that relief that OK, you know, I'm not going to end up on a on an operating table anytime soon, you know. But you know it gave a lot of information regards to what you can do to reduce, you know any ongoing risks andall that sort of stuff. So you know, I mean, you can only read so many times about dietary

and exercise and things like that. Until you know, it's like if you don't do this, you know where you're going to end up.
Participant 028_2023AUHBV

In terms of websites, I go to the Mayo Clinic. And I tried out the Heart Foundation, but that's got little information about my condition -- The hypertrophic cardiomyopathy association in the US is really good. They're excellent, actually. And the cardiomyopathy association in Australia has got people -- Individuals in it with a lot of passion, and a lot of information. It's just the internet is not always -- It's often related to themselves, yeah.
Participant 032_2023AUHBV

Information received from the Stroke Foundation.
Participant 040_2023AUHBV

When I left rehab I was given some initial information which is well-written, because it takes into account that a recent stroke survivor would have difficulty reading, with memory and all the rest of it. I was given short grabs of information. Probably the most important bit of information I was given was to get onto Enable Me, which is the Stroke Foundation's website. There would not be a week that goes by where I haven't done some research onto the Stroke Foundation's website
Participant 045_2023AUHBV

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

I suppose talking to you to validate it was my big thing, and for me, information on how to live with it. So I know what it is, I know what it does, and that's all well and good, but when you're living it, you need to know the small steps you need to take to start the journey. And I think you know, starting small, not being overwhelmed. But the big thing is, so what's next? How do I get myself from bedridden? Can't do anything on my own to living a normal life. And was there anything that you found when you read the information?
Participant 014_2023AUHBV

All of it. Whatever information I can get is helpful, because if I'm reading up about ECGs and -- it's all helpful, because if I understand to some degree what is happening to me, I'm more likely to feel at ease, if that makes sense. Does that make sense? I want to know what's happening, basically. If I don't read up, I will ask.
Participant 034_2023AUHBV

That no stroke is the same, but the after effects are very similar for each person. To acknowledge your symptom, and cope and learn to live with what that condition is that is ailing you at the time.
Participant 049_2023AUHBV

Participant describes information about lifestyle changes and risk prevention as helpful

Probably something that I probably already knew. But lifestyle, you know, keeping, keeping active, you know, it's very easy. After something major like that. You just, you know, sit on the couch and yes, I will, you know, my life's half over. But it's not. So yeah, just I'm not saying I'm perfect with diet and everything like that, but I am active so.
Participant 005_2023AUHBV

I I would say the the, the the the diet information. I've I have changed my diet and I'm buying products that have the plant-based things in them that should help. To lower cholesterol is one that has those those plants steroids in so that it helps lower cholesterol and those sorts of things.
Participant 017_2023AUHBV

Participant describes medical or scientific information as helpful

But yeah, I just make sure I'm informed about new developments and yeah, and so on. So just keep up to date-with what's in the literature and so on, and my doctor will tell me about new developments as well.
Participant 030_2023AUHBV

I can't think of really anything that has been unhelpful. I'm very, I love like facts and figures and very, you know I don't get as much value from other people's experiences as I get from say a report on some of the statistics around heart failure. So I got a lot from those kinds of reports, the scientific reports.
Participant 035_2023AUHBV

Participant describes information presented by webinar or video as helpful

I think probably the most helpful information was understanding that they're currently doing trials even though lipoprotein A is not, there's not no very good treatment for it at the moment. There's it's it's actually this trials out there that are that are happening. So it's kind of gives you a bit of hope and also listening to other people's stories as well that's a big one. So I've gone on YouTube and also through the FH Foundation they've they've got often webinars that you can watch, which has been really interesting.

> *And it there was one particular webinar talking about the stress of people that are being diagnosed with Lipoprotein A and that was just really impressive to watch, you know, but sad at the same time for them. It was. It was kind of showed all of their emotions and yeah, it was very interesting, very insightful*
> *Participant 011_2023AUHBV*

> *I feel the Stroke Foundation web page has lots of short snippet videos. Some questions that other stroke survivors have posted. I feel a sense of community and sharing of knowledge has been very beneficial*
> *Participant 047_2023AUHBV*

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes other people's experiences as helpful (Peer-to-peer)	12	25.53	3	16.67	9	31.03	1	11.11	5	29.41	6	28.57	6	22.22	6	30.00
Participant describes talking to their doctor or specialist as helpful	10	21.28	5	27.78	5	17.24	3	33.33	1	5.88	6	28.57	8	29.63	2	10.00
Participant describes health charities information as helpful	10	21.28	3	16.67	7	24.14	1	11.11	4	23.53	5	23.81	4	14.81	6	30.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	9	19.15	4	22.22	5	17.24	2	22.22	5	29.41	2	9.52	5	18.52	4	20.00
Participant describes information about lifestyle changes and risk prevention as helpful	7	14.89	3	16.67	4	13.79	2	22.22	2	11.76	3	14.29	3	11.11	4	20.00
Participant describes medical or scientific information as helpful	4	8.51	1	5.56	3	10.34	1	11.11	2	11.76	1	4.76	3	11.11	1	5.00
Participant describes information presented by webinar or video as helpful	4	8.51	0	0.00	4	13.79	1	11.11	3	17.65	0	0.00	3	11.11	1	5.00

Information that has been helpful	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes other people's experiences as helpful (Peer-to-peer)	12	25.53	9	34.62	3	14.29	3	12.50	9	39.13	4	26.67	8	25.00	6	24.00	6	27.27
Participant describes talking to their doctor or specialist as helpful	10	21.28	3	11.54	7	33.33	6	25.00	4	17.39	2	13.33	8	25.00	3	12.00	7	31.82
Participant describes health charities information as helpful	10	21.28	7	26.92	3	14.29	4	16.67	6	26.09	4	26.67	6	18.75	5	20.00	5	22.73
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	9	19.15	5	19.23	4	19.05	5	20.83	4	17.39	8	53.33	1	3.13	6	24.00	3	13.64
Participant describes information about lifestyle changes and risk prevention as helpful	7	14.89	4	15.38	3	14.29	6	25.00	1	4.35	2	13.33	5	15.63	2	8.00	5	22.73
Participant describes medical or scientific information as helpful	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	3	20.00	1	3.13	3	12.00	1	4.55
Participant describes information presented by webinar or video as helpful	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	1	6.67	3	9.38	3	12.00	1	4.55

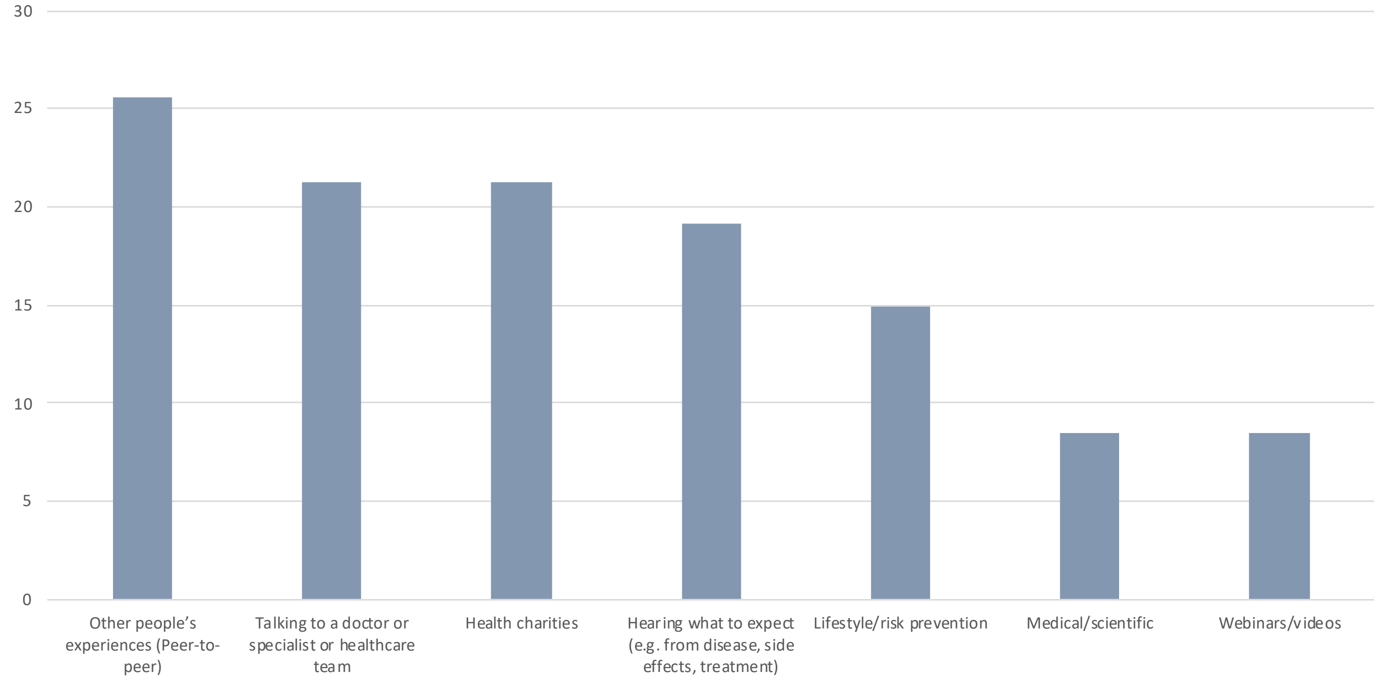

Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes other people's experiences as helpful (Peer-to-peer)	High cholesterol under 50 years of age Male Aged 25 to 44	Aged 45 and older
Participant describes talking to their doctor or specialist as helpful	Blood vessel conditions 6 to 11 other conditions	High cholesterol under 50 years of age Male Higher socioeconomic status
Participant describes health charities information as helpful	High cholesterol under 50 years of age	-
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Metropolitan	Blood vessel conditions Regional or remote
Participant describes information about lifestyle changes and risk prevention as helpful	Aged 45 and older	Aged 25 to 44
Participant describes medical or scientific information as helpful	-	Regional or remote

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (42.55%), information given by their GP or specialist was not helpful (12.77%), sources that are not credible or not evidence-based were not helpful (12.77 %), information that not type specific or too general (10.64%), and information with too much medical jargon as unhelpful (8.51%). Others described being confident in deciding themselves if information was not helpful (8.51%).

Participant describes no information being not helpful

No. I don't think there's anything that's been been really unhelpful. Yeah, all of it's been very interesting to read and watch.
Participant 011_2023AUHBV

No, I don't say that anything like this. Everything was helpful for me. From a very first day when I was a go and we don't know what is the situation.
Participant 027_2023AUHBV

Look, I haven't really come across anything that's not been helpful. All the information that I've accessed has been simply helpful. Nothing's been unhelpful in any way. Yeah.
Participant 031_2023AUHBV

Yeah so, yeah I haven't had many experiences of unhelpful things. It was more, most things were helpful that I came across, yeah.
Participant 035_2023AUHBV

Participant describes the GP/specialist as being not helpful

I wish my diagnosis experience had been different with the doctors. A lot more information at the time, would've been helpful. Or, it still would be, to be honest.

INTERVIEWER: It is difficult, isn't it? Because lots of peoples causes for heart failure is very different, and yours is very particular, isn't it?
PARTICIPANT: Exactly.
Participant 032_2023AUHBV

I can discuss things with him, and he will always point me in the right direction, but I think a lot of people miss out on that. There's a reason I haven't gone to anyone else in 13 years. I've gone to multiple GPs prior to finding NAME DOCTOR and they were useless, absolutely useless.
Participant 046_2023AUHBV

The neurologist in LOCATION because we just didn't get that continuity of care.
Participant 047_2023AUHBV

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

Not really. I mean, the only unhelpful ones was when I when I stumbled across medical journals and and things like that and I just wasn't able to obviously understand what those people are talking about. You know, you just stumble across them. But yeah, I mean I take a grain of salt with I guess what they call natural remedies and things like that, you know, where you come across. I mean to me, I'm very science based. I believe doctors, you know, whereas if someone's, you know, going oh, you should have this herbal tea or whatever. To me that's kind of, you know, medieval type stuff and and and I don't take any, I don't believe any of that sort of stuff.
Participant 028_2023AUHBV

No, it leads back to that category. So I can't get the right information on these cholesterol pills, what they're doing to me with my mobility because I wake up in the my main concern with these pills I think. I've been on them too long and I believe I've, I've been suffering a lot of aches and pains in my body and my

doctor has has no idea what's happening with me, he said. You haven't got an autoimmune disease, you haven't got myalgia, things like that. We don't know what's causing this pain in your body and that's where the subject came up. Could have been caused by the medications I've been on for a lifetime since I've been using them. The only weekly that came up was the Catavas, the cholesterol pill. They believe that causes a lot of inflammation in the body. But is that true? This is all hearsay. You get all this stuff off Google and you know, I'd rather have a professional to tell me.
Participant 025_2023AUHBV

Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)

I think receiving information for generic heart attacks, and I know that that sounds really callous to say generic a standard heart attack because. And I referenced it before as well to receive information about how to be healthier, how to reduce your cholesterol, how to lose body fat, how to all of these things when that's not who you are or what your treatment plan is or what you need to do. I think that's really not useful and not helpful at all actually. An actual fact is, it's actually a little bit damaging because it's kind of.
Participant 009_2023AUHBV

No. That's the main thing really. It's the misunderstanding from a lot of different groups of people, that when they find out that you've got heart disease, that they think exercise is what's going to fix it. Whereas exercise makes our symptoms worse for HOCM patients.
Participant 036_2023AUHBV

Participant describes feeling confident in deciding if something is not helpful (or not credible)

I probably filtered that out.
Participant 015_2023AUHBV

No, I guess it's all relevant and it's anyway it's just filtering out what applies in relation to information.
Participant 020_2023AUHBV

Participant describes information that is too technical or has too much medical jargon as unhelpful

I think for someone that potentially didn't have a science background, I think that that would get completely lost in all of the medical terms. And I get that it's a medical journal, it's written that way. I get that. But I feel for people who wouldn't understand what they're saying. So for me, it wasn't a disadvantage. I'm fine. I can read that, but for someone who doesn't have that background, it would be very overwhelming to try and get through all the stuff.
Participant 014_2023AUHBV

Yeah, again, that whole, you know, technical terms and technical jargon, you know, it's kind of like, for example. So the pharmacist said something to me the other day about Spren. And I'm like. Yeah, Okay, You know, they didn't have Spren. So he had to change it to something else. And I was like, oh, okay, You know, I didn't realize that the aspirin I took was called Spren. You know, to me, I to me, it was more or less a case of, oh, okay. And what's that? You know, you could have just said we've had to change the brand of your aspirin.
Participant 018_2023AUHBV

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes no information being not helpful	20	42.55	8	44.44	12	41.38	3	33.33	**9**	**52.94**	8	38.10	12	44.44	8	40.00
Participant describes the GP/specialist as being not helpful	6	12.77	1	5.56	5	17.24	1	11.11	**4**	**23.53**	1	4.76	2	7.41	4	20.00
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	12.77	4	22.22	2	6.90	1	11.11	2	11.76	3	14.29	3	11.11	3	15.00
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	5	10.64	**0**	**0.00**	5	17.24	1	11.11	2	11.76	2	9.52	3	11.11	2	10.00
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	8.51	2	11.11	2	6.90	**2**	**22.22**	0	0.00	2	9.52	0	0.00	**4**	**20.00**
Participant describes information that is too technical or has too much medical jargon as unhelpful	4	8.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	3	11.11	1	5.00

Information that has not been helpful	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes no information being not helpful	20	42.55	11	42.31	9	42.86	11	45.83	9	39.13	6	40.00	14	43.75	11	44.00	9	40.91
Participant describes the GP/specialist as being not helpful	6	12.77	5	19.23	1	4.76	3	12.50	3	13.04	0	0.00	6	18.75	2	8.00	4	18.18
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	12.77	2	7.69	4	19.05	3	12.50	3	13.04	3	20.00	3	9.38	4	16.00	2	9.09
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	2	13.33	3	9.38	2	8.00	3	13.64
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes information that is too technical or has too much medical jargon as unhelpful	4	8.51	2	7.69	2	9.52	4	16.67	0	0.00	3	20.00	1	3.13	4	16.00	0	0.00

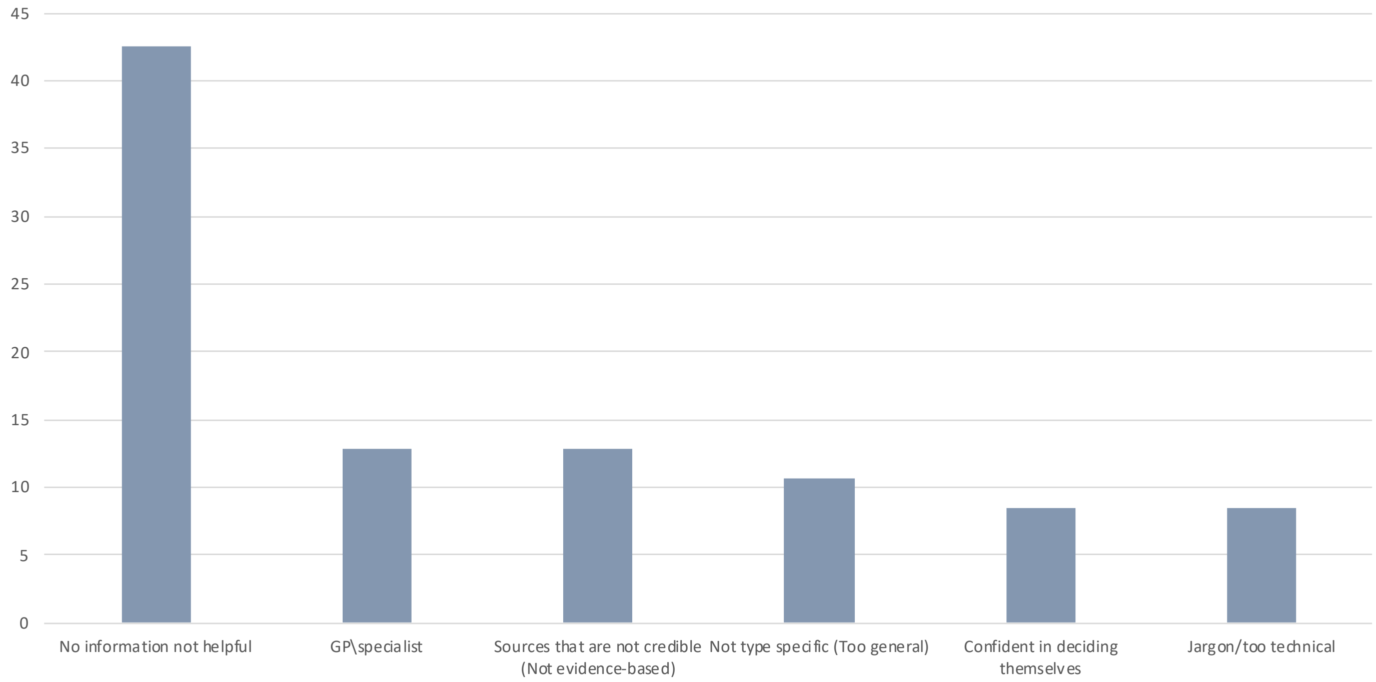

Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	-	Blood vessel conditions
Participant describes the GP/specialist as being not helpful	Regional or remote	Blood vessel conditions
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	Had LP(a) test	-
Participant describes feeling confident in deciding if something is not helpful (or not credible)	-	High cholesterol under 50 years of age 6 to 11 other conditions
Participant describes information that is too technical or has too much medical jargon as unhelpful	-	Regional or remote

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 responses were talking to someone (36.17%), talking to someone plus online information (27.66%), and written information (17.02 %). Other preferences included online information (14.89%), all forms (10.64%), and apps (2.13%).

The main reasons for a preference for talking to someone was being able to ask questions (21.28%), and the information was personalized and relevant (17.02%). Other reasons included that it was more supportive, and that body language helps with understanding (10.64%), and cognitive/sight problems make other forms not able to be used (6.38%).

The main reasons for a preference for online information were accessibility (21.28%), that you can can refer back to it and clarify information (17.02 %), and being able to digest information at their own pace (10.64%).

Participant describes talking to someone as main information preference

Talking to someone primarily because at the end of the day, you can ask the questions if you need to. Where as you can't question a piece of paper. You can't question that necessarily. Yeah. Yeah.
Participant 018_2023AUHBV

No, I would definitely prefer to talk to someone, because I can ask questions, and specifics around it, then having to plough around a whole lot of irrelevant stuff. Which results in more questions than answers, very often. Because I don't have enough of a level of knowledge, and I'm not going to … to get it.
Participant 032_2023AUHBV

Talking to someone. A two-way conversation is a richer source of information than simply reading it. I prefer a conversation as my primary source of information. Secondly, I couldn't read for a long time but now I'm back reading. Of course I'll read whatever I can around this condition called stroke, and I read whatever I can around research and stories of how people have dealt with stroke.
Participant 045_2023AUHBV

Participant describes talking to someone plus online information as main information preference

Online's great because it's accessible. I think talking to someone is better because, like we're doing now, you know? When you're talking things out loud, it triggers questions for you to ask it it it, it triggers other things so that you can ask the next question, you know query what that information means, get the get the information in the right context. So, so I think that that's that's far better
Participant 009_2023AUHBV

Look, I think they all play a part. Online is easy to access because it's there 24 hours a day, but there are times when you just need to talk to someone, and just need a pep talk about what's going on and, "Yeah, it's hard, but you will get there," and it's good to talk to other people who are also suffering from similar conditions, because you realise that you are not on your own, and that provides moral support as well.
Participant 030_2023AUHBV

I think they all play a part differently. I know early on, the reading would have been really hard for me to be able to read and then cognitively understand. So different forms, seek different people at different times, I now can see the computer and read information online. Early on, that was too exhausting.
Participant 047_2023AUHBV

Participant describes written information as main preference

And why I like to read it. I find it thinks them better if I can read it and comprehend it in my own at my own pace. And then you can also refer back to it if it's in writing. So I do like anything in writing, whether that be online or in print.
Participant 019_2023AUHBV

I'm pretty easy. I'd probably do. I'm pretty good with like my reading and stuff. I'd probably like to read, whether it was online or brochures.
Participant 029_2023AUHBV

Participant describes online information as main information preference

Online because it's easier and flexible as to when I can sit down and go into it.
Participant 020_2023AUHBV

I like online, which is natural. I like talking to someone. Booklet information is okay, but to keep up with the trends, everything's online. I'm 68, and I just love the internet. I love social media because I can get so much information from it, so to me that's where the focus should be. On information. And, like I said, there's the AF Association in England who puts out a lot of stuff. That's where I got onto social media in the first place, from there, and then they have a branch in Australia and so forth. Like I said, I just love the internet. I love the information right at hand. I don't have to go looking in books or research anything anywhere else. It's online. It's in front of you. It's great.
Participant 031_2023AUHBV

I have a preference for online information. I think that's probably because I work in a scientific writing capacity. For me, I like to have the information laid out in front of me. I like to make decisions about what links I would follow. I process information faster by reading it than listening to it. Participant 046_2023AUHBV

Participant describes preferring all forms of information

No, I tend to, I gather information from all sources, just sort of make up my mind on what I'm following, if you know what I mean. Yeah
Participant 008_2023AUHBV

And why I I really don't mind whether it's sort of done by telephone, online, in person. I I think any type of communication, yeah, is is is fine
Participant 017_2023AUHBV

No, they're all good. I'm happy with all of them. I don't have a preference
Participant 048_2023AUHBV

Participant describes apps as main information preference

I prefer apps because I'm always on apps.
Participant 044_2023AUHBV

Table 6.7: Information preferences

Information preferences	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes talking to someone as main information preference	17	36.17	7	38.89	10	34.48	3	33.33	**4**	**23.53**	**10**	**47.62**	12	44.44	**5**	**25.00**
Participant describes talking to someone plus online information as main information preference	13	27.66	**2**	**11.11**	**11**	**37.93**	3	33.33	5	29.41	5	23.81	7	25.93	6	30.00
Participant describes written information as main preference	8	17.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	2	7.41	**6**	**30.00**
Participant describes online information as main information preference	7	14.89	3	16.67	4	13.79	1	11.11	3	17.65	3	14.29	3	11.11	4	20.00
Participant describes preferring all forms of information	5	10.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	1	3.70	4	20.00
Participant describes apps as main information preference	1	2.13	0	0.00	1	3.45	0	0.00	1	5.88	0	0.00	1	3.70	0	0.00

Information preferences	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes talking to someone as main information preference	17	36.17	**6**	**23.08**	**11**	**52.38**	7	29.17	10	43.48	4	26.67	13	40.63	8	32.00	9	40.91
Participant describes talking to someone plus online information as main information preference	13	27.66	7	26.92	6	28.57	5	20.83	8	34.78	**6**	**40.00**	7	21.88	8	32.00	5	22.73
Participant describes written information as main preference	8	17.02	6	23.08	2	9.52	3	12.50	5	21.74	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes online information as main information preference	7	14.89	6	23.08	**1**	**4.76**	5	20.83	2	8.70	3	20.00	4	12.50	4	16.00	3	13.64
Participant describes preferring all forms of information	5	10.64	4	15.38	1	4.76	3	12.50	2	8.70	2	13.33	3	9.38	3	12.00	2	9.09
Participant describes apps as main information preference	1	2.13	0	0.00	1	4.76	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00

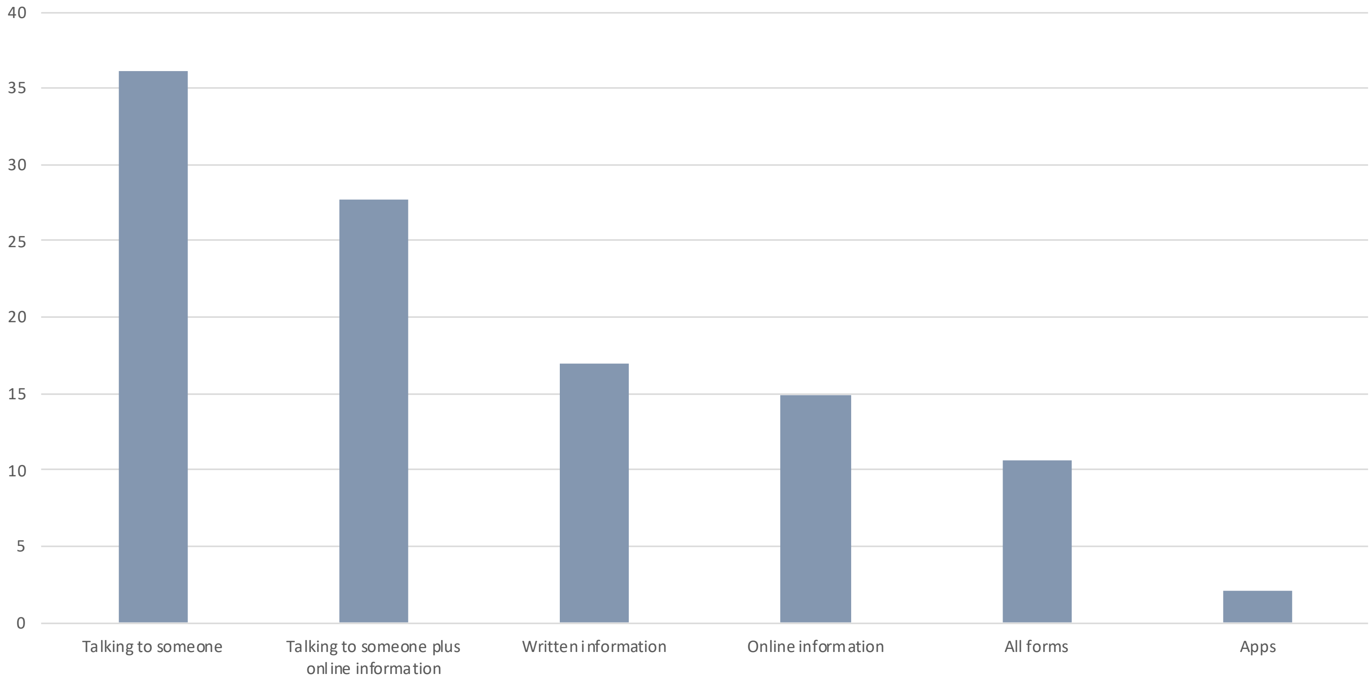

Figure 6.4: Information preferences

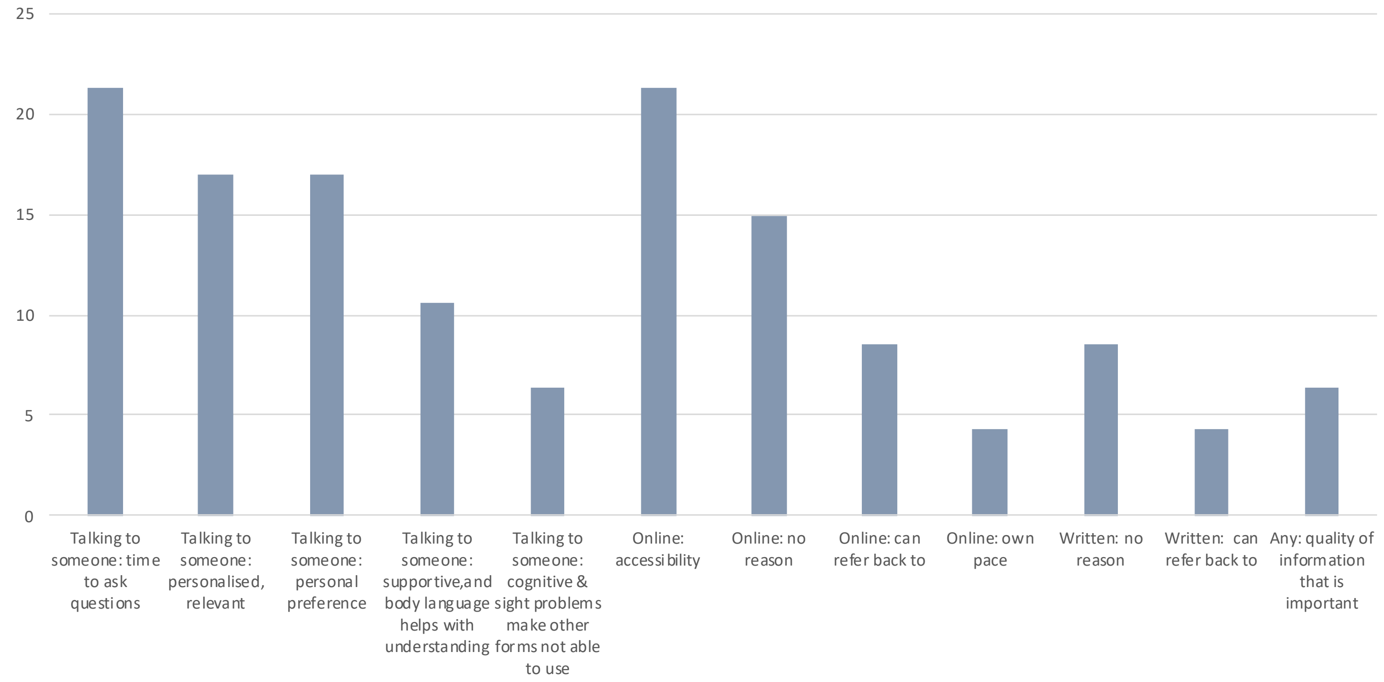

Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone as main information preference	Blood vessel conditions 6 to 11 other conditions Female	Heart conditions Male
Participant describes talking to someone plus online information as main information preference	Had LP(a) test	Did not had LP(a) test Regional or remote
Participant describes written information as main preference	-	6 to 11 other conditions
Participant describes online information as main information preference	Male	-

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (27.66%), and after the shock of diagnosis (14.89%). Other themes included continuously (12.77%), 12 months or more after diagnosis (12.77%), when medical emergency over (8.51%), after treatment (6.38%), and after test results or changes to condition (6.38%).

Participant describes being receptive from the beginning (diagnosis)

I think right back in the beginning, I was really wanting to know more. Yeah. About what it was, Yeah.
Participant 008_2023AUHBV

PARTICIPANT: That's tricky because I'm always receptive to receiving information about it. I guess in the early days I was absorbing more information because I didn't know a lot of stuff. I'm probably less receptive now because I feel like I know more.
INTERVIEWER: Oh okay. Yeah. That makes sense.
PARTICIPANT: Probably on diagnosis I suppose that's when I'm the most receptive. The most receptive I suppose, because I didn't know anything. I was the most receptive about receiving any kind of information.
Participant 036_2023AUHBV

I'm always receptive, but I was going out and finding it early on. To be honest, there was no risk of being overwhelmed with information because I wasn't getting any.
Participant 046_2023AUHBV

Participant describes being receptive to information after the shock of diagnosis

Definitely the most receptive, most needing of it at the start. Definitely better at taking it in, you know, sometime time, not immediately. Not definitely, not

immediately. I think it's so overwhelming that it's hard to take it in. Yeah.
Participant 009_2023AUHBV

I think between seeing the first cardiologist and the surgery, so. But by the time I got over my shock of the diagnosis and that that, let me tell you, was a really grim day, that that was tough. By the time I'd kind of got over the emotional shock and the immediate terror of if I don't do something about this, I'm going to die, and it might be quite soon. I think by the time I saw the 2nd cardiologist and by the time I actually met the surgeon in person, I think that was probably my most receptive. Because I was questing in all sorts of different directions, including that emotional, spiritual one, which I actually said to my surgeon, this is the most important part of it. Whatever else happens if anything goes wrong. It's OK because this is the important bit and I needed him to know that because we all know how devastated clinicians are if something does. So, yeah, that was important.
Participant 010_2023AUHBV

I think initially I think it was due to the shock of being diagnosed with atherosclerosis. I think I wasn't able to take much information in for a little while. It probably wasn't till a few much a few months later that I started to become a lot more proactive in thinking, gosh, I need to really start, you know, researching this. And ever since then I've just been continuously reading, listening to patient stories, getting as much information as I possibly can to try and safeguard myself for the future. So it has been good. It's been positive as well in getting all that information.
Participant 011_2023AUHBV

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

Probably sort of depends on the information is general day-to-day information from cardiologists or specialists or whatever it was at the time was probably pretty receptive all the time. I was pretty open minded about most things when it came to my condition. But you know I was aware that of what what the future sort of held if I didn't sort of actively do something about it. So I think in that sense I was pretty receptive. But when it came to things like you know, surgery or probably like you know, the general diagnosis and the changes in lifestyle, you know, as I got older, you know, you have to sort of stop this and stop that or be more considerate about that. I think, you know, there's a little bit of time where you're angry and pissed off a little bit about the circumstances that you've been dealt. But I think once that sort of calms down and you sort of go, all right, well, I've got to do something about this here probably a few days to a few weeks after you saw the pretty receptive to hearing what's going to happen. So my circumstances was pretty quickly, Usually I was pretty pragmatic with what's going on.
Participant 012_2023AUHBV

I think it gets easier the longer you have it because you understand it and accumulated information over time. At the beginning it's all very new. So it's like any kind of new learning. It's always hard at the beginning, but the longer you've been with it, the easier it gets.
Participant 019_2023AUHBV

Participant describes being receptive to information 12 months or more after diagnosis

That information in probably honestly years after I was told that I was even sick because I didn't care at the time. OK until I was a bit older until I got with my until I got to about 21 and then I realized, oh, I've aged my body quite a lot, right?
Participant 007_2023AUHBV

I bet 12 months after my stroke.
Participant 040_2023AUHBV

I think it took me probably close to 12 months to feel comfortable to research and investigate more information about strokes.
Participant 047_2023AUHBV

Participant describes being receptive to information after the medical emergency is over

Certainly not while you're in hospital under the stress of what's happening to you at the minute. You know what I mean? Yeah. So I'm much better. When you're sort of sitting in in with the doctor or someone and there's not a crisis happening around you, you know, so much more receptive. Like you'll just accept like, like I was saying about the angiogram, I just accepted it because I got no choice. You just do it. But if, if I had that information without having a heart attack, like it wasn't urgent that I had it, then it would be a different way that I'd. Yeah. So I think when you're in the throes of having something like that happened to you, you're not very receptive then.
Participant 013_2023AUHBV

That's a good question because when you're in the full blown episode, you can't actually remember much or

take much in. I think it wasn't until maybe six months down the track that I was able to fully get my head around it and then work out a way to move forward.
Participant 014_2023AUHBV

While I wasn't in pain and anxious, you know one of the biggest things I find is, is that you know when you're in pain. And you've got people talking to you or that's more they're talking at you. And it's just it's irritating. It's obviously when. So when I'm in pain, I'm fairly anxious. And if I'm anxious, I'm easily irritated. And once I'm irritated, don't even bother. I won't understand the word you're saying. I won't retain a word. You know, I I presented, as I say I presented at the hospital a couple of times with chest pain and they sit there, you know, question, question, question, question. You know, the only thing I care about is my pain easing. The only thing I care about at that point in time is that, you know, hey, let's make this stop, you know, so to say to me, you know, oh, but this is happening, that's happening. You know what? I don't care. Make that pain stop. That's all I'm interested in. You know, I suppose once that pain's eased up or that pain slowed down, it's a lot easier to concentrate and, you know, hold a discussion on, you know, where things are, where things are going.
Participant 018_2023AUHBV

Participant describes being receptive to information after treatment

I don't think I was terribly receptive when I was first diagnosed, I think after the surgery I would take on board what I needed to hear and what people wanted me to know.
Participant 005_2023AUHBV

I think in hospital's always a good time because you've got time on your hands there. It depends on your condition in hospital, though. There would have been times for me that it wouldn't have been appropriate. There have been times where it would have. I think post a procedure. With this one I've just had done now, I got some leaflets and things that were given to me, and that was great because when I got home -- You can remember most of it, but you kind of think, "Oh, why didn't you say about that again and I could read through and just pick out the bits," so that was actually a good time to have it.
Participant 023_2023AUHBV

Participant describes being receptive to information after receiving test results or when treatment decisions need to be made

As I say, the only information I had was that my cholesterol was high and that was it. And I suppose I did change some things, but not not change that much. And then when it continued to be high and the GP said, oh, you know, if this doesn't improve or gets gets worse, you might have to go on medication. That was at the point where I thought I need to work a bit harder and that's what I thought. I needed to make more changes to my diet and increase exercise more and those sorts of things.
Participant 017_2023AUHBV

The way, yeah, I dare say it was probably the second visit to the cardiologist just just you know at that point there, you know I'd already had the you know, I'd already done all the cardio, cardio grams and and all that sort of stuff. So it was at that point there, you know when having a a better conversation around it all that you know it really sunk in and it was I guess more receptive at that time.
Participant 028_2023AUHBV

Table 6.9: Timing of information

Timing of information	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being receptive from the beginning (diagnosis)	13	27.66	**2**	**11.11**	**11**	**37.93**	2	22.22	6	35.29	5	23.81	5	18.52	**8**	**40.00**
Participant describes being receptive to information after the shock of diagnosis	7	14.89	2	11.11	5	17.24	1	11.11	4	23.53	2	9.52	4	14.81	3	15.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	6	12.77	1	5.56	5	17.24	**0**	**0.00**	3	17.65	3	14.29	2	7.41	4	20.00
Participant describes being receptive to information 12 months or more after diagnosis	6	12.77	3	16.67	3	10.34	**3**	**33.33**	3	17.65	**0**	**0.00**	5	18.52	1	5.00
Participant describes being receptive to information after the medical emergency is over	4	8.51	2	11.11	2	6.90	0	0.00	0	0.00	**4**	**19.05**	2	7.41	2	10.00
Participant describes being receptive to information after treatment	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	3	6.38	2	11.11	1	3.45	**2**	**22.22**	0	0.00	1	4.76	1	3.70	2	10.00

Timing of information	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being receptive from the beginning (diagnosis)	13	27.66	9	34.62	4	19.05	7	29.17	6	26.09	3	20.00	10	31.25	7	28.00	6	27.27
Participant describes being receptive to information after the shock of diagnosis	7	14.89	4	15.38	3	14.29	3	12.50	4	17.39	**5**	**33.33**	2	6.25	5	20.00	2	9.09
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	6	12.77	4	15.38	2	9.52	5	20.83	1	4.35	1	6.67	5	15.63	2	8.00	4	18.18
Participant describes being receptive to information 12 months or more after diagnosis	6	12.77	1	3.85	**5**	**23.81**	3	12.50	3	13.04	2	13.33	4	12.50	3	12.00	3	13.64
Participant describes being receptive to information after the medical emergency is over	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	2	13.33	2	6.25	4	16.00	0	0.00
Participant describes being receptive to information after treatment	3	6.38	2	7.69	1	4.76	0	0.00	3	13.04	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55

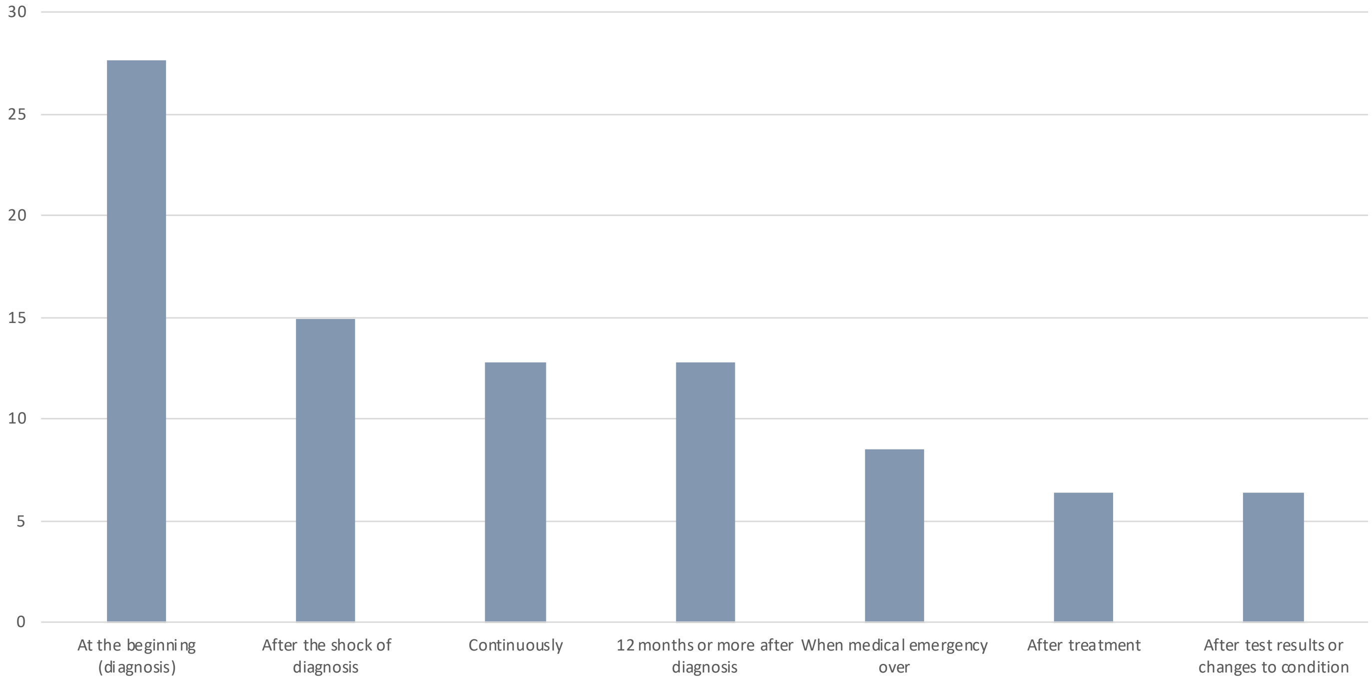

Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Had LP(a) test	Did not had LP(a) test 6 to 11 other conditions
Participant describes being receptive to information after the shock of diagnosis	-	Regional or remote
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	High cholesterol under 50 years of age	-
Participant describes being receptive to information 12 months or more after diagnosis	Heart conditions	High cholesterol under 50 years of age Male
Participant describes being receptive to information after the medical emergency is over	-	Heart conditions
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	-	High cholesterol under 50 years of age

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Participants gave descriptions that communication as overall positive (34.04%), overall positive, with the exception of one or two occasions(34.04%), and overall negative (27.66 %).

Participant describes communication with healthcare professionals as overall positive

It is. It's a good experience, you know, Because I choose to make it a good experience. I choose. I choose to be positive about what's going on and I choose to be happy about what's going on. When I choose to find out the information I want to go, we're not playing that enough. I don't need to go into the

absolute detail of it. Fair enough. That that's all I'm gonna go. Thanks very much. I'll see you later. Yeah. You're all about personal choices. You can sweat this issue and turn it into something that's really confusing, you know, and get yourself very panicky about it all. That doesn't achieve anything. So I just don't bother. Yeah, I'm pretty happy with it, you know.
Participant 004_2023AUHBV

I would say good. I mean, if anything were to come up, they'd tell me, like they do check on my heart, but nothing's ever come up. So I'd say good.
Participant 007_2023AUHBV

PARTICIPANT: Mine's been very good. Honestly. Yeah. Yeah.
Participant 013_2023AUHBV

He's really good, He's really good.
Participant 016_2023AUHBV

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

Variable. My GP's fantastic. We're on the same page. I'm very much afraid he's going to retire fairly soon. I don't know what I'm going to do. He just absolutely the right person for me. My surgeon, fantastic. I guess I I'd have liked him to be a bit more detailed in his communication, as I said, but I think that's partly personal. On his part, and partly the assumption that I sounded knowledgeable when I wasn't or I felt I wasn't. I don't know. I don't know how you make the judgment on that. How much knowledge is enough? Nothing's ever enough, is it? Not for me, anyway. There's always more, I suppose the 1st. The first appointment I had with the cardiologist was fabulous and I I was in tears with relief. The last appointment I had with the cardiologist I was in tears with misunderstanding. So it's been mixed.
Participant 010_2023AUHBV

The health professionals have all been really great, and I've found everyone to be really, really supportive, and like from my doctor to the nurses that I deal with, to you know, when I'm in hospital and so on, I just feel like I've got really good support around me, so -- But sometimes I find with GPs, is they can get into -- Like, I don't go to the doctor for no reason. So when I go to the doctor, it means I'm concerned about something. And I have found that GPs get complacent. "Oh yeah, but you've just got a heart condition," or "You've got heart failure," and I say, "But I haven't got a heart failure, and swollen ankles, I have never had them before, you know, there's something going on," and the doctor's saying, "Don't worry, we'll figure it out, you're not seeing a cardiologist for three months. You don't need to ring him. We'll work it out," and it ended up that I had major damage done to my heart in the meantime, because some-- where I realise I should have been more proactive in that since. Those GPs, even though they're great, they do get complacent and they just box you into, "Oh, you've got heart failure," when I haven't got heart failure. My heart's still really healthy, and so when we're getting signs of heart failure, it means that there's something else going on, and it needs to be investigated.
Participant 030_2023AUHBV

Participant describes communication with healthcare professionals as overall negative

When it comes to, I suppose, your your specialist field, a lot of them are fairly. Arrogant. They don't have a bedside manner in any way shape or form and they certainly don't present as if they have time to deal with you. You know, for example, you know I I was dealing with an oncologist last week, you know and he was explaining to the person that I was with that there's three options and number one's not available. Yeah, at the end of the day, you know, that person asked why not? So he gave this huge answer as to why it's not available. And this particular person got a bit of dementia, you know, and then didn't understand what was being said. And you know, he went to try and move on to the next option and they went, So what was option one? And he went, well, that's not available. You know, at the end of the day, if it wasn't available, it should have been said that there's only two options here. You know, The thing is, I suppose for myself, you know, at the end of the day, I look at things and you know, again in in such a logical way that you know something's not available, then why is it really an option? Again, you know, like the cardiologist will say, you know, use the term myocardial infection. Whereas my doctor will say, so your heart attack. Cool. What are we talking about? A heart attack? Okay. I know what that is. Straight up.
Participant 018_2023AUHBV

Not really, no. I couldn't describe it as positive.
Participant 032_2023AUHBV

Confusing, very confusing.
Participant 041_2023AUHBV

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants n=47	%	Had LP(a) test n=18	%	Did not had LP(a) test n=29	%	High cholesterol under 50 years of age n=9	%	Blood vessel conditions n=17	%	Heart conditions n=21	%	0 to 5 other conditions n=27	%	6 to 11 other conditions n=20	%
Participant describes communication with healthcare professionals as overall positive	16	34.04	7	38.89	9	31.03	5	55.56	3	17.65	8	38.10	11	40.74	5	25.00
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	16	34.04	6	33.33	10	34.48	1	11.11	7	41.18	8	38.10	11	40.74	5	25.00
Participant describes communication with healthcare professionals as overall negative	13	27.66	4	22.22	9	31.03	3	33.33	6	35.29	4	19.05	4	14.81	9	45.00
Other/no response	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00

Healthcare professional communication	All participants n=47	%	Female n=26	%	Male n=21	%	Aged 25 to 44 n=24	%	Aged 45 and older n=23	%	Regional or remote n=15	%	Metropolitan n=32	%	Mid to low socioeconomic status n=25	%	Higher socioeconomic status n=22	%
Participant describes communication with healthcare professionals as overall positive	16	34.04	7	26.92	9	42.86	10	41.67	6	26.09	4	26.67	12	37.50	7	28.00	9	40.91
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	16	34.04	10	38.46	6	28.57	4	16.67	12	52.17	8	53.33	8	25.00	10	40.00	6	27.27
Participant describes communication with healthcare professionals as overall negative	13	27.66	9	34.62	4	19.05	8	33.33	5	21.74	3	20.00	10	31.25	7	28.00	6	27.27
Other/no response	2	4.26	0	0.00	2	9.52	2	8.33	0	0.00	0	0.00	2	6.25	1	4.00	1	4.55

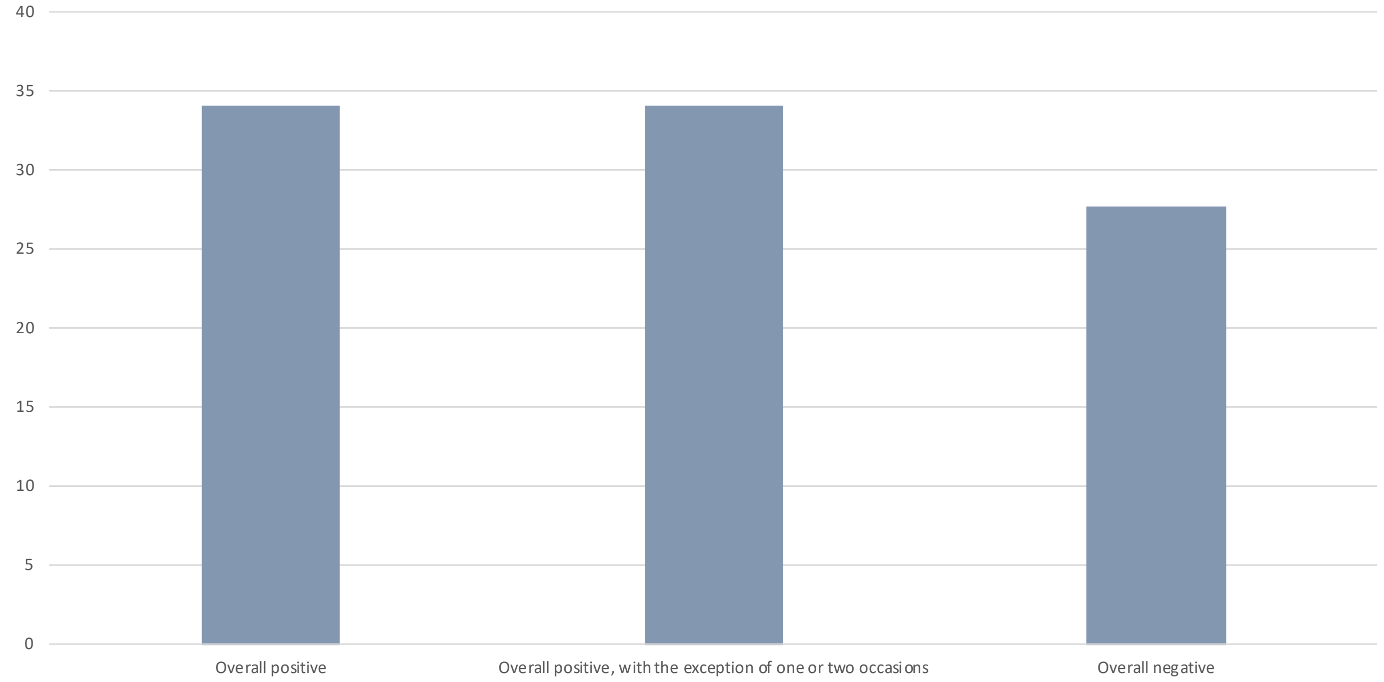

Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes communication with healthcare professionals as overall positive	Blood vessel conditions	High cholesterol under 50 years of age 0
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	High cholesterol under 50 years of age Aged 25 to 44	Aged 45 and older Regional or remote 0
Participant describes communication with healthcare professionals as overall negative	0 to 5 other conditions	6 to 11 other conditions 0

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because it was holistic with two way, supportive and comprehensive conversations (31.91%).

Participants that had negative communication, described the reasons for this were that communication was dismissive (One way conversation) (19.15 %), limited in multi-disciplinary communication and care coordination (10.64%), limited in relation health professionals not having a lot of time (8.51%), and limited in that they have not had a lot (6.38%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Yeah, Just in general, like on scale or whatever, yeah. Yeah it's it's it's been good. I mean it's a two way street and as long as myself as the patient like I I try to be respectful of them and their time and their position And because I'm like yeah I'm typically focused on you know building a decent relationship with the GP. I think there's some reciprocity and I it's been pretty good because I think because I'm. Building a relationship and I I am keen to learn about the condition what have you and I expressed that I think I'm viewed positively in the sense that like I'm just earnest to learn more so that I can help myself and so I think you know any of my conversations are are received pretty well because I I think the GP can see where I'm coming from and and they're and they're responding like in a in a good way so yeah I've I've had you know. Yeah, I've had positive communications, yeah. And just to add to that, it's just even when I was presenting the idea that I think at my last console that hey, I've been learning learning about some of this nuance and there might be some other extra information around this this, this condition, she, my GP was positive as as in you know told me just to send through. Send through what I was talking about or looking at like reference. Yeah. So that's what I've done. So they were, Yep, receptive to that. So that was another positive sign of communication.
Participant 001_2023AUHBV

Now, I write an email once a month to Team PARTICIPANT, usually on the first or the second day of the month just to give them all a brief summary of what I've done or how I feel or what's been achieved in the month leading up to that email. I do that because communication between doctors has been great. I have lots of little chats with each and every one of them. I don't know what each and every one of them is missing out on and then I'd get to appointments- for example, let's say I get to the cardiologist and he says, "You saw the gastroenterologist last week, what happened there? I haven't received any notifications
Participant 050_2023AUHBV

Participant describes health professional communication as being dismissive (One way conversation)

I don't know. I can't. Yeah, the rest of it wasn't great to be honest. Yeah, the whole this is a short term thing. Don't panic, you'll be OK. This is a short term problem. It was not beneficial. That was not that wasn't something because they're not held on to that you see. And I think that was, you know, when I tried to go back to work at the start of the year and I started passing out at work and hitting my head on things and losing vision. I think that was a false sense of security or helped me live in a bit of denial then saying don't worry, it's a short term thing. So that would, yeah.
Participant 014_2023AUHBV

Well like I say it's just been this is the information you've got high cholesterol and that's it that that's the start and finish. There's been no no broader discussions or conversations other than that.
Participant 017_2023AUHBV

Participant describes health professional communication as limited in multi-disciplinary communication and care coordination

PARTICIPANT: Generally, pretty atrocious. With NAME DOCTOR, fantastic. There was just nothing. In hospital, there was nothing. I couldn't read. I couldn't see properly. I couldn't judge distance. I couldn't cook for myself, but I was just booted out of the hospital with nothing.
INTERVIEWER: That must have been difficult.
PARTICIPANT: I'm really lucky. My mum is lovely, and we have a great relationship. She actually moved in with me for a short time, and I recovered my ability to read after a few weeks, and I actually went back to work after two and a half weeks part-time because obviously the fatigue was an issue and adjusting to the limitations that I had was an issue. My mum came and cooked for me and then helped me start getting used to cooking for myself and that sort of thing. If I hadn't had family support I don't know what would have happened.
Participant 046_2023AUHBV

PARTICIPANT: Overall, it's been fine. Yeah, sure. So initially my first two weeks I was in hospital. I've not had any proactive communication. I don't really know that I need proactive communication. It's all been based around when the appointment, like when I'm in an appointment at checkup the the communication initially in the hospital. To be honest, I don't know what the communication was like to my family, but to

me, I guess. I have a little bit of a short term memory problem which is much improved, which is probably a side effect I should have thought about earlier, but but at the time I may have got information, they may have given me information, things that I wished I'd been told. I don't remember receiving a lot of communication around things around much when I was in hospital, you know? Not about what happens when I leave hospital. Not about, you know, what happens with the physician. Not about not a lot about my about what about about what scat is. So I I think that that was probably where communication was probably lacking. But as I say, I may have received it and just can't remember receiving it. Also I think if I'd received too much. Like that. In that moment. I don't know that I would have absorbed it anyway, but I do think that it's been good, except for that little cracked part, yes.
Participant 009_2023AUHBV

Participant describes health professional communication as limited in relation health professionals not having a lot of time

It's been good whilst I've been engaged. Outside of those scheduled appointments, it's non-existent, really.
Participant 043_2023AUHBV

Participant describes healthcare communication as limited (they have not had any/a lot)

Well probably they didn't give me very much information. They just probably gave me a script and said, "Come back and see me in so many months. We'll send a letter to NAME DOCTOR." I mean to be perfectly honest, I never discussed anything really
Participant 037_2023AUHBV

I can't say I really received any information. Even when I joke around my illness, I've got more problems.
Participant 039_2023AUHBV

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes healthcare communication as good, with no particular reason given	19	40.43	9	50.00	10	34.48	**2**	**22.22**	6	35.29	**11**	**52.38**	13	48.15	**6**	**30.00**
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	15	31.91	5	27.78	10	34.48	**4**	**44.44**	5	29.41	6	28.57	9	33.33	6	30.00
Participant describes health professional communication as being dismissive (One way conversation)	9	19.15	5	27.78	4	13.79	**3**	**33.33**	**1**	**5.88**	5	23.81	6	22.22	3	15.00
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	5	10.64	1	5.56	4	13.79	**0**	**0.00**	3	17.65	2	9.52	1	3.70	4	20.00
Participant describes health professional communication as limited in relation health professionals not having a lot of time	4	8.51	2	11.11	2	6.90	0	0.00	3	17.65	1	4.76	1	3.70	3	15.00
Participant describes healthcare communication as limited (they have not had any/a lot)	3	6.38	2	11.11	1	3.45	0	0.00	2	11.76	1	4.76	1	3.70	2	10.00
Participant describes health professional communication as limited, without giving a reason	3	6.38	0	0.00	3	10.34	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00
Participant describes health professional communication as limited in relation to their understanding of the condition	2	4.26	0	0.00	2	6.90	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00
Participant describes health professional communication as limited in using language that is too technical	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00
Participant describes health professional communication as limited as it was unprofessional	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00
Participant describes health professional communication as limited in withholding information	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Healthcare professional communication (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes healthcare communication as good, with no particular reason given	19	40.43	10	38.46	9	42.86	10	41.67	9	39.13	7	46.67	12	37.50	10	40.00	9	40.91
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	15	31.91	7	26.92	8	38.10	6	25.00	9	39.13	6	40.00	9	28.13	7	28.00	8	36.36
Participant describes health professional communication as being dismissive (One way conversation)	9	19.15	3	11.54	6	28.57	7	29.17	2	8.70	3	20.00	6	18.75	4	16.00	5	22.73
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	5	10.64	5	19.23	0	0.00	1	4.17	4	17.39	1	6.67	4	12.50	3	12.00	2	9.09
Participant describes health professional communication as limited in relation health professionals not having a lot of time	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes healthcare communication as limited (they have not had any/a lot)	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55
Participant describes health professional communication as limited, without giving a reason	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55
Participant describes health professional communication as limited in relation to their understanding of the condition	2	4.26	2	7.69	0	0.00	0	0.00	2	8.70	2	13.33	0	0.00	2	8.00	0	0.00
Participant describes health professional communication as limited in using language that is too technical	2	4.26	1	3.85	1	4.76	2	8.33	0	0.00	0	0.00	2	6.25	1	4.00	1	4.55
Participant describes health professional communication as limited as it was unprofessional	2	4.26	2	7.69	0	0.00	1	4.17	1	4.35	2	13.33	0	0.00	1	4.00	1	4.55
Participant describes health professional communication as limited in withholding information	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	1	6.67	1	3.13	2	8.00	0	0.00

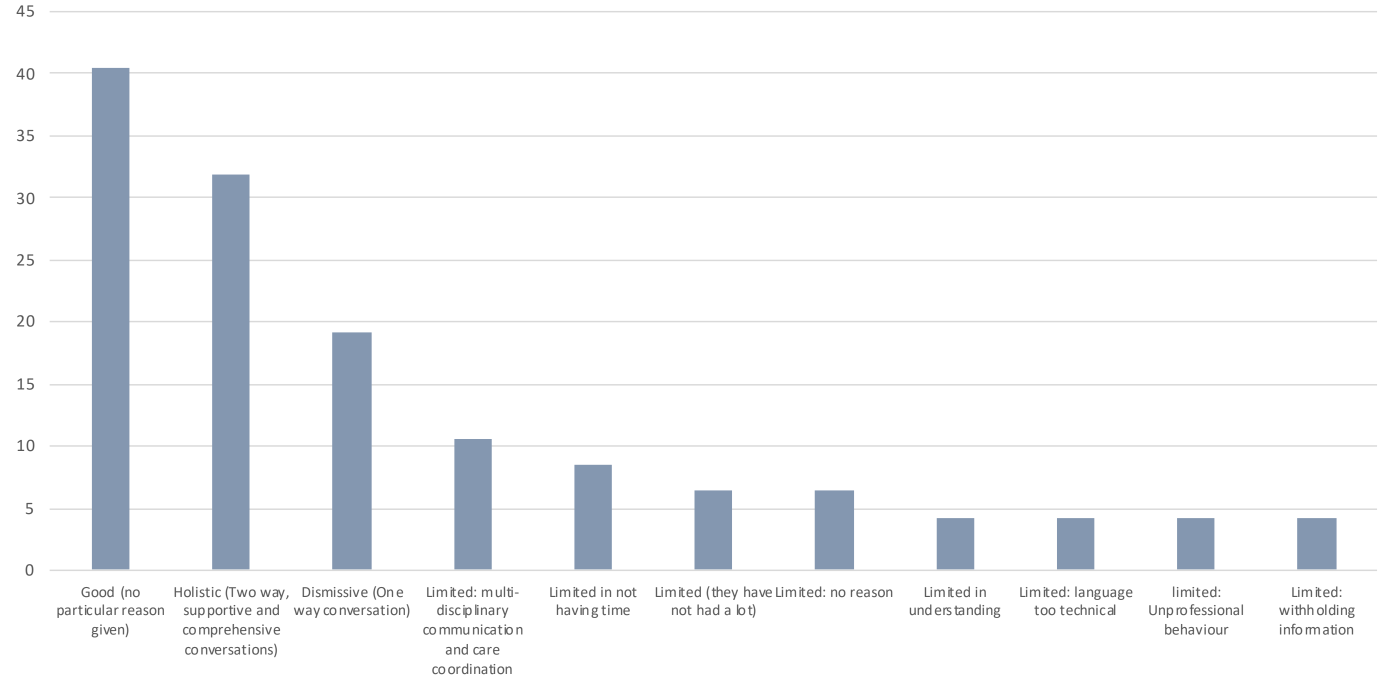

Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Healthcare professional communication (reasons)	Reported less frequently	Reported more frequently
Participant describes healthcare communication as good, with no particular reason given	High cholesterol under 50 years of age 6 to 11 other conditions	Heart conditions
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	-	High cholesterol under 50 years of age -
Participant describes health professional communication as being dismissive (One way conversation)	Blood vessel conditions Aged 45 and older	High cholesterol under 50 years of age Aged 25 to 44 -
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	High cholesterol under 50 years of age Male	-

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. 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 the table below.

The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=27.00, IQR=8.75), Partners in health: Recognition and management of symptoms (median=21.00, IQR=5.75), Partners in health: Adherence to treatment (median=15.00, IQR=3.00), indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment.

The overall scores for the cohort were in the second highest quintile for Partners in health: Coping (median=16.50, IQR=7.00), Partners in health: Total score (mean=74.46, SD=13.75) indicating good coping, good overall ability to manage their health

Comparisons of Partners in health have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.44	5.65	27.00	8.75	0 to 32	5
Coping	15.82	5.71	16.50	7.00	0 to 24	4
Recognition and management of symptoms	19.44	3.78	21.00	5.75	0 to 24	5
Adherence to treatment	13.76	2.85	15.00	3.00	0 to 16	5
Total score*	74.46	13.75	74.50	19.50	0 to 96	4

*Skewed distribution use median and IQR as measure of central tendency

Partners in health by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

No significant differences were observed between participants by **LP(a) test** for any of the Partners in health scales.

Table 6.16: Partners in health by LP(a) test summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Had LP(a) test	19	38.00	71.95	13.66	-1.01	48	0.3166
	Not had LP(a) test	31	62.00	76.00	13.79			

Table 6.17: Partners in health by LP(a) test summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Had LP(a) test	19	38.00	24.00	8.50	244.00	0.3157
	Not had LP(a) test	31	62.00	28.00	7.00		
Coping	Had LP(a) test	19	38.00	16.00	7.50	267.00	0.5874
	Not had LP(a) test	31	62.00	17.00	7.00		
Recognition and management of symptoms	Had LP(a) test	19	38.00	21.00	5.00	256.50	0.4501
	Not had LP(a) test	31	62.00	21.00	4.50		
Adherence to treatment	Had LP(a) test	19	38.00	15.00	6.00	263.00	0.5199
	Not had LP(a) test	31	62.00	15.00	2.00		

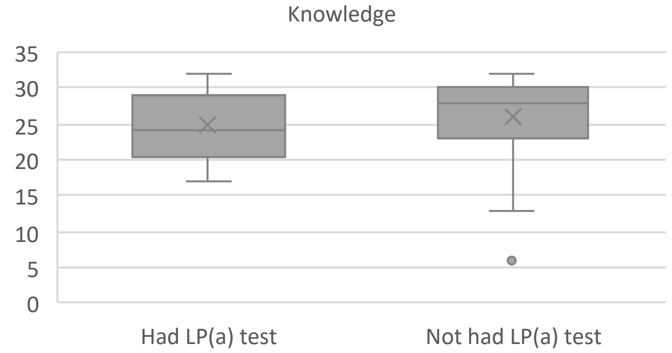

Figure 6.9: Boxplot of Partners in health: knowledge LP(a) test

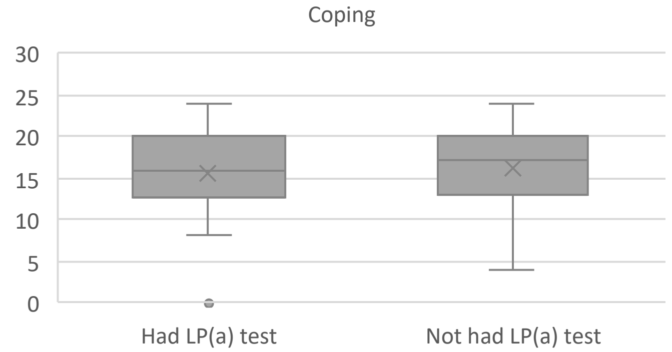

Figure 6.10: Boxplot of Partners in health: coping LP(a) test

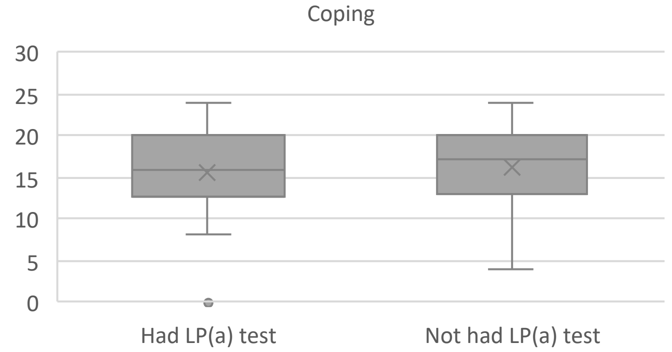

Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms LP(a) test

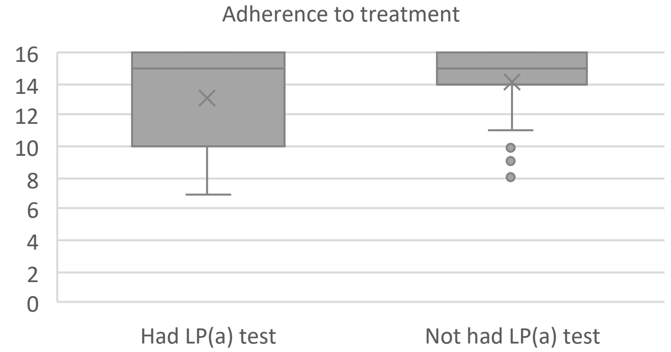

Figure 6.12: Boxplot of Partners in health: adherence to treatment LP(a) test

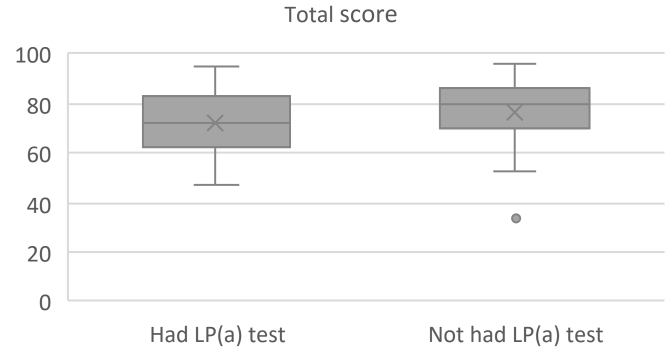

Figure 6.13: Boxplot of Partners in health Total score LP(a) test

Partners in health by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used.

No significant differences were observed between participants by **main condition** for any of the Partners in health scales.

Table 6.18 Partners in health by main condition summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	High cholesterol under 50 years of age	8	16.33	86.25	20.90	Between groups	481.00	2	240.50	1.29	0.2850
	Blood vessel conditions	19	38.78	78.78	14.48	Within groups	8779.00	47	186.80		
	Heart conditions	22	44.90	35.68	25.47	Total	9260.00	49	427.30		

Table 6.19: Partners in health by main condition summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	High cholesterol under 50 years of age	8	16.33	28.00	7.00	1.9896	2	0.3698
	Blood vessel conditions	19	38.78	28.00	7.00			
	Heart conditions	22	44.90	24.00	7.00			
Coping	High cholesterol under 50 years of age	8	16.33	18.00	6.25	0.38061	2	0.8267
	Blood vessel conditions	19	38.78	16.00	8.00			
	Heart conditions	22	44.90	14.00	9.00			
Recognition and management of symptoms	High cholesterol under 50 years of age	8	16.33	20.50	4.00	2.3413	2	0.3102
	Blood vessel conditions	19	38.78	21.00	3.00			
	Heart conditions	22	44.90	19.00	5.00			
Adherence to treatment	High cholesterol under 50 years of age	8	16.33	15.50	3.00	1.5765	2	0.4546
	Blood vessel conditions	19	38.78	15.00	2.00			
	Heart conditions	22	44.90	14.00	5.00			

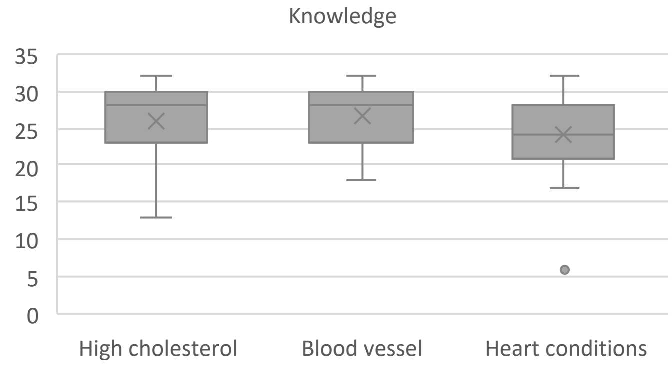

Figure 6.14: Boxplot of Partners in health: knowledge by main condition

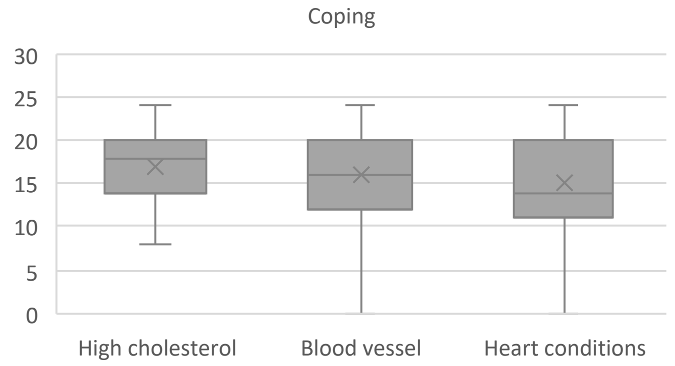

Figure 6.15: Boxplot of Partners in health: coping by main condition

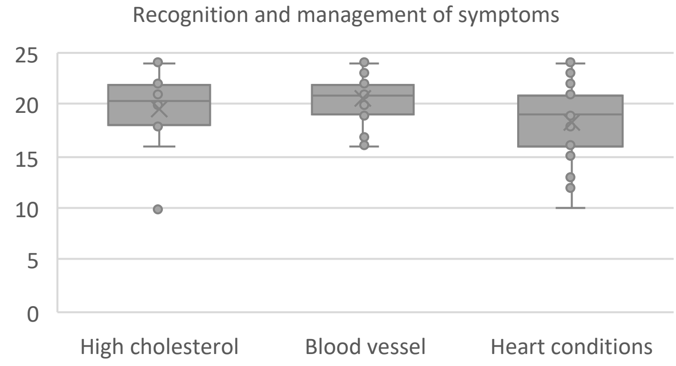

Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by main condition

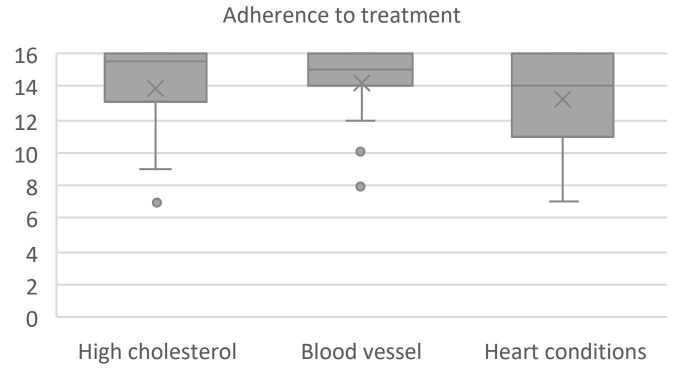

Figure 6.17: Boxplot of Partners in health: adherence to treatment by main condition

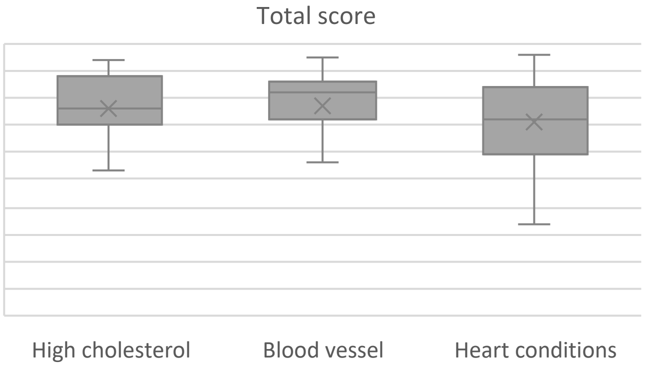

Figure 6.18: Boxplot of Partners in health Total score by main condition

Partners in health by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

No significant differences were observed between participants by **other conditions** for any of the Partners in health scales.

Table 6.20: Partners in health by other conditions summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	74.44	14.75	-0.01	48	0.9932
	6 to 11 other conditions	23	46.00	74.48	12.80			

Table 6.21: Partners in health by other conditions summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	0 to 5 other conditions	27	54.00	26.00	8.00	284.50	0.6182
	6 to 11 other conditions	23	46.00	28.00	9.00		
Coping	0 to 5 other conditions	27	54.00	19.00	7.50	344.50	0.5120
	6 to 11 other conditions	23	46.00	15.00	7.00		
Recognition and management of symptoms	0 to 5 other conditions	27	54.00	21.00	5.50	335.50	0.6309
	6 to 11 other conditions	23	46.00	20.00	5.00		
Adherence to treatment	0 to 5 other conditions	27	54.00	15.00	5.50	292.00	0.7160
	6 to 11 other conditions	23	46.00	15.00	2.00		

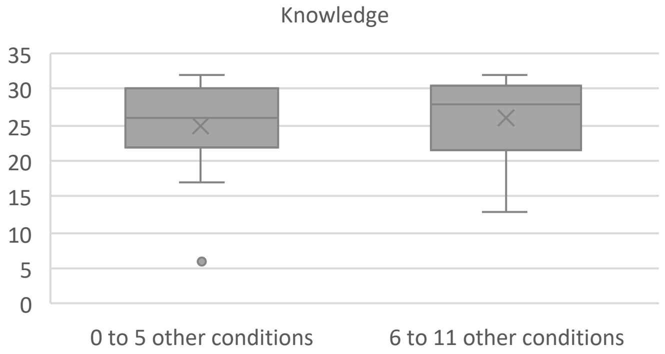

Figure 6.19: Boxplot of Partners in health: knowledge by other conditions

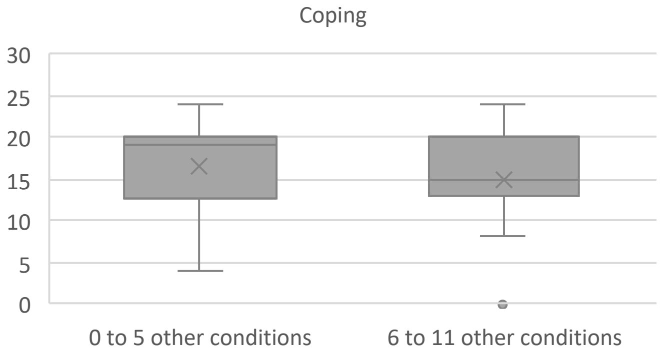

Figure 6.20: Boxplot of Partners in health: coping by other conditions

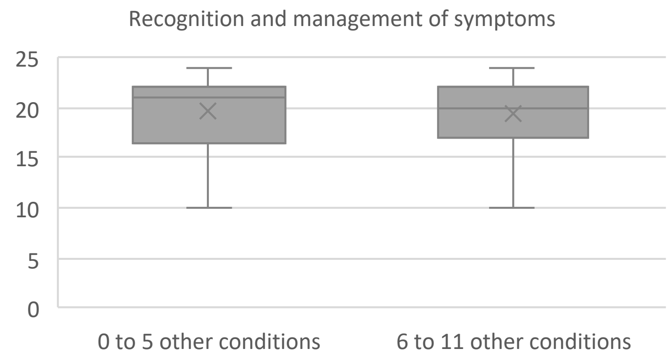

Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by other conditions

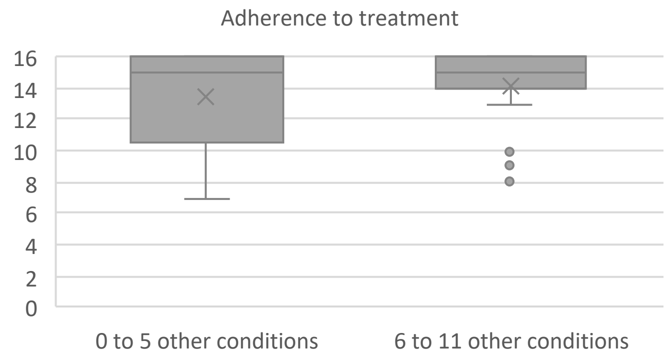

Figure 6.22: Boxplot of Partners in health: adherence to treatment by other conditions

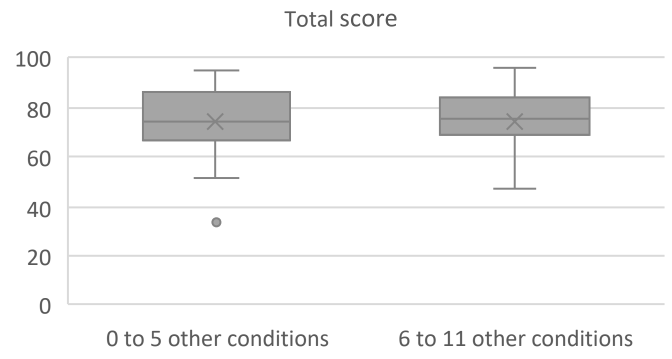

Figure 6.23: Boxplot of Partners in health Total score by other conditions

Partners in health by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

A two-sample t-test was used when assumptions for normality and variance were met, or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

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

Table 6.22: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Female	28	56.00	74.00	12.73	-0.26	48	0.7926
	Male	22	44.00	75.05	15.23			

Table 6.23: Partners in health by gender summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Female	28	56.00	26.50	7.25	289.00	0.7166
	Male	22	44.00	27.50	9.25		
Coping	Female	28	56.00	14.00	8.25	266.50	0.4204
	Male	22	44.00	17.50	5.75		
Recognition and management of symptoms	Female	28	56.00	20.00	4.50	299.00	0.8671
	Male	22	44.00	21.00	5.75		
Adherence to treatment	Female	28	56.00	15.00	2.00	316.50	0.8710
	Male	22	44.00	15.00	5.50		

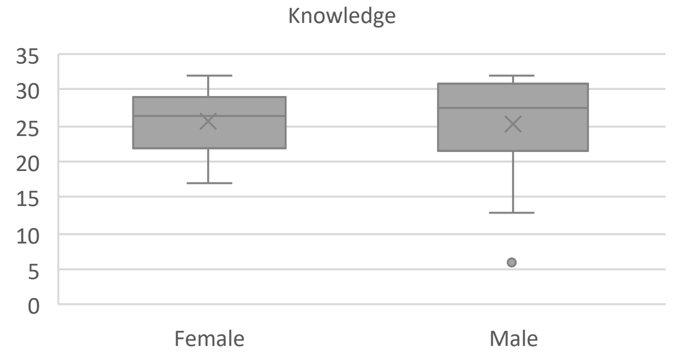

Figure 6.24: Boxplot of Partners in health: knowledge by gender

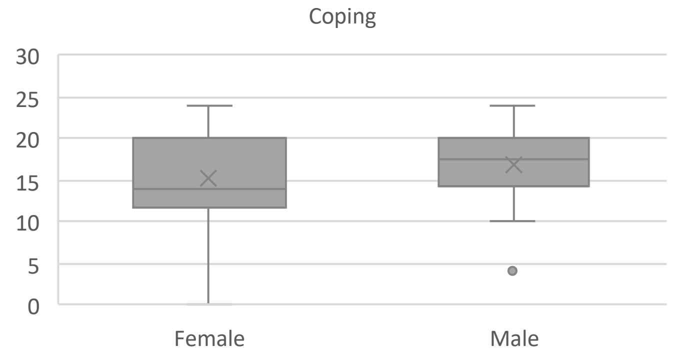

Figure 6.25: Boxplot of Partners in health: coping by gender

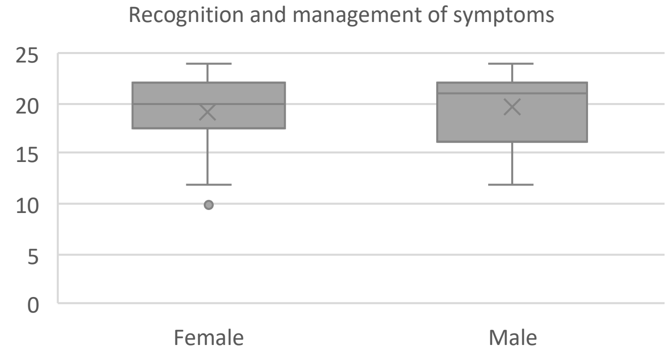

Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by gender

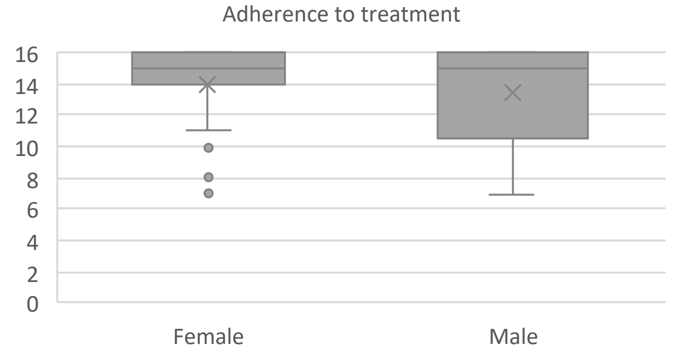

Figure 6.27: Boxplot of Partners in health: adherence to treatment by gender

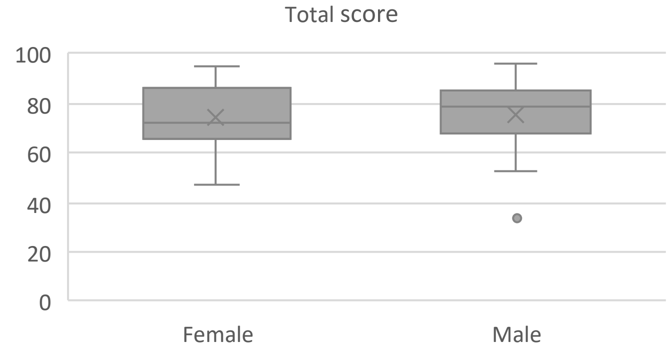

Figure 6.28: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

A two-sample t-test was used when assumptions for normality and variance were met or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

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

Table 6.24: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 44	27	54.00	73.15	15.18	-0.73	48	0.4704
	Aged 45 and older	23	46.00	76.00	12.00			

Table 6.25: Partners in health by age summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 44	27	54.00	27.00	9.50	305.50	0.9299
	Aged 45 and older	23	46.00	27.00	7.00		
Coping	Aged 25 to 44	27	54.00	15.00	6.50	263.50	0.3627
	Aged 45 and older	23	46.00	18.00	7.50		
Recognition and management of symptoms	Aged 25 to 44	27	54.00	20.00	5.50	245.50	0.2059
	Aged 45 and older	23	46.00	21.00	3.00		
Adherence to treatment	Aged 25 to 44	27	54.00	16.00	5.50	358.50	0.3370
	Aged 45 and older	23	46.00	14.00	1.50		

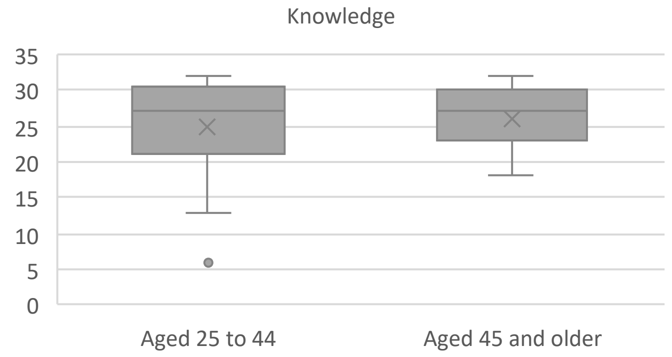

Figure 6.29: Boxplot of Partners in health: knowledge by age

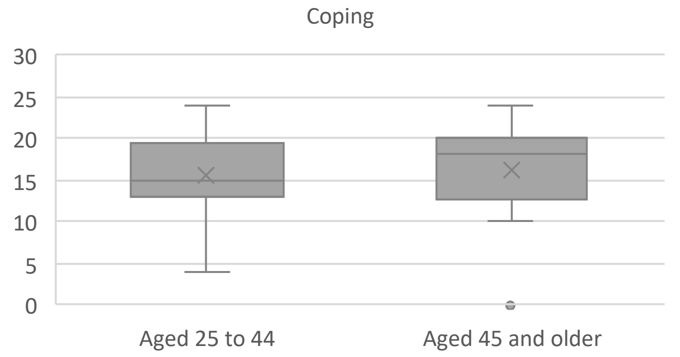

Figure 6.30: Boxplot of Partners in health: coping by age

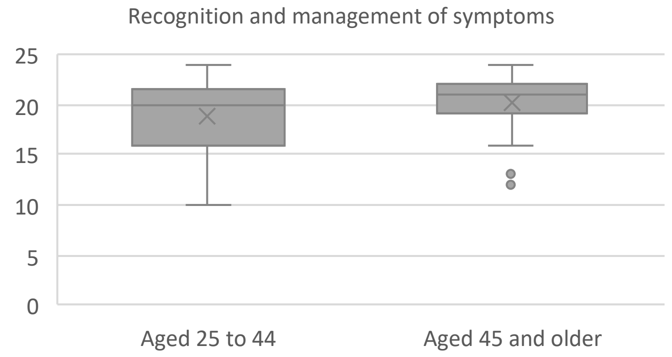

Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by age

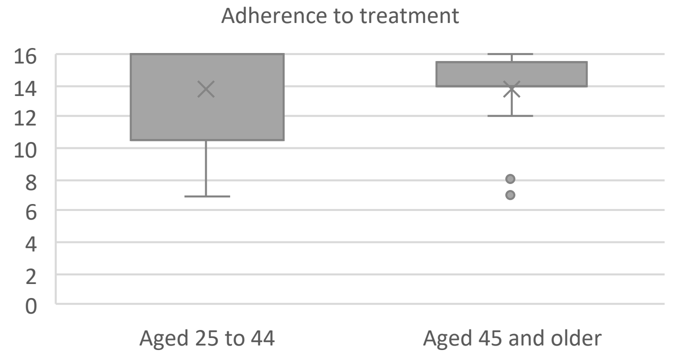

Figure 6.32: Boxplot of Partners in health: adherence to treatment by age

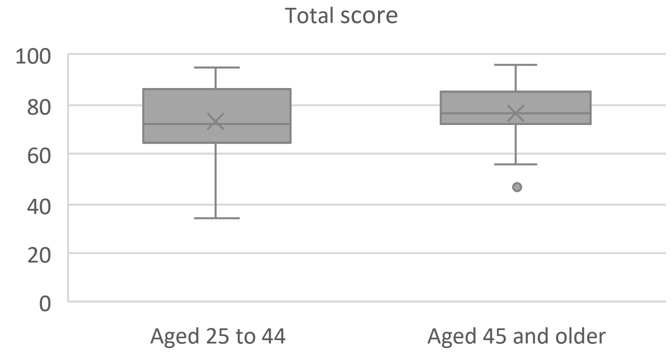

Figure 6.33: Boxplot of Partners in health Total score by age

Partners in health by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

A two-sample t-test was used when assumptions for normality and variance were met or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

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

Table 6.26: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	30.00	75.87	17.23	0.47	48	0.6406
	Metropolitan	35	70.00	73.86	12.20			

Table 6.27: Partners in health by location summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	15	30.00	28.00	7.50	287.50	0.6025
	Metropolitan	35	70.00	25.00	8.50		
Coping	Regional or remote	15	30.00	17.00	6.50	305.00	0.3713
	Metropolitan	35	70.00	16.00	7.50		
Recognition and management of symptoms	Regional or remote	15	30.00	21.00	5.00	304.50	0.3760
	Metropolitan	35	70.00	20.00	5.50		
Adherence to treatment	Regional or remote	15	30.00	14.00	3.50	250.50	0.8004
	Metropolitan	35	70.00	15.00	3.00		

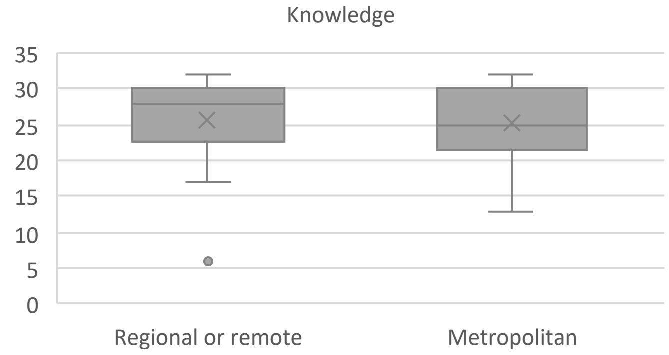

Figure 6.34: Boxplot of Partners in health: knowledge by location

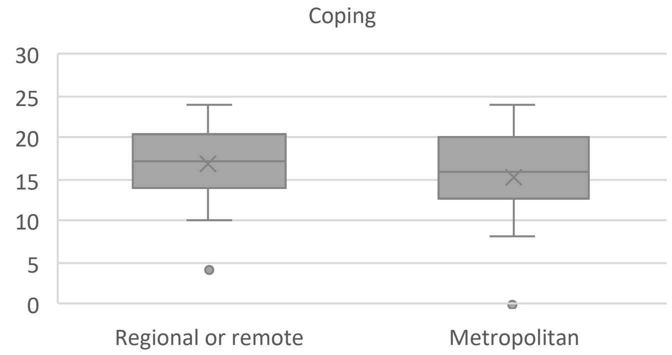

Figure 6.35: Boxplot of Partners in health: coping by location

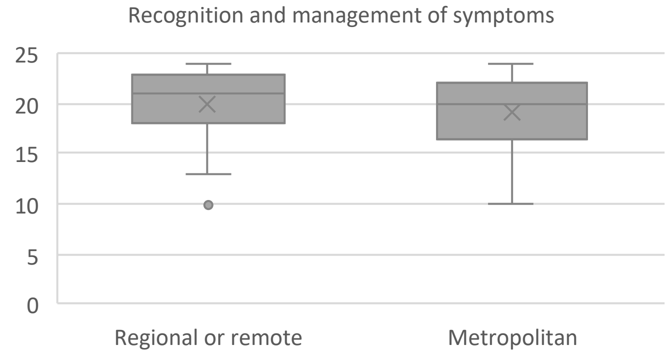

Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by location

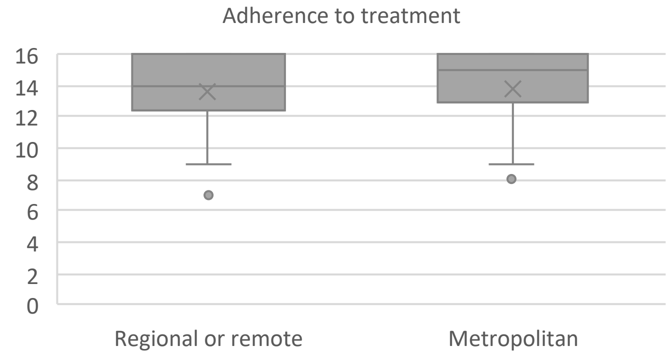

Figure 6.37: Boxplot of Partners in health: adherence to treatment by location

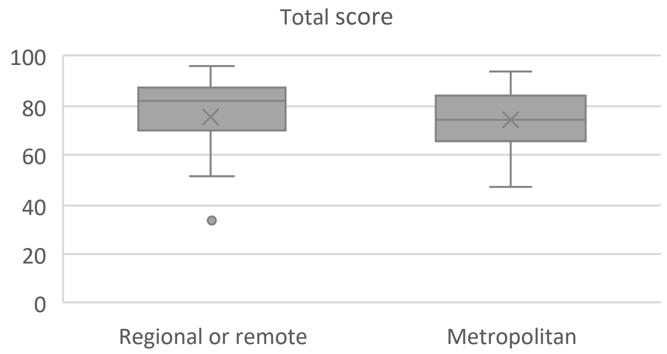

Figure 6.38: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Coping scale [W = 457.00 , p = 0.0050] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 19.00, IQR = 5.00) compared to participants in the Higher socioeconomic status subgroup (Median = 13.00, IQR = 8.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Recognition and management of symptoms scale [W = 437.00 , p = 0.0153] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 21.00, IQR = 5.00) compared to participants in the Higher socioeconomic status subgroup (Median = 19.00, IQR = 5.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Total score scale [W = 422.00 , p = 0.0342] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 80.00, IQR = 16.00) compared to participants in the Higher socioeconomic status subgroup (Median = 72.00, IQR = 23.00.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that participants in the Mid to low socioeconomic status subgroup were good at coping with their condition, and participants in the Higher socioeconomic status subgroup were average at coping.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that recognition and management of symptoms was very good for participants in the Mid to low socioeconomic status subgroup, and good for participants in the Higher socioeconomic status subgroup.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Mid to low socioeconomic status subgroup, and good for participants in the Higher socioeconomic status subgroup.

Table 6.28: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low socioeconomic status	25	50.00	28.00	7.00	369.00	0.2753
	Higher socioeconomic status	25	50.00	25.00	9.00		
Coping	Mid to low socioeconomic status	25	50.00	19.00	5.00	457.00	0.0050*
	Higher socioeconomic status	25	50.00	13.00	8.00		
Recognition and management of symptoms	Mid to low socioeconomic status	25	50.00	21.00	5.00	437.00	0.0153*
	Higher socioeconomic status	25	50.00	19.00	5.00		
Adherence to treatment	Mid to low socioeconomic status	25	50.00	15.00	3.00	312.50	1.0000
	Higher socioeconomic status	25	50.00	15.00	3.00		
Total score	Mid to low socioeconomic status	25	50.00	80.00	16.00	422.00	0.0342*
	Higher socioeconomic status	25	50.00	72.00	23.00		

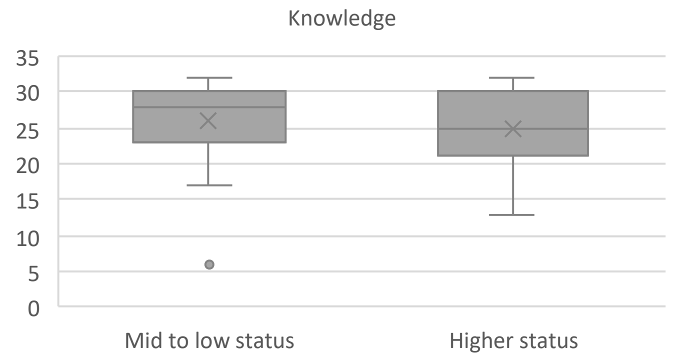

Figure 6.39: Boxplot of Partners in health: knowledge by socioeconomic status

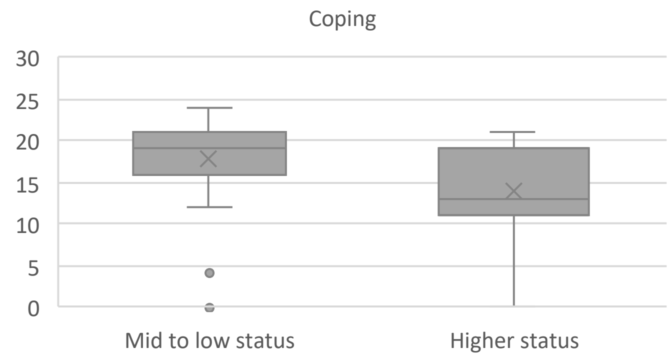

Figure 6.40: Boxplot of Partners in health: coping by socioeconomic status

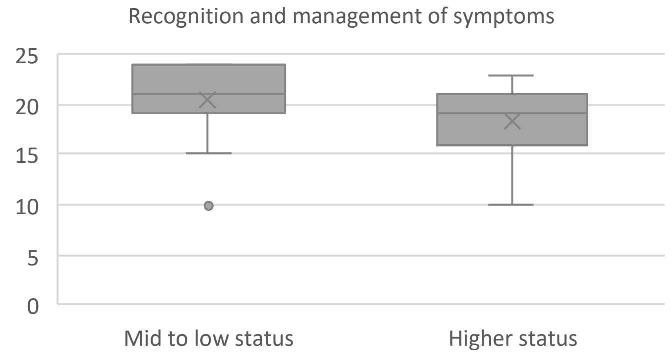

Figure 6.41: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

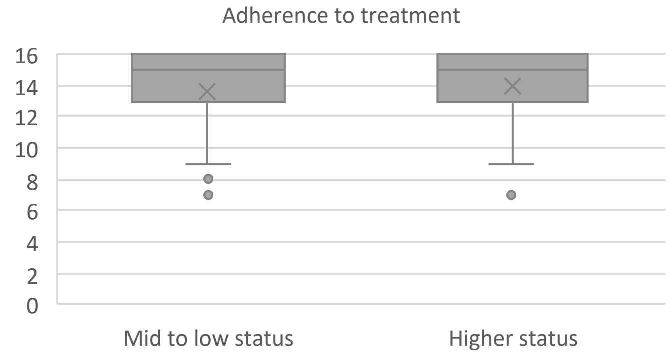

Figure 6.42: Boxplot of Partners in health: adherence to treatment by socioeconomic status

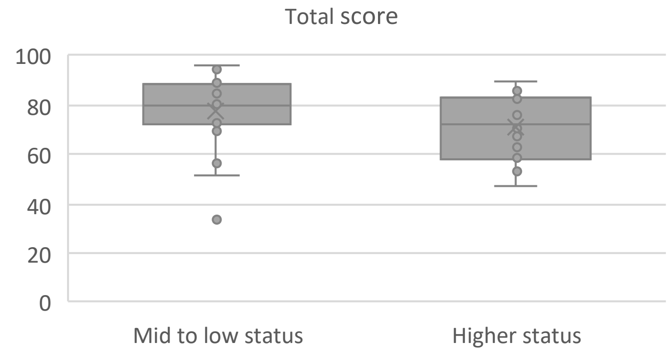

Figure 6.43: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=29, 58.00%), and 17 participants (34.00%) responded that they took medicines as prescribed most of the time. There were 2 participants (4.00%) that sometimes took medicines as prescribed.

Table 6.29: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=50	Percent
All of the time	29	58
Most of the time	17	34
Sometimes	2	4
Rarely	2	4

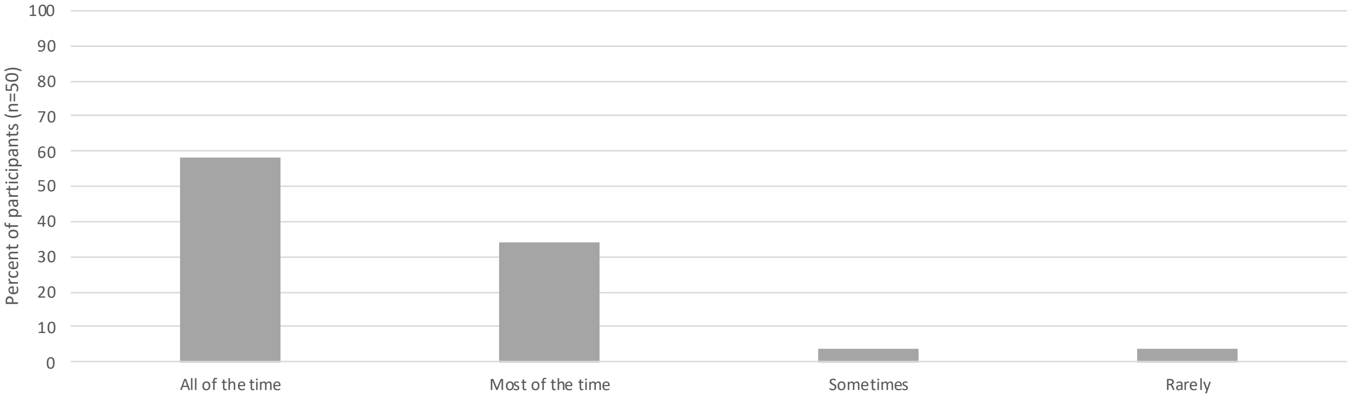

Figure 6.44: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=28, 56.00%), disease cause (n=19, 38.00%), disease management (n=18, 36.00%) and, dietary (n=18, 36.00%) were most frequently given to participants by healthcare professionals, and, information about hereditary considerations (n=4, 8.00%), and complementary therapies (n=2, 4.00%) were given least often. No participants (0.00%) were given information about clinical trials.

Table 6.30: Information given by health professionals

Information given by health professionals	n=50	Percent
Disease Cause	19	38.00
Treatment options	28	56.00
Disease management	18	36.00
Complementary therapies	2	4.00
Interpret test results	8	16.00
Clinical trials	0	0.00
Dietary	18	36.00
Physical activity	18	36.00
Psychological/ social support	10	20.00
Hereditary considerations	4	8.00
No information	1	2.00

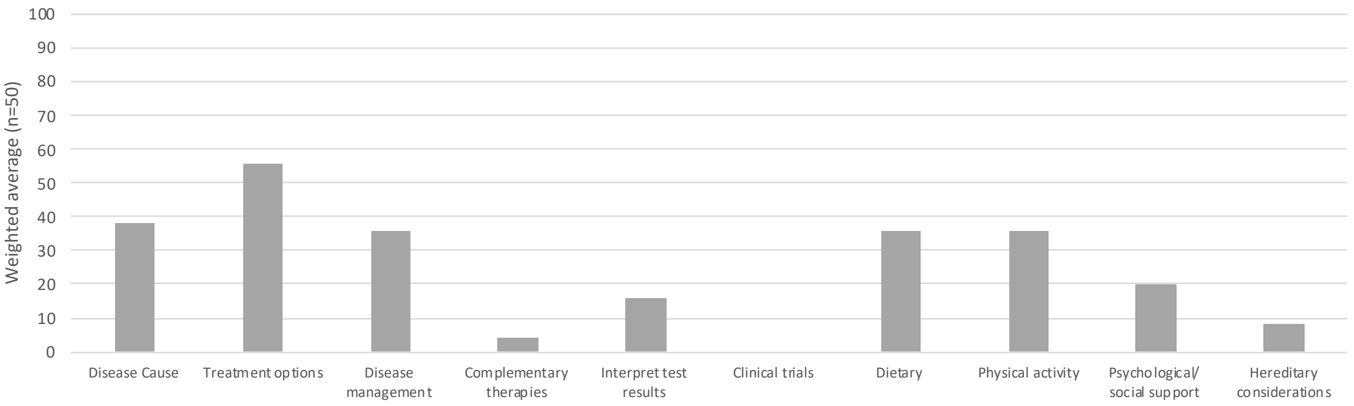

Figure 6.45: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease cause (n=22, 44.00%), treatment options (n=19, 38.00%), disease management (n=19, 38.00%) and, how to interpret test results (n=17, 34.00%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=11, 22.00%), complementary therapies (n=10, 20.00%) and clinical trials (n=4, 8.00%) were searched for least often

Table 6.31: Information searched for independently

Information searched independently	n=50	Percent
Disease Cause	22	44.00
Treatment options	19	38.00
Disease management	19	38.00
Complementary therapies	10	20.00
Interpret test results	17	34.00
Clinical trials	4	8.00
Dietary	16	32.00
Physical activity	13	26.00
Psychological/ social support	11	22.00
Hereditary considerations	12	24.00
No information	1	2.00

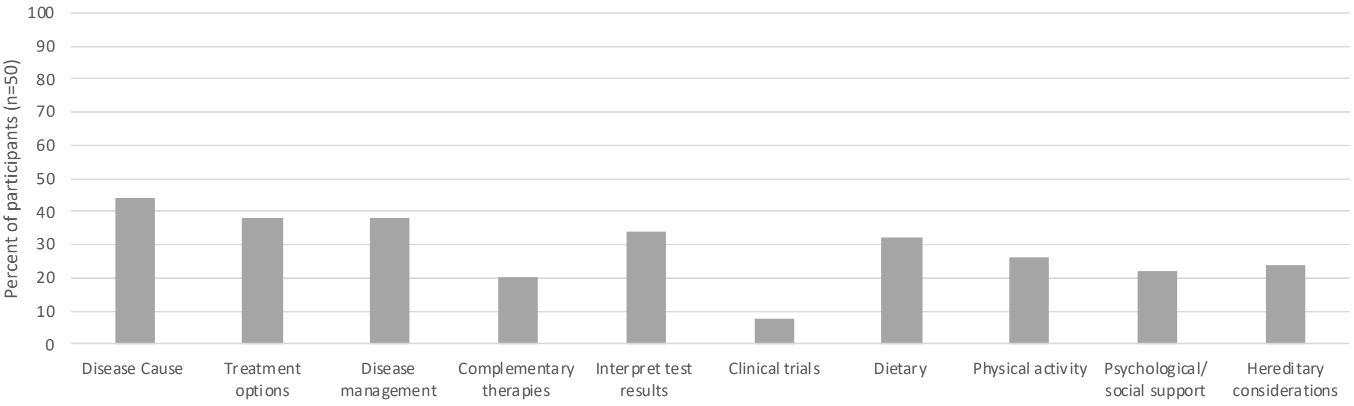

Figure 6.46: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=46, 92.00%) and complementary therapies (n=39, 78.00%).

The topics that participants were given most information from healthcare professionals but not searched for independently for were treatment options (n=16, 32.00%) and physical activity (n=15, 30.00%).

The topics that participants searched for independently after receiving information from healthcare professionals were treatment options (n=12, 24.00%) and disease management (n=8, 16.00%)

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=15, 30.00%) and interpret test results (n=13, 26.00%).

Table 6.32: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=50	%	n=50	%	n=50	%	n=50	%
Disease cause	16	32.00	12	24.00	7	14.00	15	30.00
Treatment options	15	30.00	16	32.00	12	24.00	7	14.00
Disease management	21	42.00	10	20.00	8	16.00	11	22.00
Complementary therapies	39	78.00	1	2.00	1	2.00	9	18.00
How to interpret test results	29	58.00	4	8.00	4	8.00	13	26.00
Clinical trials	46	92.00	0	0.00	0	0.00	4	8.00
Dietary information	23	46.00	11	22.00	7	14.00	9	18.00
Physical activity	22	44.00	15	30.00	3	6.00	10	20.00
Psychological/social support	31	62.00	8	16.00	2	4.00	9	18.00
Hereditary considerations	36	72.00	2	4.00	2	4.00	10	20.00

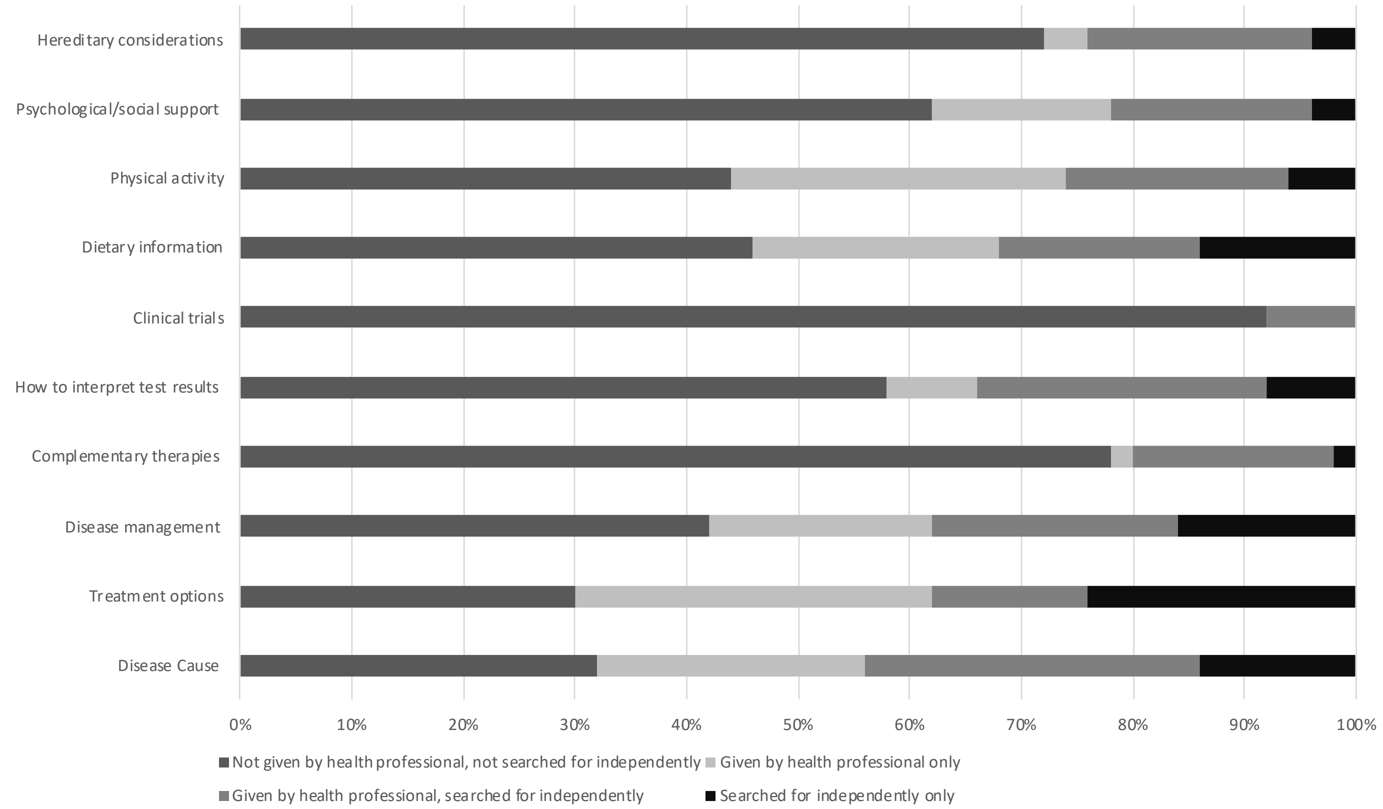

Figure 6.47: Information gaps

Most accessed information

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

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

Table 6.33: Most accessed information

Information source	Weighted average (n=50)
Non-profit organisations, charity or patient organisations	3.63
Hospital or clinic where being treated	3.45
Government	3.16
Medical journals	2.95
Pharmaceutical companies	2.29

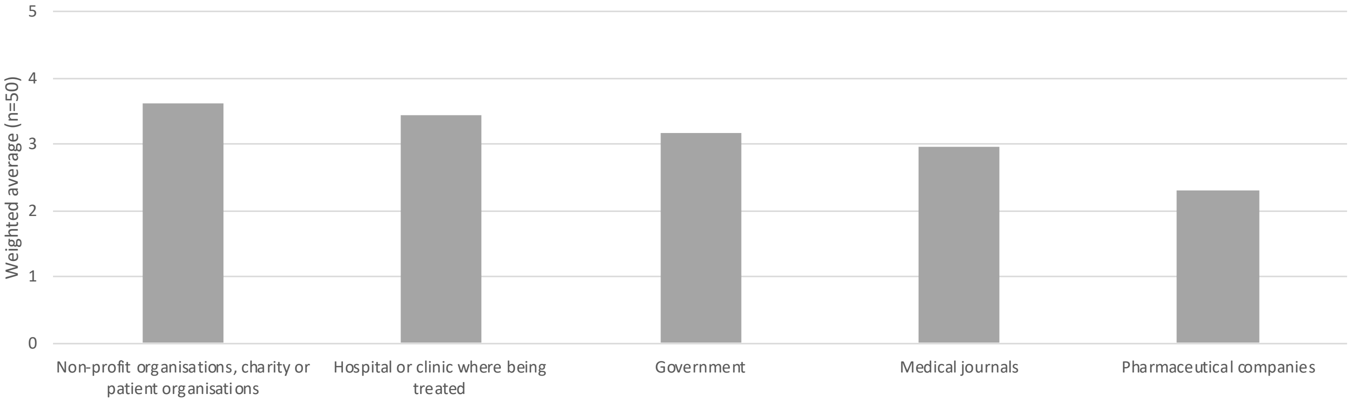

Figure 6.48: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 20 participants (40.00%) that had accessed My Health Record.

Of those that had accessed My Health Record, there were 8 participants (42.11%) who found it to be poor or very poor, 4 participants (21.05%) who found it acceptable, and 7 participants (36.84%) who found it to be good or very good.

Table 6.34: Accessed My Health Record

Accessed “My health record”	Number (n=50)	Percent
Yes	20	40.00
No	16	32.00
Not sure	9	18.00
Doesn't know what ‘My Health Record’ is	6	12.00

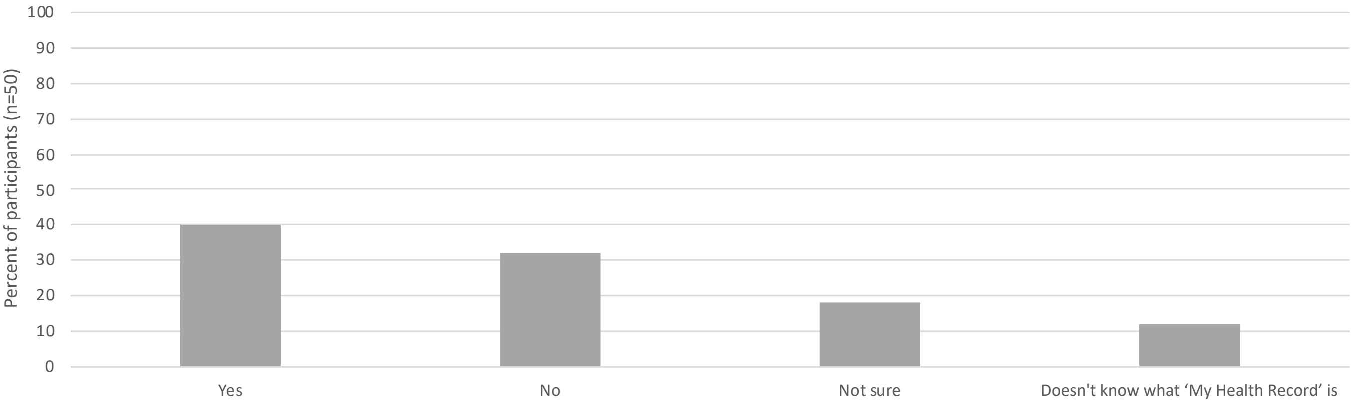

Figure 6.49: Accessed My Health Record

Table 6.35: How useful was My Health Record

How useful was "My health record"	Number (n=19)	Percent
Very poor	5	26.32
Poor	3	15.79
Acceptable	4	21.05
Good	4	21.05
Very good	3	15.79

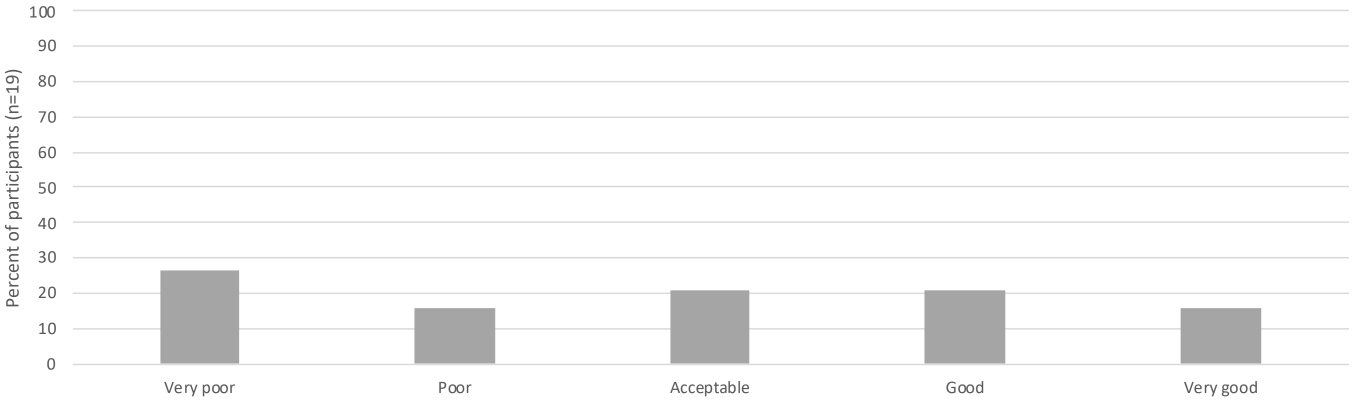

Figure 6.50: How useful was My Health Record