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) (59.45%), from a specific health charity (32.34%) and from Facebook and\or social media (26.12%). Other themes included their treating clinician (25.62%), from journals (research articles) (22.89%), from other patient's experience (Including support groups) (18.41%), from books, pamphlets and newsletters (14.68%).

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 (26.37%), health charity information (16.67%), hearing what to expect (e.g. from disease, side effects, treatment) (15.92%), and talking to a doctor or specialist or healthcare team (15.92%). Other themes included medical or scientific sources (11.19%), and information on triggers and managing exacerbations (6.97%).

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 response was that there was no information that was not helpful (31.09%). The most common types of unhelpful information included information from their GP or specialist (11.94%), sources that are not credible (10.20%), other people's experiences (9.20 %), information that was not type specific or too general (8.46%). Other themes included a lack of new information (7.46%) and worse case scenarios (7.46%).

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 online information (29.35%), talking to someone plus online information (23.63%), and talking to someone (21.64 %). Other themes included written information (13.68%), all forms (5.47%), and apps (2.49%).

The main reasons for a preference for online information were accessibility (27.86%) and being able to digest information at their own pace (18.41%).

The main reasons for a preference for talking to someone was being able to have time to ask questions (18.41%), and that it was personalised (14.43%). The main reason for a preference for written information were written information is that they can refer back to/highlight important information (3.23%).

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) (31.34%), continuously (19.65%), after the shock of diagnosis (12.44%) and 12 months or more after diagnosis (10.70 %).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative (34.83%), overall positive (26.62%), and overall positive, with the exception of one or two occasions (24.63%).

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.

The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=26.00, IQR=8.00), Partners in health: Adherence to treatment (median=14.00, IQR=4.00), indicating very good knowledge, very good adherence to treatment.

The overall scores for the cohort were in the second highest quintile for Partners in health:Recognition and management of symptoms (median=19.00, IQR=5.75), Partners in health:Total score (median=72.00, IQR=20.00) indicating good recognition and management of symptoms, good overall ability to manage their health.

The overall scores for the cohort were in the middle quintile for Partners in health:Coping (median=14.00, IQR=7.00), indicating moderate coping.

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=173, 57.10%), and 120 participants (39.60%) responded that they took medicines as prescribed most of the time. There were 6 participants (1.98%) that sometimes took medicines 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=188, 58.02%), disease management (n=147, 45.37%), disease cause (n=119, 36.73%) and, physical activity (n=85, 26.23%) were most frequently given to participants by healthcare professionals, and, information about interpret test results (n=54, 16.67%), clinical trials (n=43, 13.27%) and, complementary therapies (n=34, 10.49%) were given least often.

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 management (n=212, 65.43%), treatment options (n=210, 64.81%), disease cause (n=207, 63.89%) and, complementary therapies (n=167, 51.54%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=123, 37.96%), interpret test results (n=120, 37.04%) and, hereditary considerations (n=103, 31.79%) 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=177, 54.63%) and interpret test results (n=172, 53.09%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=66, 20.37%) and disease cause (n=58, 17.90%).

The topics that participants were given most information from both healthcare professionals and searching independently for were disease cause (n=146, 45.06%) and complementary therapies (n=145, 44.75%).

The topics that participants searched for independently after not receiving information from healthcare professionals were treatment options (n=122, 37.65%) and disease management (n=96, 29.63%).

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) (59.45%), from a specific health charity (32.34%) and from Facebook and\or social media (26.12%). Other themes included their treating clinician (25.62%), from journals (research articles) (22.89%), from other patient's experience (Including support groups) (18.41%), from books, pamphlets and newsletters (14.68%).

Participant describes accessing information through the internet in general

Mainly Google. I sought out possible causes. I sought out whether vaccines have anything to do with it. That's just recent. I sought out diets that might be good. That's just recent too.
Participant 060_2023AUDNS

The only information I've got initially is just about the CHARGE syndrome. Well, all of it really I've just got off the Internet.
Participant 09_2023AUDPA

The Internet. The American Natural Library of Medicine has a lot of information. Mayo Clinic has information not so many Australian websites.
Participant 003_2023AUDNS

Participant describes accessing information primarily through Facebook and/or social media

The biggest one was to get onto the support page…on Facebook with the registered nurses and just listening to everyone else, and seeing what everyone else was going through, that's where I got all the information from.
Participant 067_2023AUDNS

Yep. So CHARGE online community Facebook groups. And the CHARGE of Australasia is fairly active. They have like regular conferences and courses and that kind of thing. There's also a fairly big online like social media presence these days, not so much when PATIENT was a baby, but these days it's a bit more active and otherwise, just like mining through medical journals, really more in the early days, but yeah. These days I don't tend to freak myself out.
Participant 018_2023AUDPA

Participant describes accessing information from a specific health charity

The AMDF has been very good. They've produce booklets, and of course there's what's online as well.
053_2023AUENM

Well from the Scleroderma, NSW and Australia. I'm actually a support person for Scleroderma Australia in my area in, I mean, I don't have meetings because we tried to get together. There was five of us from a range, from a long area like you know, it was over 200 kilometers. There was only five of us in that area. And it was just too hard for everyone to get together because someone was always sick or couldn't do it. And it cancelled. And so I said to the I won't be doing the meetings like, but I'll be, I could be in the book as a support person and I will post out any brochures, which I do if anyone gives me a call.
Participant 088_2023AUENM

The 22 Q Australia Foundation is awesome. NAME is a wealth of information. We've also got a local WA group which has been amazing. But the end yeah, there's also there's international groups which have got a wealth of information as well. Education's a big one because she learns differently, and it's been really helpful to have that sort of information for her teachers.
Participant 021_2023AUDPA

Participant describes primarily accessing information through treating clinician

Well, a bulk of the information came from my personal research. And the other part of it came from my doctor, you know, most of the information I got from Google or random search and goggle and you know, I actually to read through people's experience, you know, to get us some clue and knowledge about what the thing is all about. So it's was mostly largely from the Internet. I got an idea of what this is.
Participant 006_2023AUORC

Yeah, sure. So I guess we sort of tried to speak to the various doctors that are involved in her care. So the genetic doctor plus our pediatrician plus the GP just to find out information, but also doing things like looking on the Internet. Looking up journal articles and also looking on the various social media support groups that have out there for that condition and also talking to a couple of sort of like patient support or advocacy groups that look into these sort of rare syndromes or

genetic conditions. And also got in contact with a researcher from somewhere in NSW who had an interest in the issue.
Participant 022_2023AUORC

Obviously the Internet is a major source of information, but when we first found out and went to the hospital, the hospital provided us with an in depth information booklet regarding the condition which was really helpful. And then the other main source of information for us is being his specialist team. Every time we talk to them, we have a list of questions and they answer them all for us. They're very thorough, yes. So that's been the main source, his care team and information.
Participant 029_2023AUORC

Lots of Google, pretty much everything we can find our hands on the Internet. We've joined sort of support groups online like on Facebooks and have gotten information from actual parents with experience that probably where we get a lot of our information from because there isn't a lot of information about the duplication online. So when we sort of done our own research, it's been there or it's with the specialists that we have a really close relationship that we can just sort of bounce ideas of one another.
Participant 032_2023AUDPA

Participant describes accessing information primarily through journals (research articles)

As much as I could from 2003. I began the database what was published on the disease up until up until the end of 2021. I was pretty update on everything that was published and I'm just not behind now. This is a lot that's being published now. I still have my own databases published stuff, so the stuff I look at is what's published in peer reviewed journals. Yeah, yeah.
Participant 008_2023AUDSK

Probably the biggest source has been online, so just searching and then the CHARGE Foundation in the US website journals again found them online though medical journal articles and mums and dads who have children. With charge or adults with charge syndrome that they care for is often the biggest access for information or strategies and all that kind of stuff, yes.
Participant 095_2023AUENM

Lots, lots and lots. So initial Google searches and sort of got logins and paid for subscriptions for medical journals where it's mentioned and talked about done the research on what the specific, I guess the variants are of it and your side effects for children and yeah there's lots of things.
Participant 020_2023AUDPA

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 and it's actually really interesting too, because my physio has never had anyone with POTS, but she's really into it now, so she's doing a lot of study into POTS as well. So we have quite good conversations about it, but sort of that's where it ends I suppose.
Participant 031_2023AUORC

Participant describes primarily accessing information through other patient's experience

So we, I go straight to the doctors first and foremost to get any information I need. Then I, I check on like the the medical databases for the university, so like bring up journal articles. I also every now and then I'll jump onto a forum just to get like the real world experience of people that have tried it. So I I kind of like to get a a full review of of treatments and ideas and and suggestions. To get all my information from.
Participant 025_2023AUORC

A lot from support groups, scleroderma support group. I actually was helping run the one here in CITY at one point, so that's been a major thing. Facebook, we got another support group on Facebook, a bit off the doctor's, GP. There was one at LOCATION where the group was, there was a rheumatologist there and she has a wealth of information. Bits and pieces, a lot of it's from other people.
Participant 007_2023AUDIS

I guess I just googled it and yeah, got the information off the Internet and the support group that we I don't always go every month. Just depends on what you know how I'm feeling and what I'm up to and they all know. They all know that as well and we just sort of it's just a best friendship and and all of that. So it's you know and you know someone says all they tried this will you know try that you know sort of creams and stuff like that or whatever.
Participant 019_2023AUDIS

Participant describes receiving information from books, pamphlets and newsletters

I try and look at the Scleroderma Association. Obviously, the Australian one, the US one, and the UK one predominantly, as the strong English-speaking, and look at things that are on their newsletters, I get information about different trials and things coming up. I am on a number of Facebook groups, which can be good, but I think you have to be careful how much of that you read. That can be really, really depressing. Really, some people are carrying on, and you think, "Oh my gosh, your symptoms are so mild, you have no idea." Other people, it's just so shocking and awful, some of the stuff they're going through.
Participant 017_2023AUDIS

Yeah, the pediatrician gave us pamphlets to start with like a, you know, medical information. Since then that was pretty much all I used. Since then I've also bought myself resources for 22 Q in education and learning to see how that's how they work and what's the best way to teach them. I've also now joined the 22 Q Australian New Zealand group so I get information from them as well and that's about as far as I've gone so far.
Participant 010_2023AUDPA

Okay, there are printed pamphlets. I know when I get my Botox. It's a public clinic that's St Vincent, and there are Dystonia pamphlets there, and I found them pretty light on, but they're good to give to family and friends to give them an idea. I have scraped the Internet, reading stuff, and I'm also trying to get into the NDIS, and that's been a huge scrape of the Internet. So I feel fairly well-informed, but there's nothing there that's very encouraging.
Participant 002_2023AUDNS

Participant describes accessing information from clinicians and researchers (including webinars/seminars/conferences)

After I actually had the surgery and for the first time I had a few weeks at home, I, I reached out and started sort of finding more, I suppose patient, not support groups, but information sites and and there you would there was a there was one, I think it's called my HS, where they actually then also ran webinars and information sessions hosted by different dermatologists and practitioners and and lived experienced people mainly from the state. And so I was able to link in with some of those to hear about other people's experiences and then I, yeah, joined a couple of Facebook groups. In which did sort of hear about people lived experience and and what they were trying. Sometimes they had different sort of suggestions for things like lotions and creams and stuff that the dermatologists hadn't come up with. So there, yeah, there were a couple of times I tried some of those things but on a minor scale, whereas some of the suggestions was pretty out there.
Participant 007_2023AUDSK

So there's a lot of really good resources for cystic fibrosis, like they've got the cystic fibrosis, fibrosis Australia and then all the states have their own little subsidiary branches of it that really help with connecting you with that information. We also get a lot from the clinic itself. And they have a lot of events quite regularly where I can't remember what they call them, but pretty much they're like open community forums, but they actually get the doctors that are out there, you know, doing all the research. They get families in to just have a talk and let everyone know what the the latest information available out there is, what's happening.
Participant 020_2023AUORC

Table 6.1: Access to information.

Access to information	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Internet (Including health charities)	239	59.45	24	35.82	60	74.07	62	65.26	21	65.63	54	56.84	18	56.25	180	67.16	59	44.03	179	60.88	59	55.66
Specific health charity	130	32.34	20	29.85	22	27.16	26	27.37	4	12.50	45	47.37	13	40.63	87	32.46	43	32.09	97	32.99	32	30.19
Facebook and\or social media	119	29.60	12	17.91	35	43.21	31	32.63	16	50.00	18	18.95	7	21.88	89	33.21	30	22.39	93	31.63	26	24.53
Treating clinician	105	26.12	14	20.90	22	27.16	20	21.05	6	18.75	24	25.26	19	59.38	69	25.75	36	26.87	82	27.89	23	21.70
Journals (research articles)	92	22.89	13	19.40	14	17.28	24	25.26	12	37.50	21	22.11	8	25.00	59	22.01	33	24.63	73	24.83	18	16.98
Other patient's experience (Including support groups)	74	18.41	15	22.39	18	22.22	10	10.53	12	37.50	8	8.42	11	34.38	53	19.78	21	15.67	58	19.73	16	15.09
Books, pamphlets and newsletters	59	14.68	14	20.90	20	24.69	3	3.16	0	0.00	16	16.84	6	18.75	42	15.67	17	12.69	41	13.95	16	15.09

Access to information	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Internet (Including health charities)	239	59.45	24	35.82	60	74.07	62	65.26	21	65.63	54	56.84	18	56.25	180	67.16	59	44.03	179	60.88	59	55.66
Specific health charity	130	32.34	20	29.85	22	27.16	26	27.37	4	12.50	45	47.37	13	40.63	87	32.46	43	32.09	97	32.99	32	30.19
Facebook and\or social media	119	29.60	12	17.91	35	43.21	31	32.63	16	50.00	18	18.95	7	21.88	89	33.21	30	22.39	93	31.63	26	24.53
Treating clinician	105	26.12	14	20.90	22	27.16	20	21.05	6	18.75	24	25.26	19	59.38	69	25.75	36	26.87	82	27.89	23	21.70
Journals (research articles)	92	22.89	13	19.40	14	17.28	24	25.26	12	37.50	21	22.11	8	25.00	59	22.01	33	24.63	73	24.83	18	16.98
Other patient's experience (Including support groups)	74	18.41	15	22.39	18	22.22	10	10.53	12	37.50	8	8.42	11	34.38	53	19.78	21	15.67	58	19.73	16	15.09
Books, pamphlets and newsletters	59	14.68	14	20.90	20	24.69	3	3.16	0	0.00	16	16.84	6	18.75	42	15.67	17	12.69	41	13.95	16	15.09

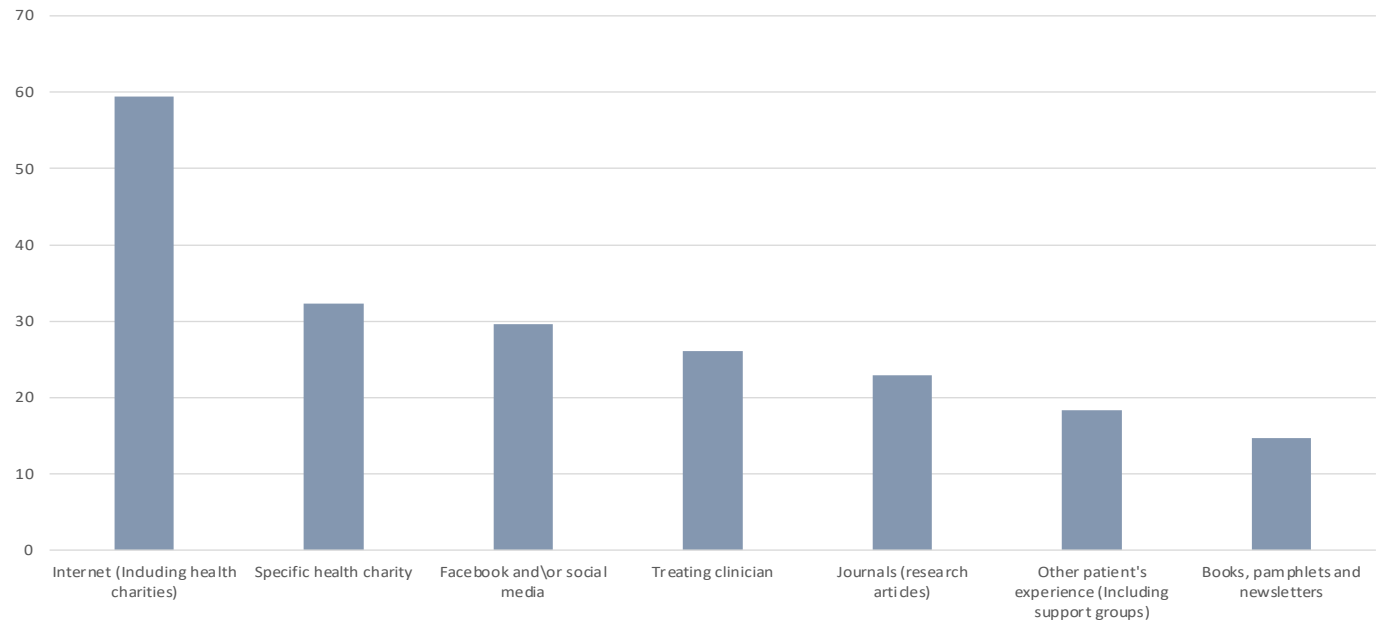


Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Internet (Including health charities)	Developmental anomalies Family or carer Aged under 18	Diseases of the immune system
Specific health charity	Diseases of the skin	Endocrine, nutritional or metabolic diseases
Facebook and\or social media	Developmental anomalies Endocrine, nutritional or metabolic diseases Aged 65 plus	Diseases of the immune system Diseases of the skin
Treating clinician		Other rare condition
Journals (research articles)		Diseases of the skin
Other patient's experience (Including support groups)		Diseases of the skin Other rare condition
Books, pamphlets and newsletters	Diseases of the nervous system Diseases of the skin	Diseases of the immune system Aged 65 plus

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 (26.37%), health charity information (16.67%), hearing what to expect (e.g. from disease, side effects, treatment) (15.92%), and talking to a doctor or specialist or healthcare team (15.92%). Other themes included medical or scientific sources (11.19%), and information on triggers and managing exacerbations (6.97%).

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

Yeah, made me feel I'm not alone. That was quite good because they said, they said most people don't talk about it, they just tend to hide it.
Participant 024_2023AUDSK

I suppose being in contact with the other parents and and finding out what's worked for them. And it was very interesting when we found out about. The, the gene that was probably responsible for most of the symptoms.
Participant 093_2023AUENM

Yeah, yeah. They're the people who know, you know it. I mean, you say 22 Q, the average person, they haven't got a clue and that's the most common genetic syndrome after Down syndrome. Yeah, when we're educating doctors, it's not a good thing. When you go and see a specialist and they Google 22 Q in front of you, it's not a good thing.
Participant 021_2023AUDPA

Going to the conferences is really good because you meet other families there as well as the kids, and they're all different ages. And yeah, so it's good to see how people are going.
Participant 026_2023AUDPA

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

And I guess myself one has been just finding out about some of the potential symptoms and what the prognosis might be moving forward in terms of how people display, how they demonstrate the condition in labor life, what sort of symptoms have been.
Participant 022_2023AUORC

Just knowing what the hell scleroderma was and why the symptoms were what they were, very useful, worst case scenarios and best case scenarios and all that kind of thing and I said the wound stuff was very useful and more recently, information around disability. I've found that an interesting transition for me is now I am someone with a disability and the permission to be that person. Working with NDIS and disability support people and all that has been really useful and has made a big difference more recently. I'm someone with scleroderma but I am someone with a disability and my disability is caused by scleroderma as opposed to I'm someone with scleroderma if that makes sense.
Participant 026_2023AUDIS

What what sort of things that you see with a person with DiGeorge like the learning difficulties and the thought processes and yeah, understanding all that and seeing that that's very clearly what's happening with my daughter. So symptoms, I guess symptoms and examples of what you you will see and expect as normal and to not get frustrated because that person is doing their best. Yeah.
Participant 08_2023AUDPA

Participant describes talking to their doctor or specialist as helpful

I guess the information from the doctor from the specialist has been the most helpful because he's told me what to expect and everything like that, and I trust him. When he's told me this could happen, that could happen, that's been helpful in helping me understand what my body's going through and help me cope with the changes if that makes sense.
Participant 39_2023AUDIS

I think speaking directly to the the doctors or the specialists, so obviously there's there's a lot out there on types of nebulizers that are the best and what people have brought and have used for them, but I tend to always find what I speak directly to the doctors about. Is most helpful I suppose, cuz I can ask a question and have it answered, or they look into it specifically and get back to me instead of just looking at the general frequently asked sections.
Participant 025_2023AUORC

Receiving the information, what was the most helpful? I suppose some of the things that the neurologist just said to us where she has actually probably had some clients that she has seen that are in their teens and early 20s. Well, I guess helpful probably would be more that it's being more easing on our minds, that's positive information from her that she's had clients that are older than NAME, in their late teens and doing really well and they've continued to thrive regardless of having Leigh's disease.
Participant 066_2023AUENM

Participant describes health charities information as helpful

I would say the information located on the Hep Queensland website, I think it's a great overview and you can pass that to people that. Need to know, I need to teach themselves about it, because talking to potential partners about it, for some people it's a very big deal and it's it's a huge deal for them. For other people, it hasn't been a big deal. They've just gotten blood tests and checked their immunity, so. It's really interesting. I guess the stigma from that. I thought that maybe COVID would have helped that, but I think other people are more germaphobic than others, yeah.
Participant 004_2023AUORC

Yeah, so I contacted the CHARGE foundation and they sent a lot of helpful links to webinars. From the

leading experts on this field. A few journal articles, yeah, things like that.
Participant 094_2023AUENM

Oh look, I certainly don't want to discredit the information and the conversations that I'll have with my neurologist. I value those greatly because, I trust, that he's always looking for, the newest things available. I trust that he does keep me up-to-date on what's available out there, but from the support side of it, the Dystonia Network of Australia is just fantastic.
Participant 006_2023AUDNS

Participant describes information about triggers and managing or avoiding exacerbations

I guess the most helpful thing was I went to a workshop that the autoimmune resource centre ran on, it was health and looking after yourself and it was I guess it wasn't new information but it was just looking at things from a different perspective. It was about all the different symptoms that you can have and what different ways, I guess, you should go about tackling them. I guess I didn't really learn anything new because I'd already looked up a lot of my own symptoms.
Participant 31_2023AUDIS

More management plans. Knowing about the different types…what are the effects, whether is a one-off thing, whether it's relapsing form and management plan. What sensation will Residual symptoms, mainly residual symptoms because I need to work out whether is it residual symptoms or is it a relapse or whether I need to go to hospital. Actually, it's that kind of thing that sort of help me.
Participant 059_2023AUDNS

Participant describes no particular information being especially helpful

Not, no it's all very dismal prognosis. Very, very negative. What I can say as well, very, very frighteningly, is anything definitive about what your symptoms are or will be in the future? Do they get worse? What I mean is this deteriorating condition, it's gotten worse over the years. How much worse is it going to get and is it going to affect me so? That's it.
Participant 015_2023AUDSK

None.
Participant 006_2023AUDIS

I really do not have the answer to this question. That is probably my biggest problem with them, my condition is, I have to manage it myself and then try to seek out people with qualifications to help me. Then I find that I get nowhere. That probably the answer to one of your very first questions, that's probably my biggest thing. I need to have a team around me and I just don't have that.
Participant 014_2023AUDIS

Participant describes information specific to their condition (and sub-types) as helpful

After nine years of wondering where she fitted on the umbrella. It was it was comforting to at least know where she sat with her genetic diagnosis and that yes, we're doing what we can. Yes, we're following the guidelines. And it was, you know, great to know that there's someone else in the world with the same thing. It wasn't just us. So that was good for me. It was, I've wondered for five years whether I was more like NAME and why I wasn't responding to treatment and things like that. And I'm a bit annoyed that, you know, I wasn't offered this ten years ago and, you know, just a little things like that that that at least let her know, you know, what is the problem and why she is the way she. But we do have other genes that came up in the sequencing, mutations and they're not sure where they fit either. So, you know, there's still more science to come, yeah.
Participant 080_2023AUDIS

Yes. It's all helpful in different ways. Some of the information-- What's the information that's been-- I'm going to talk about types of information, I think. Because my manifestation is quite severe now, I mostly appreciate the information that incorporates that reality in its paradigm. I don't know how else to put it, so a lot of the time you'll come across something about movement in hypermobility and it's just really important to keep moving or do this, do this, do this. That information wasn't really very useful to me because too much of the wrong movement is actually just as bad if not more detrimental than no movement. So I like specific detailed stuff that, the difficulty there is that I don't have the cognitive capacity to read like whole papers and things, but in general, accessing all of that stuff was really important just in terms of getting a handle on it, not feeling alone, understanding that there are ways of managing all of that stuff, but really the most useful information that's come to me is what I get from my physiotherapist about how to manage my body.
Participant 041_2023AUDPA

Participant describes information from medical or scientific sources as helpful

When I looked up articles on what certain things did for my lungs, like some of the physio stuff, I…so I don't know why I didn't take it as seriously when they said, you know, it works and whatnot. And I just thought you just told me that because you want me to do it. I went and read articles about it and, you know, it was had facts behind it from people that had, you know, had scholarly stuff behind it. So I was like, oh, okay, well, yeah, that makes sense.
Participant 013_2023AUORC

Yeah, yeah. Medical, medical articles and having been researching medical things for so many years, I'm pretty well up on terms. And occasionally I'll stumble across a word I've never heard before. But not very often.
Participant 003_2023AUDIS

I think the National Library of Medicine. PubMed. Whether I would, especially when they'll give an abstract of an article, because I'm not particularly interested in waiting my way all the way through, but they will give an abstract of a scientific article. Like I was trying to work out whether coffee was a problem and some sites said don't drink coffee. So I found a site that said really just work it out for you because some people can't. Because I went on to decaf for a week, thought, you know, would for instance, would decaf coffee make a difference? No, it didn't.
Participant 003_2023AUDNS

Participant describes information about treatment options as helpful

I guess maybe the medication, the information about the medication on how it can like control the blood. Yeah, we don't really have much information.
Participant 003_2023AUORC

You know, there's definitely the the cleaning, you know, using the antibacterial stuff as much you know that's and then obviously new treatments, you know, like finding out people talking about what they're on and how good it's been and, you know, like I didn't know anything about this sort of stuff, so and I told them I was telling my GP. So yeah, not very good, yeah.
Participant 025_2023AUDSK

Participant describes information from international sources as being helpful

It's helped me in understanding part of what the issues are. The best bit of information I've actually found is I've been listening to EDS, I think it's the American version, and I actually have a monthly discussion/info program that's basically a TED Talk type where they're talking about various parts of various types of EDS and talking about what works and what doesn't work is what I've actually found most helpful. Dr. Google, not a good place to start.
Participant 005_2023AUDPA

Articles from the Mayo Clinic in America and Johns Hopkins, and a little bit from the Dystonia Support Network.
Participant 007_2023AUDNS

Participant describes information in lay language or that is easy to understand as helpful

PARTICIPANT The information can get through the UK Association website. They've got very easy-to-read one. They've been amazing. The forum has been helpful. Sorry, I forgot the question. It was about what?
INTERVIEWER Just when you've received information, what information has been most helpful?
PARTICIPANT Those sorts of things. The handouts break down what the issue is and what to do about it. They're quite clear and easy to use and easy to hand on to others if I've needed to.
Participant 004_2023AUDPA

I just wanted worded in layman terms, just just more about where the future studies are going how it's leaped forward since when I was first diagnosed to what's on offer now. There's heaps of clinical trials and better education. The doctors are actually at hospitals are being educated and I also work as a PROFESSION and I'm actually looking after patients. Who have this diagnosis? So it's getting out there.
Participant 013_2023AUDSK

Information that's written in like non-medical terms I guess if that's what you mean, easy to read, easy to understand, the medical journals get a little bit hard to read, a little bit too technical from me. Is that is that what you mean?
Participant 010_2023AUDPA

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Other people's experiences (Peer-to-peer)	106	26.37	13	19.40	24	29.63	33	34.74	9	28.13	18	18.95	9	28.13	71	26.49	35	26.12	81	27.55	24	22.64
Health charities	67	16.67	9	13.43	12	14.81	25	26.32	0	0.00	17	17.89	4	12.50	45	16.79	22	16.42	50	17.01	16	15.09
Hearing what to expect (e.g. from disease, side effects, treatment)	64	15.92	11	16.42	16	19.75	14	14.74	5	15.63	5	5.26	13	40.63	42	15.67	22	16.42	44	14.97	19	17.92
Talking to a doctor or specialist or healthcare team	64	15.92	6	8.96	11	13.58	20	21.05	2	6.25	17	17.89	8	25.00	45	16.79	19	14.18	45	15.31	19	17.92
Medical or scientific sources	45	11.19	2	2.99	10	12.35	1	1.05	3	9.38	28	29.47	1	3.13	37	13.81	8	5.97	34	11.56	11	10.38
Triggers and managing exacerbations	28	6.97	2	2.99	13	16.05	3	3.16	4	12.50	1	1.05	5	15.63	23	8.58	5	3.73	25	8.50	3	2.83

Information that has been helpful	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Other people's experiences (Peer-to-peer)	106	26.37	28	28.87	38	29.01	27	23.68	13	21.67	54	27.27	52	26.53	30	27.03	76	26.12	59	29.50	47	23.27
Health charities	67	16.67	17	17.53	18	13.74	15	13.16	17	28.33	33	16.67	33	16.84	16	14.41	51	17.53	34	17.00	33	16.34
Hearing what to expect (e.g. from disease, side effects, treatment)	64	15.92	16	16.49	25	19.08	12	10.53	11	18.33	29	14.65	34	17.35	20	18.02	44	15.12	33	16.50	31	15.35
Talking to a doctor or specialist or healthcare team	64	15.92	16	16.49	16	12.21	20	17.54	12	20.00	28	14.14	36	18.37	17	15.32	47	16.15	24	12.00	40	19.80
Medical or scientific sources	45	11.19	5	5.15	10	7.63	19	16.67	11	18.33	18	9.09	24	12.24	14	12.61	31	10.65	24	12.00	21	10.40
Triggers and managing exacerbations	28	6.97	4	4.12	10	7.63	12	10.53	2	3.33	15	7.58	13	6.63	4	3.60	24	8.25	12	6.00	16	7.92

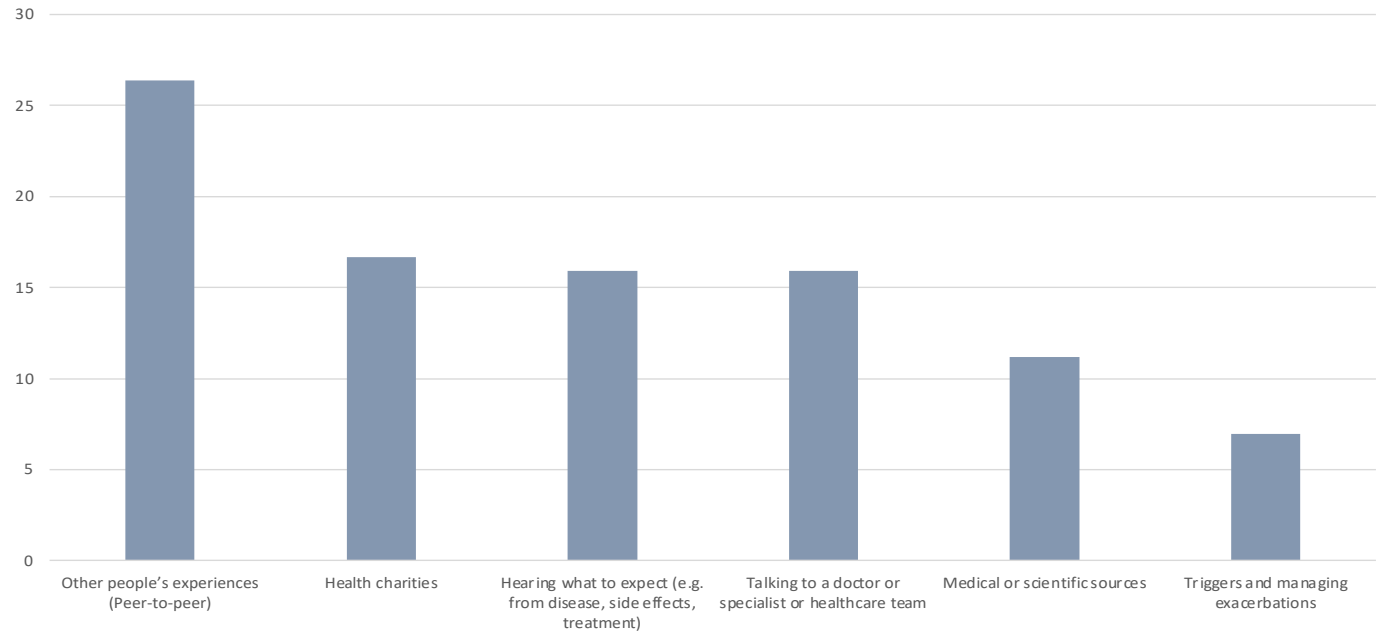


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Other people's experiences (Peer-to-peer)		
Health charities		
Hearing what to expect (e.g. from disease, side effects, treatment)		
Talking to a doctor or specialist or healthcare team		
Medical or scientific sources		
Triggers and managing exacerbations		

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 response was that there was no information that was not helpful (31.09%). The most common types of unhelpful information included information from their GP or specialist (11.94%), sources that are not credible (10.20%), other people's experiences (9.20 %), information that was not type specific or too general (8.46%). Other themes included a lack of new information (7.46%) and worse case scenarios (7.46%).

Participant describes no information being not helpful

Not really, no, because I just all information is useful in some way and I and it didn't really. I didn't find it scary or anything. I think the only thing that was frustrating to me is what causes it. No one could tell me what caused it. So in the back of your mind you're always thinking, did I do something to cause it? But you know, they they just keep saying that it's just new in NAME'S sort of the first one in the line genetic line to get it out of nowhere, which is weird.
Participant 09_2023AUDPA

No. You always seem to gleam a little bit from it. Always got something in there that you didn't realise or remind you of, 'Oh, yes, that's right. I forgot about that' Sometimes you're gone, sometimes, I said... Sometimes it's a little bit overwhelming because there's so much. There's such a difference in symptoms between people with 22 Q that it's a very, very, very large field that can go wrong or can can affect the body in so many ways.
Participant 010_2023AUDPA

No, no, it's all been helpful. This was anything when you're researching or looking into anything. I always just sort of think everyone's experience is different for taking bits and pieces from other people's experiences. Or it's like a doctor, they may not have experienced it on a day-to-day. They're just going from the theory and nothing. That's been unhelpful because when the first time it was all helpful, you sort of want to cover the basis of everything just to see what is, what your focus is gonna be to find out how far reaching the condition was for her.
Participant 017_2023AUDPA

Participant describes the GP/specialist as being not helpful

Every service provider I ever visited, ever. Except for my current physician. OK?
Participant 015_2023AUDSK

The actual not paying attention. When you go in and you say, listen, there's something wrong, all right? And I think it's this or it's in this area and the GP goes, Nah, you don't know what you're talking about. We'll do this instead. And it's like, no, man, hang on. It's like the chest infections that I've been treated for, for the last six years. I kept saying to the doctor, it's not in the chest, it's in the throat, in the throat, somewhere in the throat there. I finally got a lung function test and my lungs, even though I've been an asthmatic since I was three months old, have operating at 98% and I have no scarring on them.
Participant 014_2023AUORC

Yeah, don't suggest moogoo for rough skin. This is a bit more than a bit of chafing, but this is what this twit who supposed that he was… I think he's what's running training wheels, I don't know, but he obviously know very much that was, was very much almost like you know give me a real medical diagnosis. I mean you know a bit of rough skin is not exactly being sick do you know what I mean? And I was actually having to educate this twit because he, he, when he was took…I was there about the kidney business and he was talking about my kidneys and saying I used to know your creatinine's 145 and you're geo fast 30 and blah blah blah blah and you know. Do I know what's caused the kidney injury? It must be a kidney injury that's happened at some point. And I said, well, I presume it's from the Scleroderma. He said no, that's just for the skin. If you tried moogoo, that's what he knew about Scleroderma. This was the doctors, the registrar.
Participant 002_2023AUDIS

Participant describes other people's experiences as being not helpful

Yeah, just a lot of, you know, the keyboard warriors with their personal advice when they're not clinicians, it's you see things that I can see, things that could be very harmful, but I choose not to engage in that kind of stuff.
Participant 018_2023AUDSK

Some things I suppose more, so you try to take some things on board from other people in forums, but some people can be quite one-minded. I think too, again, like I said, a lot of physicians or people that I've come across over the years they haven't treated you holistically.
Participant 001_2023AUDIS

PARTICIPANT: Yes, sometimes people go on and on about which medications they're on and stuff that's worked for them and rave on about it a bit too much and it, but one thing doesn't fit everyone, you know what I mean?
INTERVIEWER: That's right.
PARTICIPANT: Oh, you should see this doctor and this advice about, oh you should eat this and do that. That's not particularly helpful always because you get too much advice, do you know what I mean?
Participant 007_2023AUDIS

Not helpful as I told you, everybody's different. Some people can eat things and others they can't, but that's not helpful because it's not a true information. It's based on only a few people, a few opinion. It's not globally. Some people can eat anything. Information that will not be helpful.
Participant 020_2023AUDIS

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

If you search the symptoms of HS on Doctor Google, you have just about every disease ever known to men. And you're probably going to die from cancer.
Participant 005_2023AUDSK

Oh, probably a lot of stuff about life outcomes because they life expectancy is because they range so massively.
Participant 08_2023AUDPA

PARTICIPANT: Yes, when I, the very first time, this is back in 2014, I just Googled dystonia, and I don't know what site I got up, but it was just full of pictures of people in wheelchairs that were very contorted. And I went, "Oh my God, is that going to happen to me now?" I sort of spoke to the neurologist, and he said no, that's some other sort of thing, nothing else you've found. But it was just labeled as dystonia, and that was a shock to think, mm.
Participant 002_2023AUDNS

Participant describes a lack of new information as not helpful

Yeah, definitely. So like dreadful research studies or outdated information or lack of information is a real one. Like there's just not really anything out there. Yeah, I think that's probably it.
Participant 021_2023AUORC

A lot that you you read is outdated. You know series. Yeah, old papers of series haven't been updated. So you so you sort of get misinformation and what you know, a big one is you know lots of sites say that CMT is a form of muscular dystrophy, but it's not. So there's a lots of misinformation. Which can, you know, lead you down lots of wrong paths.
Participant 026_2023AUORC

Yeah, for sure. The Internet has been a terrible source of information. It's all outdated because it's…Because the medications and treatments with this progressing so quickly, when you research it on the Internet, everything is outdated and it's quite scary, particularly for someone who doesn't know much about the condition. It can be really depressing reading some of the material that's no longer actually applicable. But you don't know that until you you know you called by the. By the specialist team that it's not right anymore.
Participant 029_2023AUORC

Well, you open up websites sometimes and sometimes, you know, I suppose they just say the same old thing, so if that, you know, you're not learning anything new, so I just go on to the next one, so to speak. So, but nothing that's not negative.
Participant 016_2023AUDPA

Participant describes information about worse case scenarios and negative information as being not helpful

No, no, no, not at all. No, not that at all. I found the meetings are very much the opposite. In that, we all love so much. That is true. It's uplifting, but people, particularly there are online groups for scleroderma, and often, I think it's a good thing that people have somewhere they can vent or ask questions, but some people seem to be relentlessly negative. I find that difficult to cope with because I'm more a, I don't know, glass-half-full.
Participant 004_2023AUDIS

Probably some of the stuff on the Internet, like the horror stories and so much on the Internet where people are telling their story with the disease and everyone is different with Scleroderma, like you know you can't just read something on the Internet and think that's what's going to happen to you. Yeah, just the terrible pictures there and stuff.
Participant 022_2023AUDIS

PARTICIPANT: Yes, when I, the very first time, this is back in 2014, I just Googled dystonia, and I don't know what site I got up, but it was just full of pictures of people in wheelchairs that were very contorted. And I went, "Oh my God, is that going to happen to me now?" I sort of spoke to the neurologist, and he said no, that's some other sort of thing, nothing else you've found but it was just labeled as dystonia, and that was a shock to think, mm.
Participant 002_2023AUDNS

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

There's a lot I would say out there online that hasn't been helpful when. When those potential boyfriends have gone searching the facts that they came up with and put in front of me really made me question like how is that true and how is that accurate? So I would give them a bit more, something a bit more accredited, but yeah, I think whether the information was out of date. I'm not sure, but I think that was definitely a hard part to counterbalance.
Participant 004_2023AUORC

I don't, I don't think these anti-inflammatory diets and give up milk, give up gluten and wheat are helpful. I think the research that I've read more in relation to how the genes are working and processing your DNA has been more educational.
Participant 013_2023AUDSK

I don't think so. As I said, she's selective in what she researches. She's not into populist treatments, if you like, from our alternative people.
Participant 062_2023AUDNS

Participant describes information that is not comprehensive as being not helpful

When you read like there's one set of papers that's available through them, the long version is actually fantastic and it's six pages long and it's written about how GPs in primary care can really cater to people like me. Oh, I was going to send you some of these things. Anyway, there's a short version of that paper and most GPs are going to jump to the short version of the paper, but there are some salient bits of information in that longer version that aren't in the short version that could cause someone with severe manifestation some issues if those nuances aren't. That's because of the complexity of the condition. I think that's just maybe the nature of the situation is that inevitably no information can cover the nuances of someone's individual expression, so generalizations can be just as, not harmful, probably too strong a word, troublesome as not having generalizations.
Participant 001_2023AUDPA

To be honest with the information from the medical, if we're looking at from that point of view, I find it's very limited because they don't know and some may may treat the condition like any other, like another condition. Yes. And that's the part that we find very difficult because we know these condition can be varying.
Participant 016_2023AUORC

There is, and again, it's with support groups that the newly diagnosed persons can sometimes overreact, and I, I sometimes don't find that helpful. I want to. I want to be caring and empathetic. But when you first diagnosed with Scleroderma, the natural thing is to Google and that's pretty much what everyone does and it's off three years if it hits your heart and lungs and you panic. And I did the exact same myself. So I feel like doctors could reassure patients better when they give that diagnosis and minimise the shock and the horror and the… but they don't. They don't give enough information about the disease when they diagnose you. I think that's the most unhelpful, that the reassurance could be a lot better in telling you that this, this disease affects everybody differently. And some people will live 30 years or 40 years with it, but they don't tell you that, they just tell you you have, and that's really frightening for a newly diagnosed person, it's mind bending. So I think yeah, that not giving enough information is not helpful. Yeah.
Participant 016_2023AUDIS

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

Well, any information that wasn't helpful to me during this. I just simply choose to ignore.
Participant 006_2023AUORC

No, not, not necessarily. I think you have to, you have to sort of siphon out what's what's right for you and what's not.
Participant 001_2023AUDSK

PARTICIPANT: Websites. So you know there again when you're reading when I'm reading anything from the web, I just take what I need, you know.
INTERVIEWER: Yes.

PARTICIPANT: And I don't worry about the others, the other things, you know, it's just what I need.
Participant 005_2023AUDIS

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
No information not helpful	125	31.09	19	28.36	17	20.99	27	28.42	8	25.00	43	45.26	11	34.38	88	32.84	37	27.61	88	29.93	36	33.96
GP\specialist	45	11.19	4	5.97	19	23.46	6	6.32	6	18.75	6	6.32	4	12.50	36	13.43	9	6.72	33	11.22	11	10.38
Sources that are not credible (Not evidence-based)	41	10.20	4	5.97	18	22.22	1	1.05	3	9.38	10	10.53	5	15.63	33	12.31	8	5.97	35	11.90	6	5.66
Other people's experiences/unsolicited advice	37	9.20	2	2.99	14	17.28	7	7.37	5	15.63	9	9.47	0	0.00	28	10.45	9	6.72	30	10.20	7	6.60
Not type specific (Too general)	34	8.46	3	4.48	8	9.88	15	15.79	1	3.13	6	6.32	1	3.13	25	9.33	9	6.72	31	10.54	3	2.83
Worse case scenarios	30	7.46	7	10.45	11	13.58	3	3.16	1	3.13	4	4.21	4	12.50	19	7.09	11	8.21	23	7.82	7	6.60

Information that has not been helpful	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher statu	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
No information not helpful	125	31.09	23	23.71	44	33.59	34	29.82	24	40.00	63	31.82	59	30.10	38	34.23	87	29.90	56	28.00	69	34.16
GP\specialist	45	11.19	7	7.22	9	6.87	20	17.54	9	15.00	19	9.60	26	13.27	20	18.02	25	8.59	26	13.00	19	9.41
Sources that are not credible (Not evidence-based)	41	10.20	6	6.19	11	8.40	20	17.54	4	6.67	15	7.58	25	12.76	13	11.71	28	9.62	24	12.00	17	8.42
Other people's experiences/unsolicited advice	37	9.20	6	6.19	13	9.92	12	10.53	6	10.00	15	7.58	21	10.71	6	5.41	31	10.65	15	7.50	22	10.89
Not type specific (Too general)	34	8.46	9	9.28	12	9.16	7	6.14	6	10.00	15	7.58	19	9.69	9	8.11	25	8.59	20	10.00	14	6.93
Worse case scenarios	30	7.46	8	8.25	7	5.34	12	10.53	3	5.00	16	8.08	13	6.63	8	7.21	22	7.56	14	7.00	16	7.92

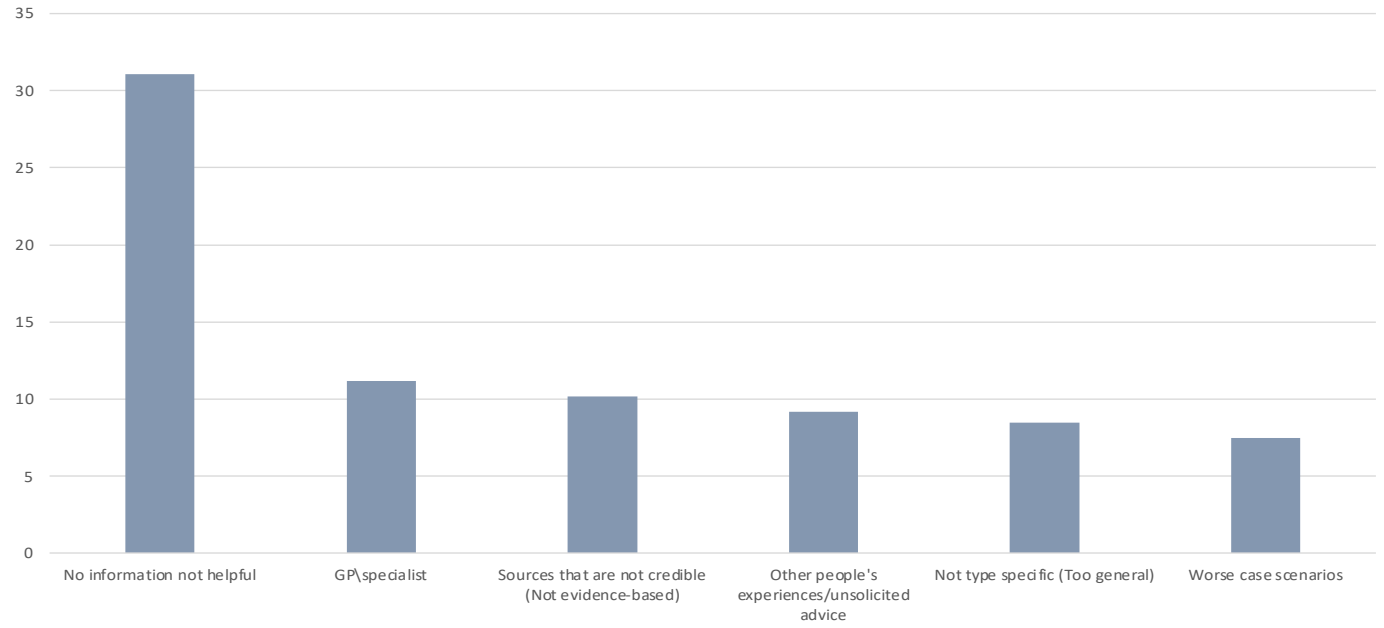


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
No information not helpful	Diseases of the immune system	Endocrine, nutritional or metabolic diseases Diseases of the immune system
GP\specialist		Diseases of the immune system
Sources that are not credible (Not evidence-based)		
Other people's experiences/unsolicited advice		
Not type specific (Too general)		
Worse case scenarios	Diseases of the nervous system Diseases of the skin	Diseases of the immune system Aged 65 plus

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 online information (29.35%),

talking to someone plus online information (23.63%), and talking to someone (21.64 %). Other themes included written information (13.68%), all forms (5.47%), and apps (2.49%).

The main reasons for a preference for online information were accessibility (27.86%), and being able to digest information at their own pace (18.41%).

The main reasons for a preference for talking to someone was being able to\have time to ask questions (18.41%), and that it was personalised (14.43%).

The main reason for a preference for written information were written information is that they can refer back to/highlight important information (3.23%).

Participant describes online information as main information preference

Well, I, I largely prefer online information because it's easily accessible, you can access it from anywhere at any time and you know, having to compare and hear from people who are first and who are first and experience about this is also helpful because the ideas and what they went through all brought together would provide a huge knowledge that can, you know, guiding the one through the process. And you know, it's easily accessible. That's it for me.
Participant 006_2023AUORC

Well, the option to talk to someone is probably limited. Yeah, quite happy to look stuff up online and read it at my leisure.
Participant 002_2023AUDPA

No, it's primarily online because I wanna know, well, there's not a lot great deal that even the like, the doctors and medical, medical people, they really don't know a great deal about it. Like my GP had to our GP had to to really look it up. The psychologist that we're seeing that my son's seeing doesn't know anything, didn't know anything about it. He and…he's had to to look it up. So it's a, you know, it's a, it's a condition that whilst it's common and it's very under diagnosed. And very few people know about it. Everyone knows about MS but nobody knows about HS.
Participant 009_2023AUDSK

Why online? Because I can access it as when I need it and nothing sort of presented. As a video or audio is much preferred than having to read because I'm with a special needs a child and I never have time to read anything, but I can get it in my headphones and put one thing. Participant 087_2023AUENM

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

I would say online is really good because you can access it 24/7 as long as you've got a good place to go. There are times when you just don't quite fit that mold or that doesn't quite add up, that it's great to be able to have someone to contact and clarify as well. For me, in-person they need to do the skin scoring and moderation and some of the clinical tests, but for the other stuff as a check-in in between, absolutely. Either phone or video; a Teams or Zoom type meeting, yes, it's really helpful.
Participant 017_2023AUDIS

And why I like to I guess online, because then I can do it in my own time. However, I really do like to talk to people about it because sometimes, especially face to face, you can sort of, you know, engage them I guess, and they can come up with. Different people have got different strategies of dealing with situations.
Participant 015_2023AUDPA

I like to be able to talk to someone because then that way I feel like I can carry on like in a flowchart kind of manner during the conversation, whereas if talking to someone online, you only ask a question and get a couple of different answers. With talking, it's a lot easier to branch to something else that's relatable or whatever. I do prefer it that way. If I'm wanting to do my own research, I do like the fact that I can look up stuff online as things pop into my head and I need to research. Probably a bit of both of those two.
Participant 040_2023AUDIS

Talking to someone if they're a specialist because the interaction back and forth to ask questions is helpful. Being able to access stuff online is convenient, provided you know the source and can interrogate that. Booklets in general are only useful for very high-level information, and I feel like I'm well past needing high-level information on things because I acquired that ages ago. If I have questions now, it's far more specific things that you won't find in the books.
Participant 067_2023AUDPA

Participant describes talking to someone as main information preference

Prefer. I actually prefer to be able to sit and talk with the doctors and nurses and that and then secondary to that would be information booklets that you can take away. But generally I'll just have the conversation and that's. That's enough for me to get what I feel I need to know. Participant 007_2023AUORC

I can't…I don't really have a preference. I think they all have their place. I mean, you can do research at any point in time, online or paper, you know, books or anything you know. But again, I don't think anything beats face to face. I think that or just talking to someone on the phone.
Participant 078_2023AUDIS

I would prefer face to face with with somebody that understood the condition and displayed a level of of competency around it that that, you know, that gave me reassurances and, and yeah, some, yeah, some empathy. I can't get that online. Yeah.
Participant 027_2023AUORC

Participant describes written information as main preference

I like something that I can read and that way I can refer back to it later. So if the doctors can e-mail me or send me a pamphlet or something like that. And then I would prefer that then face to face or in person just so I can refer back to it.
Participant 013_2023AUORC

Why I like I'm an old person, older person, so I like the physical booklets so I can read and highlight and go back and read again. I'm not a very clever learner online or reader online. I think it's all to do with our upbringing, I think. Even though I do do it, don't get me wrong, because I'm a researcher, I actually advocate and I do lots of research so I can do it. But personally, when like PATIENT's plan, I want to see every single therapy report in paper so I can read it, highlight it and you know, and that's the way I work. Whereas I don't find highlighting it online easy. So gaining it online. I find it. I do look online, but I always print it out. So and talking to families, of course it's great to talk to families, but for us it's not beneficial because PATIENT is so much worse than them. So I can help them, but they can't really help me. Does that make sense?
Participant 06_2023AUDPA

The booklets that they put out from Scleroderma Australia, they just have them online. I find them somewhat helpful. They give a little a broad scope of questions and answers. Not in-depth enough if it's actually happening to you, but sometimes that led me to being able to educate the doctors, "Look, this is what's they've said in the booklet, can we go further?" Sometimes it's led the conversation a bit better.
Participant 014_2023AUDIS

Participant describes prefering all forms of information

PARTICIPANT: All of the above. Everyone takes things in differently and sometimes you need to read it and see it and hear it five different ways for it to sink in because we are working in an area where there's not just one issue.
INTERVIEWER: Yep. Very good point.
PARTICIPANT: The thing is different personalities. Some people take it by diagram. Some people hear it, some people need it in paper.
Participant 092_2023AUENM

I don't have a preference because part of my pacing strategy is breaking things up into little bits and different things. I can't do too much of any one thing. I try not to preference in fact.
Participant 041_2023AUDPA

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 032_2023AUORC

Participant describes apps as main information preference

I guess. Maybe just like, yeah, phone apps are easy to use because I'm so used to doing it anyway. But I guess talking to someone is easier as well because then they can explain it to you. So yeah.
Participant 014_2023AUDSK

And why I prefer online and apps because I like to read things in my own time. I want them though, I want them to be from accredited sources. So for instance with this condition I, I like the fact that there's an international body and and also a body of professionals for this particular condition that are putting the information down the line. The problem is in that area, the professionals in, in our country and not adopting them, adopting these, So yeah, so that would be it. Online, I love it. Online and apps, I love apps.
Participant 025_2023AUDPA

Table 6.7: Information preferences

Information preferences	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Online information	118	29.35	16	23.88	29	35.80	26	27.37	11	34.38	29	30.53	7	21.88	83	30.97	35	26.12	90	30.61	28	26.42
Talking to someone plus online information	95	23.63	14	20.90	21	25.93	20	21.05	9	28.13	18	18.95	13	40.63	64	23.88	31	23.13	70	23.81	23	21.70
Talking to someone	87	21.64	5	7.46	16	19.75	25	26.32	4	12.50	31	32.63	6	18.75	68	25.37	19	14.18	66	22.45	21	19.81
Written information	55	13.68	7	10.45	17	20.99	11	11.58	5	15.63	10	10.53	5	15.63	43	16.04	12	8.96	46	15.65	9	8.49
No strong preference	24	5.97	1	1.49	2	2.47	7	7.37	1	3.13	11	11.58	2	6.25	18	6.72	6	4.48	16	5.44	8	7.55
All forms	22	5.47	4	5.97	3	3.70	5	5.26	2	6.25	5	5.26	3	9.38	15	5.60	7	5.22	18	6.12	4	3.77
Apps	10	2.49	2	2.99	4	4.94	0	0.00	1	3.13	3	3.16	0	0.00	8	2.99	2	1.49	9	3.06	1	0.94

Information preferences	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Online information	118	29.35	23	23.71	38	29.01	36	31.58	21	35.00	58	29.29	58	29.59	35	31.53	83	28.52	66	33.00	52	25.74
Talking to someone plus online information	95	23.63	24	24.74	31	23.66	30	26.32	10	16.67	47	23.74	47	23.98	26	23.42	69	23.71	42	21.00	53	26.24
Talking to someone	87	21.64	14	14.43	31	23.66	28	24.56	14	23.33	46	23.23	39	19.90	18	16.22	69	23.71	39	19.50	48	23.76
Written information	55	13.68	8	8.25	18	13.74	16	14.04	13	21.67	25	12.63	30	15.31	15	13.51	40	13.75	28	14.00	27	13.37
No strong preference	24	5.97	3	3.09	6	4.58	10	8.77	5	8.33	10	5.05	13	6.63	6	5.41	18	6.19	11	5.50	13	6.44
All forms	22	5.47	5	5.15	9	6.87	6	5.26	2	3.33	11	5.56	11	5.61	6	5.41	16	5.50	12	6.00	10	4.95
Apps	10	2.49	0	0.00	7	5.34	3	2.63	0	0.00	7	3.54	3	1.53	5	4.50	5	1.72	6	3.00	4	1.98

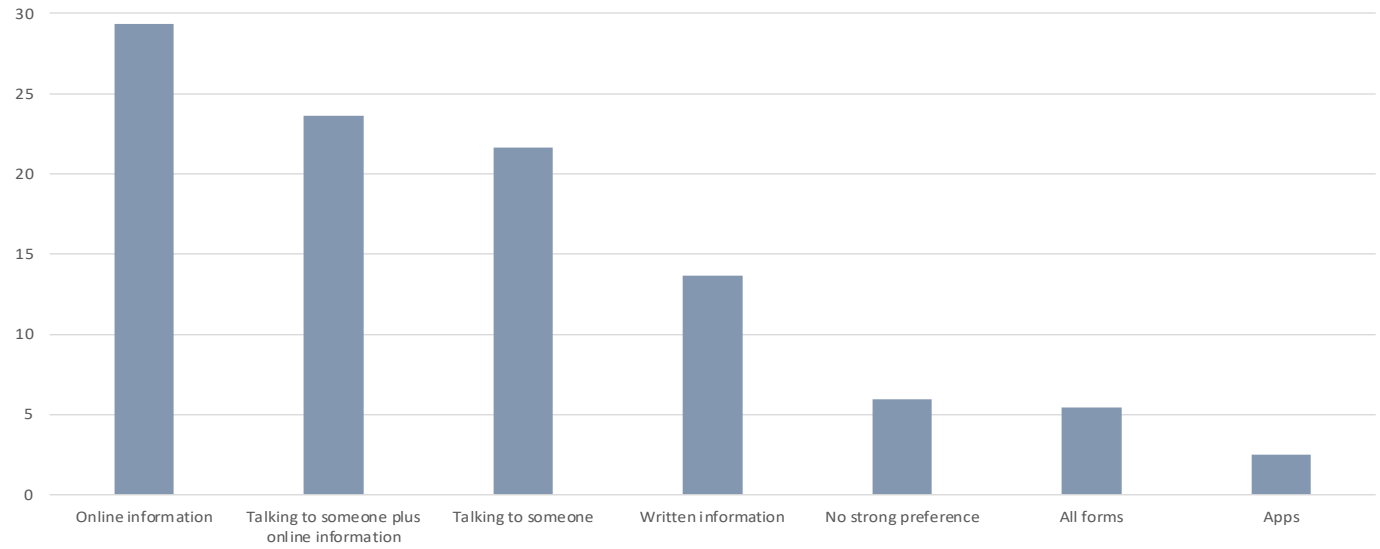


Figure 6.4: Information preferences

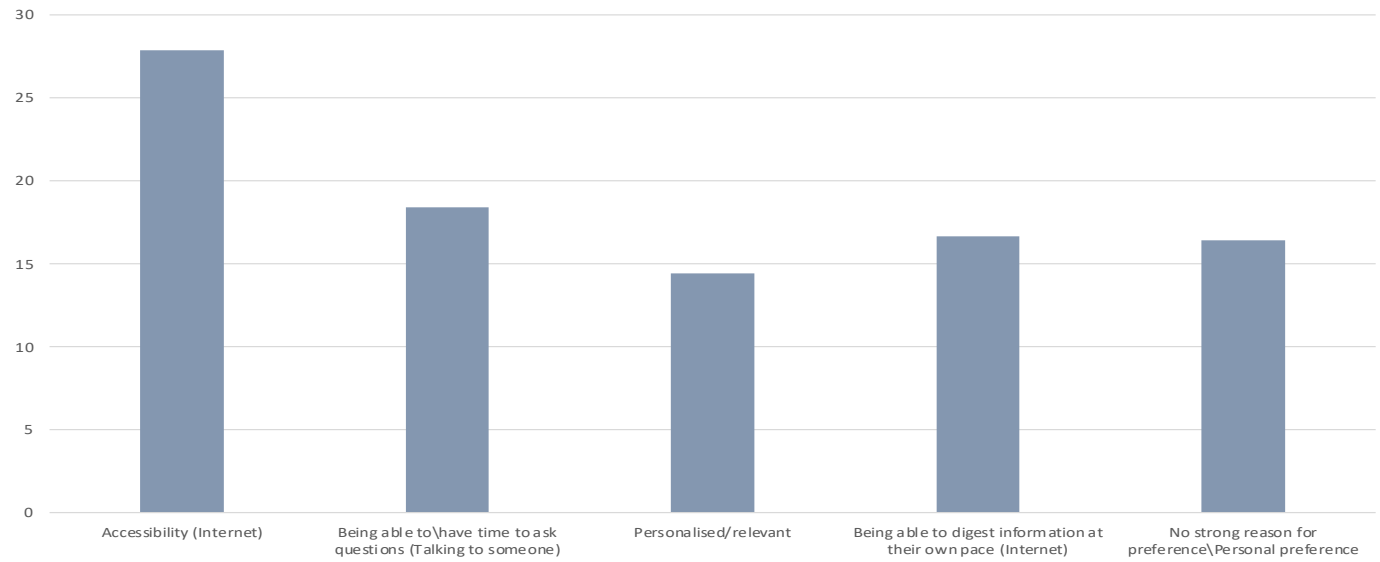


Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Online information		
Talking to someone plus online information		
Talking to someone		
Written information		
No strong preference		Other rare condition
All forms	Developmental anomalies	Endocrine, nutritional or metabolic diseases
Apps		

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) (31.34%), continuously (19.65%), after the shock of diagnosis (12.44%) and 12 months or more after diagnosis (10.70 %).

Participant describes being receptive from the beginning (diagnosis)

Yeah, that's a really good question and I'm actually glad you asked, just cuz I was speaking to someone about this yesterday and I think, and it's related to my own, obviously my diagnosis, I don't think you necessarily give someone too…there can be too much information at the point of diagnosis. Like I, for the record, I mean this course is a record, but you know, I still maintain that I wasn't given enough information when I was when I was diagnosed.
Participant 011_2023AUORC

I'd say probably in the like month leading up to the diagnosis. It's when I thought I was pretty sure of what I had and I was just hungry for information. I was, you know, taking on any little snippet that I could find really heavily reading into things. So kind of a month leading up to my diagnosis and probably around that time, month after I'd say as well it's kind of settled down now.
Participant 027_2023AUDSK

Yeah, that's a great question. Obviously, initially, you know, you're trying to take as much information in and you need that information to try and understand when it's a rare disease because there's nothing, you can't really find anything. But at the same time your ability to absorb that information is really impaired. I would say at the very beginning it's really important because then you can kind of pace that information out if you're having a moment where you can understand it. But also, you know, when you're able to do a lot of self-directed research, you're open to the idea of receiving that information which will be at different times for different people depending on their processes, you know, how they cope with the information and grieving and all of that sort of stuff. So I would just say throughout, throughout the whole journey, like when my brain's working probably.
Participant 021_2023AUORC

All of information straight away-- I didn't share what was going on with many people but I wanted the information straight away. I wanted to know everything. Actually, that was when I found it best to talk to someone because you could ask specific questions.
Participant 065_2023AUDPA

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

Well, when someone had something decent to say. So anytime, anytime's a good time if it's helpful, if if they want to experiment, I'm fine with that too. You go for your life. It's going to work great if trial and error, so I'm always just have to do it. If someone's got a solution and you give it your best shot, go for it.
Participant 006_2023AUDIS

I think I've always been able to take the information in it's just been a lack of information more than anything, my parents were warned apparently when I was first diagnosed not to research it on their own because it was so broader disease that it would freak them out. Just stick to the…your fingers freeze, and don't smoke.
Participant 014_2023AUDIS

I have been fairly receptive to all along. I've just, I've wanted to know as much as I can. Yeah, yeah. I guess. I think at diagnosis I could have done with a whole lot more information than we were given, rather than having to go and find it myself.
Participant 021_2023AUDPA

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

Probably within the last year or two. I mean, I would have been diagnosed around four years ago. And I mean, it took a year. I was literally in tears about it for because this wasn't a sebaceous cyst anymore. This wasn't, do you know what I mean? Like, this was, this was serious, this was bad. This is not just gonna go away. And the doctors don't even know how to help you. So, you know, it was pretty upsetting. And yeah, I was pretty depressed about it because I was just like, what do I do? Like, there's nothing to do. Like, yeah. So yeah, I was pretty depressed about it.
Participant 006_2023AUDSK

Probably after like after about 18 months when it was out of major grief and is she going to die?
Participant 087_2023AUENM

Oh, probably in one to two years after diagnosis, because it all happened when her baby was born and it was life and death. Whether this baby would get through and she had massive heart surgeries, tube feeding, everything was just about the baby. It was only after that. That I could really sit back and say, yes, my daughter has has some. To George, now's my time to find out more about it. All right. If we hadn't had the baby born, I probably would have been on to it, you know, much sooner.
Participant 08_2023AUDPA

Participant describes being receptive to information after the shock of diagnosis

Yeah, I think, I think you want all the information at the beginning, but it's extremely overwhelming. So I think it was good that you sort of need a bit more time. So we definitely, I definitely like went back and saw like every time. You'd go back, you'd ask more questions or different questions. Yeah. So I'd say the first like probably the first three or four months after diagnosis look like, like I probably received a lot of information. I don't know if I took it all in properly. There's probably a little bit after that that you really need like continued access to it because eventually you, you know, you can move past the kind of initial stress of diagnosis and then you can. Sort of deal with the next step, yeah, okay.
Participant 079_2023AUDIS

Yeah, it's a good question. Definitely not within the first few days when we did receive most of the information that was really hard. We were to we were so overwhelmed with his diagnosis, it was impossible for me to focus on the info that we were being given by the team as like they're doing their best. But we just went in a position to be able to absorb all at that point. So I think it took us maybe nearly a week before we got over the shock of it all and were able to actually start to read the information with clear heads.
Participant 029_2023AUORC

Probably a couple of weeks after he was diagnosed. Because it was although we were reading it, it was finally then I really absorbed it because I could sit down calmly. Even now I still go back and re-read stuff I've read a hundred times and pick up different things and see it differently. A while after diagnosis I was able to absorb everything, I think.
Participant 048_2023AUDPA

Participant describes being receptive to information when emotionally and physically able to take in the information (eg when not having symptoms)

Probably when I started feeling a bit less fatigued and was a little less worried. You know, about the more serious outcomes. So once I wrap my head around what that actually looked like and that, yeah, and that I was starting to feel better than I was more able to process more information. Whereas when you like to people sometimes because you just got that time right there and duty of care and so on and so forth and they throw a lot of information at you, it's really hard to process that because you're processing the oh, there's actually something wrong in the moment.
Participant 024_2023AUDIS

Look at the beginning. It was very emotional I guess, you know, thinking that yeah, I've just had a child who now has this condition. Personally, I have a lot going on. I have a 15 month old daughter as well and my mum passed away like two days after she was born. So I you know, and my pregnancy was not planned, I guess. Not that we regretted in any way at all, but so I guess, you know, I was still grieving, but I was excited, you know, to have another baby. But then you know, this information bombarded us as well. Yeah, so definitely the beginning was the hardest and not knowing anything and not knowing anyone. You could sort of just talk to and not knowing, not having a clear answer I guess on you know she's got this condition you know and surgery would fix that sort of thing like whereas now, I'm more you know let's just go along and see what happens and when we come across it we'll we'll fix it. So I guess now I'm feeling, you know, not more supported, but more willing to take on the information, I guess.
Participant 034_2023AUDPA

Definitely not initially. The spectrum of possible things that could happen I found completely overwhelming and very scary. I don't even know how I logged on to the website, initially. I was very different to my husband. My husband wanted to know everything about it right away, whereas I didn't. I had to have a number of counselling sessions to get to a place where I had accepted the diagnosis. It was really only at that point where I could invite more information about it in. At what point was that? Maybe six months after the diagnosis. By the time she turned two just over a year after the diagnosis I was comfortable with it but maybe between six months up to eighteen months. Six months to twelve months, yes.
Participant 061_2023AUDPA

Participant describes being receptive to information during adolescence or adulthood (once they appreciated their personal responsibility for health)

You should answer this one. This is a good one for you. As remember we were talking about how you weren't interested and then all of a sudden you started becoming interested and you booked wanting to know the information that was being talked about. So, so how long ago was that do you think? So you're 20, I think 24, it was May, it was maybe 2014/2015. So I think I would have been 16 or 17 or 20, but anyway, but it was like this is I was leaving school, so whatever at age.
Participant 037_2023AUDPA

Participant describes being receptive to information when condition changes or there are new symptoms

Took a lot of information in when we got the, yeah, in the early, you know, days, there was a lot of lot of stuff to look at. There were a lot of medical interventions that needed to be addressed and checked. And also, being a child, you know, I was very, you know, wanted to make sure that we were getting whatever I could to help her along the way. I'm always open to getting information now, but I must admit I'm at a stage of quite a lot of fatigue and so tend to respond to things as they happen and I need to. And there's always there's a whole pile of things there that I want to read one day that you need to have some time out to yourself. So I haven't sat and done that cuz I'm too exhausted. But there was nothing. I was just gonna say I've lost it now, but anyway.
Participant 038_2023AUDPA

Well, I think when something changes in me or the condition, I sort of, I don't know what which it is exactly. It's sometimes it's hard to pinpoint, but yeah, when there's a change. To see change anyway, whether it's good or bad.
Participant 005_2023AUDNS

Participant describes being receptive to information five to six months after diagnosis

I think it would mean after a good few months, like four or five months before they before I'd kind of accepted it enough to hear what was being said. I suppose in the beginning, once something becomes too overwhelming, you shut off. You stop listening, you just can't hear it anymore. So after a few months, then like a few like Doctor visits and hearing it over and over again, it become easier to accept and then digest what was being said. Yeah?
Participant 025_2023AUORC

Probably three to six months after her diagnosis. I think once you accept it and you, you know, sort of get on with life, yeah, you stop that crisis management, then you become more receptive to it. And I think it also depends on the medical team you're working with. If you still, if you feel heard and listened to, I think it makes it easier to absorb the information. Because I do know a couple of times going into the neurologist that I was so focused on what I wanted to find out, that I wasn't really listening to what he was saying. Yes. Yeah. So you're right. Having those channels to follow up informally, the thing that I found really frustrating was trying to, you know, you confine to appointment times and sometimes you have a question that you don't need a whole appointment for, but you just need to clarify something.
Participant 090_2023AUENM

That's a good question because when you're in the full blown pots, 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 031_2023AUORC

Participant describes being receptive to information more than 6 months, less than 12 months after diagnosis

I that's tricky. I think definitely initially when she was diagnosed and stuff, I definitely wasn't in the right headspace to take on the information and understand it fully. But I think as she got older, probably from, you know, that 6 to 8 month mark when things started to calm down a little bit more. I was probably more proactive myself, trying to find out what this all

actually meant and what it meant for her for the future and what it was going to mean for us going forward. Participant 027_2023AUDPA

When do I feel like? Probably just more recently. Yes, it's probably around six, well, more than six to ten months. I think I needed to come to accepting the diagnosis first before receiving any more information. Participant 059_2023AUDNS

Definitely not in the first couple of weeks because it was all just overwhelming, and I was I guess in shock about it. Probably anywhere from six months onwards it started to sink in a bit, and I was able to take it all in and like, this is where we need to go, this is what we need to do now.
Participant 060_2023AUDPA

Participant describes being receptive to information two months after diagnosis

I mean, I didn't really think in what I had until. At least two months after I was diagnosed. I heard the doctor. I heard what he was saying. I'm like, great. So I have to have this for the rest of my life. Like there's no cure for it. That's when it sunk in. Like, damn, you can't fix me.
Participant 003_2023AUENM

Look, I'd probably say in the in the couple of months, proceed like following. The diagnosis was when I was really looking for information. Yeah, I I know I would have. Yeah, I suppose I would have liked to have had the confidence to act on that a bit sooner too, because it might not have gotten in the stage it did.
Participant 007_2023AUDSK

Probably sort of now. I only found out two months ago maybe... And I think I was just so angry that I hadn't actually been told formally that I had it. And now that they've confirmed it and I've started doing my own research, I think I'm sort of interested to learn as much as I can.
Participant 096_2023AUDNS

Table 6.9: Timing of information

Timing of information	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
At the beginning (diagnosis)	126	31.34	21	31.34	24	29.63	31	32.63	10	31.25	32	33.68	8	25.00	81	30.22	45	33.58	95	32.31	31	29.25
Continuously	79	19.65	21	31.34	16	19.75	7	7.37	11	34.38	16	16.84	8	25.00	53	19.78	26	19.40	54	18.37	24	22.64
Combined minor themes	59	14.68	10	14.93	10	12.35	12	12.63	6	18.75	12	12.63	9	28.13	42	15.67	17	12.69	44	14.97	15	14.15
After the shock of diagnosis	50	12.44	11	16.42	7	8.64	15	15.79	0	0.00	10	10.53	7	21.88	24	8.96	26	19.40	34	11.56	16	15.09
12 months or more after diagnosis	43	10.70	14	20.90	15	18.52	5	5.26	3	9.38	2	2.11	4	12.50	29	10.82	14	10.45	30	10.20	12	11.32

Timing of information	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
At the beginning (diagnosis)	126	31.34	31	31.96	43	32.82	37	32.46	15	25.00	57	28.79	67	34.18	36	32.43	90	30.93	57	28.50	69	34.16
Continuously	79	19.65	18	18.56	28	21.37	21	18.42	12	20.00	39	19.70	40	20.41	25	22.52	54	18.56	45	22.50	34	16.83
Combined minor themes	59	14.68	14	14.43	13	9.92	25	21.93	7	11.67	30	15.15	29	14.80	21	18.92	38	13.06	33	16.50	26	12.87
After the shock of diagnosis	50	12.44	22	22.68	13	9.92	10	8.77	5	8.33	23	11.62	25	12.76	14	12.61	36	12.37	24	12.00	26	12.87
12 months or more after diagnosis	43	10.70	10	10.31	13	9.92	14	12.28	6	10.00	25	12.63	18	9.18	10	9.01	33	11.34	22	11.00	21	10.40

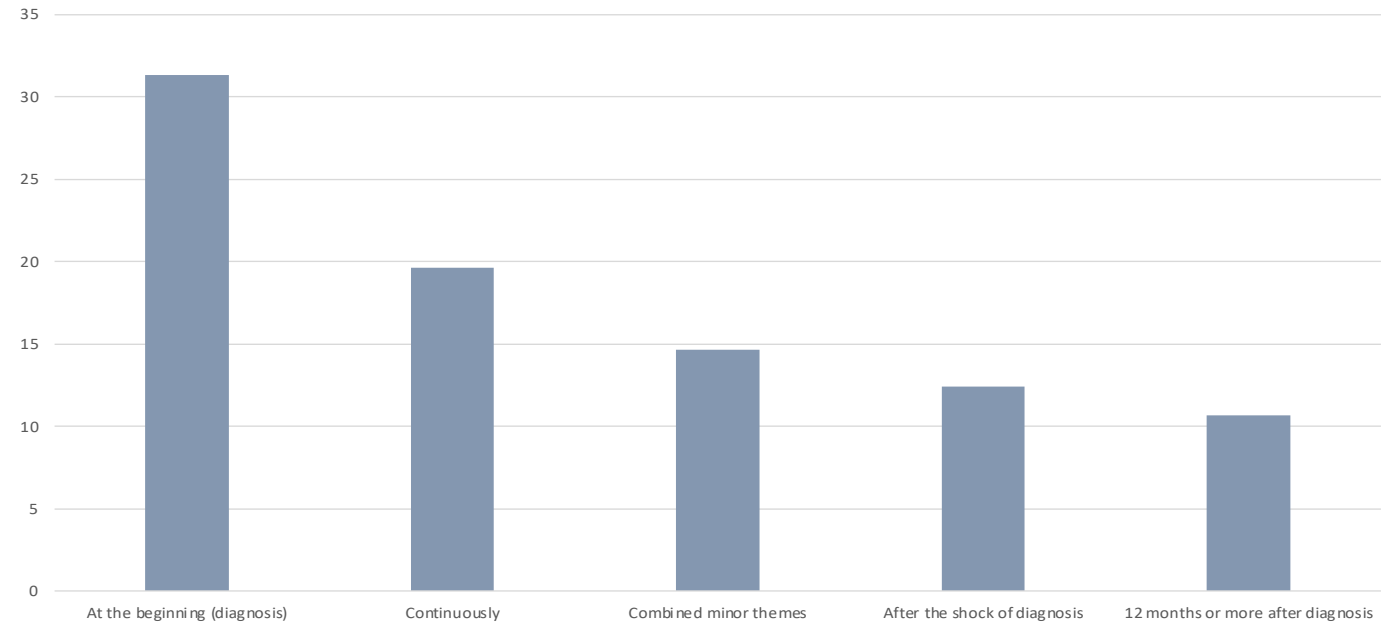


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
At the beginning (diagnosis)		
Continuously	Diseases of the nervous system	Developmental anomalies Diseases of the skin
Combined minor themes		Other rare condition
After the shock of diagnosis	Diseases of the skin	Aged under 18
12 months or more after diagnosis		Developmental anomalies

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative (34.83%), overall positive(26.62%), and overall positive, with the exception of one or two occasions (24.63%).

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

Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (28.36%).

Participants that had negative communication, described the reason for this was because there were limits in understanding (33.33%), because of and dismissive (One way conversation) (16.42%). Other themes included limited in relation health professionals not having a lot of time (8.46%).

Participant describes communication with healthcare professionals as overall negative

Yeah, that there wasn't the communication wasn't great. Like I said there was a you know earlier in the interview there was there's basically a 10 year…where this is just ignored any even. Yes there was an actual medication available but there was still like treatment. There was treatment plans and and medical care that could have been provided. As far as counseling or just lifestyle stuff I kind of needed to know. So yeah, I'd say it is not not been very good.
Participant 011_2023AUORC

Crap, not good. Like costed hundreds of dollars to see the dermatologist and I think he spent about 9-9 to 10 minutes with me. Probably not even 10 minutes. Like, literally, like, just looked at me in and out because he's in demand and he's got a whole bunch of stuff going on. And other than that, the doctor, you know, if I'm like, oh, this is really bad, like, he doesn't want to have a look, he'll take my word for it.
Participant 006_2023AUDSK

Inadequate. I really felt that most of the time I was driving the understanding research, how to get help, who to get help from, what to do from professionals and that they would sort of. Not explain things like I was intelligent enough to like absorb the information. Yeah, and and therefore would miss things out and and not give me full picture.
Participant 087_2023AUENM

Yeah, very limited. And I have to say before we were diagnosed, there were some medical professionals who probably wasn't convinced of my concern. So yeah.
Participant 094_2023AUENM

Limited, I would say the pediatrician, you know, you get a small window every six months, so that's you know well, that's pretty much with all specialists. You just don't get their time. You just don't and you can't access them. In between, it's very difficult to communicate with them. In between the assigned appointments that you're given, yeah. So I, I feel like a lot more on researching information, finding information, going to them and talking about rather than the other way around
Participant 095_2023AUENM

Participant describes communication with healthcare professionals as overall positive

Brilliant. The Doctors are fantastic. Yeah. Any questions I've got that more than happy to ask, even if I ring up, but you know, short notice kind of thing that they're really good.
Participant 032_2023AUDSK

Yeah, really good. His team is great. We've got a phone number that we can call or text anytime 24/7 if we have any questions and we get responses straight away. And yeah, as I said earlier that every time we meet with his team and we've got questions, they've always been really, they've been really clear with this and able to answer everything that we've come to them with.
Participant 029_2023AUORC

It's been very good. The the pediatrician was very knowledgeable so was able to help. It was very good, but he said read it, that that she's not going to get all of that. That's just what could happen. You're best to just yeah, take it as it comes. And the doctor, our GP is very good. Whenever we need something, he's happy to to delve in and help with that or refer.
Participant 010_2023AUDPA

Oh, gosh, I couldn't speak highly enough of them. They're wonderful. Every person I've contacted with has has been, oh, they've been explicit but but kind. And I couldn't fault them. They were scientific, as I need them to be. And then at other times they're practical. Yeah. No, it's very good.
Participant 019_2023AUDPA

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

In general it's been good. When it's somebody, I guess you know, being especially with Doctor NAME has been a really good experience. The surgeon prior wasn't was pretty good. It's more when it's somebody new, especially GP's wise or yeah, doctors that I've met through ED and that sort of thing. That's when I think. I've had the most negative experiences and it's been the most difficult, yeah.
Participant 022_2023AUDSK

I mean just very, very mixed, I think. When we've in general, when we've talked to people who are knowledgeable about it, it's quite positive. Yeah, it's quite positive and there's a lot that we've been able to learn. Yeah, I guess in general, quite positive. I think maybe there's more negative or confusing experiences have been with people who maybe don't know as much about CHARGE syndrome as a whole and they're more just focusing on the their smaller specialty. Yeah, I think, yeah, generally generally positive with most people who have had. With charge syndrome with health professionals.
Participant 089_2023AUENM

Well, that depends. Yeah. So once once I got a diagnosis, it was all really positive. The people that I have seen since then, I have been really good at communicating. Yeah, with the exception of one Doctor, he was quite a junior doctor. It was when the pandemic started and everyone was all over the place. And I did. I did do a phone appointment for that. And he didn't seem to know like the last year about the COVID vaccines and priority groups and all of those kinds of things. And he didn't seem to have any of the answers that I was looking for. But I like I said, I don't think he was. I think he was just kind of put in to the position to to do the cause. But

yeah, on the whole. Yeah, on the whole, really positive. And the same with the maternity doctors. People are pretty upfront about saying, you know, if they don't know anything and they've not heard of scleroderma, but also that they're going to go and consult with more senior people and come back for answers and things like that, which is which is good.
Participant 024_2023AUDIS

Some are good, some are not so good. Some medical professionals go above and beyond for us to explain things and make sure she's getting the right level care and things like that. Others, they can be quite dismissive because it's not, especially with the duplication, a lot of doctors, when you go into a new specialist, they're just like, 'Oh yeah, it's the it's the deletion' or they'll be like, 'oh, it's not as bad, it's the deletion. So you probably don't need help'. So it was a matter of finding our right team, which did take about five years to get it all the right people in there. So some of it's been really good and some of it has not.
Participant 032_2023AUDPA

Overall, great. Like my last cardiologist is amazing. She's been really, really good right back in the beginning. The cardiologist that I saw when I was first admitted to hospital weren't weren't really very nice. I didn't like them anywhere as much as my second and third cardiologist.
Participant 032_2023AUORC

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Overall negative	140	34.83	18	26.87	33	40.74	41	43.16	12	37.50	25	26.32	11	34.38	103	38.43	37	27.61	113	38.44	27	25.47
Overall positive, with the exception of one or two occasions	107	26.62	14	20.90	21	25.93	22	23.16	9	28.13	31	32.63	10	31.25	73	27.24	34	25.37	80	27.21	25	23.58
Overall positive	99	24.63	6	8.96	22	27.16	25	26.32	6	18.75	32	33.68	8	25.00	73	27.24	26	19.40	66	22.45	33	31.13

Healthcare professional communication	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher statu	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Overall negative	140	34.83	21	21.65	62	47.33	39	34.21	18	30.00	80	40.40	59	30.10	35	31.53	105	36.08	75	37.50	65	32.18
Overall positive, with the exception of one or two occasions	107	26.62	24	24.74	29	22.14	37	32.46	17	28.33	45	22.73	59	30.10	36	32.43	71	24.40	53	26.50	54	26.73
Overall positive	99	24.63	23	23.71	24	18.32	30	26.32	22	36.67	50	25.25	48	24.49	22	19.82	77	26.46	45	22.50	54	26.73

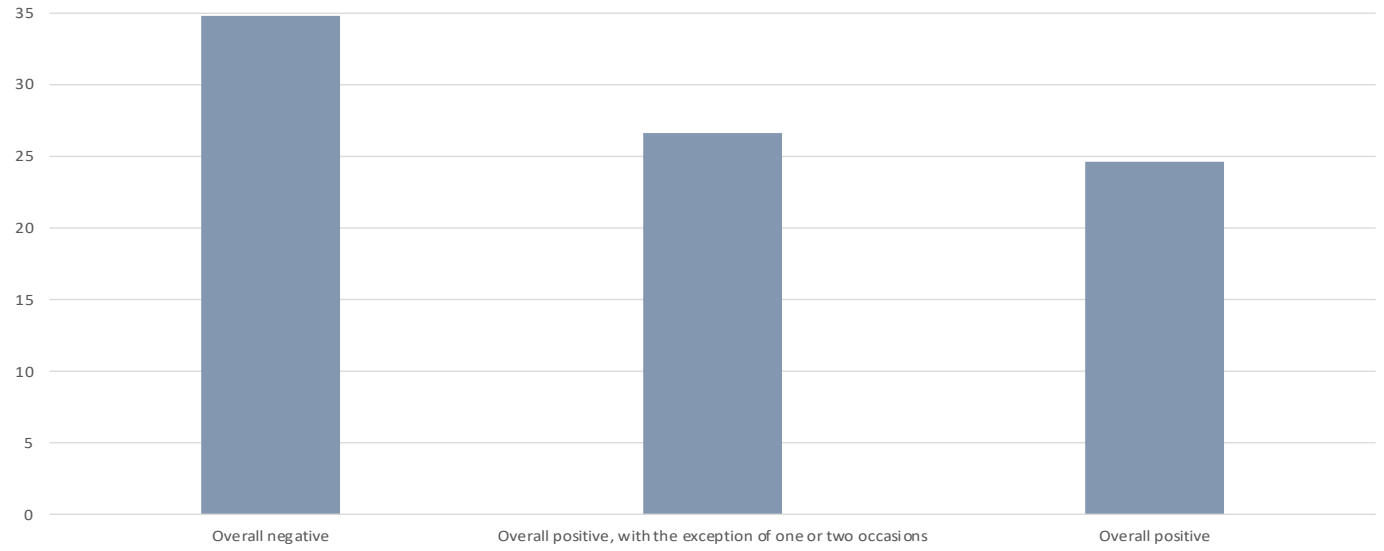


Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Overall negative	Aged under 18	Aged 18 to 44
Overall positive, with the exception of one or two occasions		
Overall positive	Developmental anomalies	Aged 65 plus

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (reasons)	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Limited in understanding	134	33.33	20	29.85	38	46.91	30	31.58	13	40.63	27	28.42	6	18.75	96	35.82	38	28.36	109	37.07	24	22.64
Holistic (Two way, supportive and comprehensive conversations)	114	28.36	14	20.90	16	19.75	38	40.00	8	25.00	28	29.47	10	31.25	72	26.87	42	31.34	84	28.57	29	27.36
Dismissive (One way conversation/not empathetic)	66	16.42	10	14.93	19	23.46	16	16.84	3	9.38	11	11.58	7	21.88	49	18.28	17	12.69	52	17.69	14	13.21
Limited in not having time	34	8.46	5	7.46	9	11.11	8	8.42	1	3.13	6	6.32	5	15.63	25	9.33	9	6.72	26	8.84	8	7.55

Healthcare professional communication (reasons)	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Limited in understanding	134	33.33	23	23.71	41	31.30	47	41.23	23	38.33	72	36.36	59	30.10	37	33.33	97	33.33	67	33.50	67	33.17
Holistic (Two way, supportive and comprehensive conversations)	114	28.36	35	36.08	32	24.43	29	25.44	18	30.00	49	24.75	63	32.14	30	27.03	84	28.87	58	29.00	56	27.72
Dismissive (One way conversation/not empathetic)	66	16.42	10	10.31	33	25.19	17	14.91	6	10.00	33	16.67	33	16.84	16	14.41	50	17.18	35	17.50	31	15.35
Limited in not having time	34	8.46	7	7.22	11	8.40	13	11.40	3	5.00	19	9.60	15	7.65	7	6.31	27	9.28	18	9.00	16	7.92

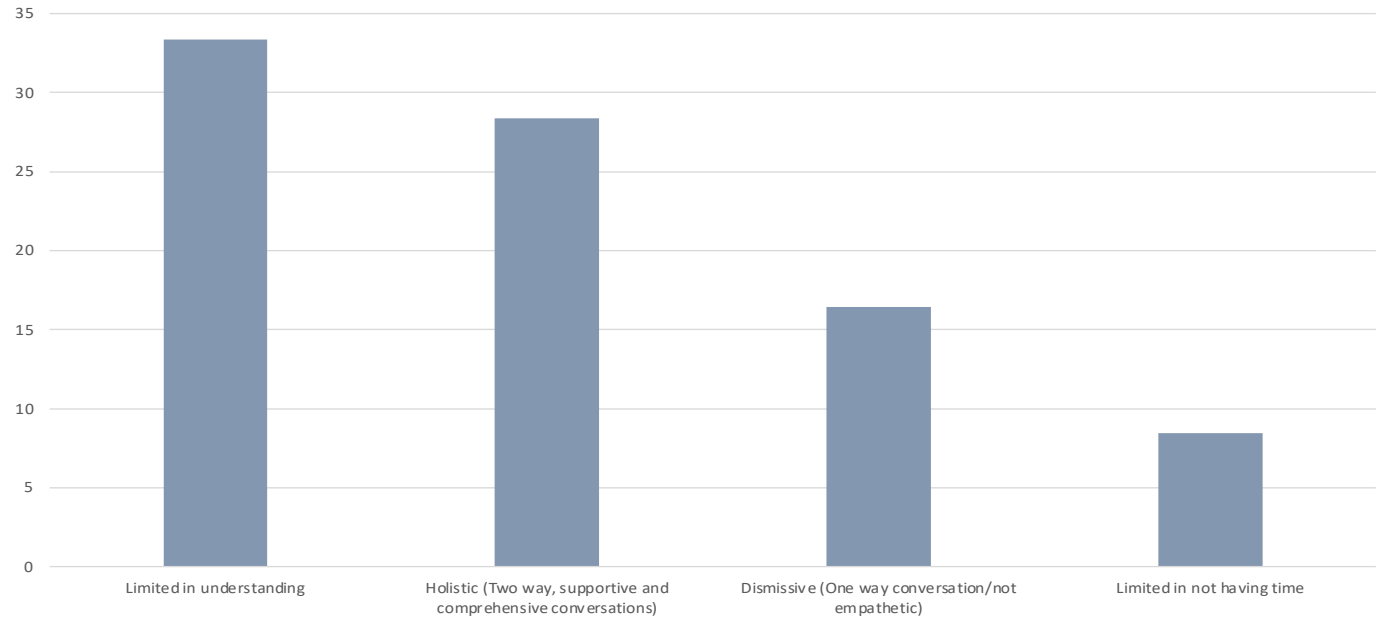


Figure 6.8: Healthcare professional communication (Rationale for response)

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

Healthcare professional communication (reasons)	Reported less frequently	Reported more frequently
Limited in understanding	Other rare condition Male	Diseases of the immune system
Holistic (Two way, supportive and comprehensive conversations)		Diseases of the nervous system
Dismissive (One way conversation/not empathetic)		
Limited in not having time		

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=26.00, IQR=8.00), Partners in health: Adherence to treatment (median=14.00, IQR=4.00), indicating very good knowledge, very good adherence to treatment.

The overall scores for the cohort were in the second highest quintile for Partners in health:Recognition and management of symptoms (median=19.00, IQR=5.75), Partners in health:Total score (median=72.00, IQR=20.00) indicating good recognition and management of symptoms, good overall ability to manage their health.

The overall scores for the cohort were in the middle quintile for Partners in health:Coping (median=14.00, IQR=7.00), indicating moderate coping.

Comparisons of Partners in health have been made based on condition, participant type, gender, age, education, 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 moderate 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 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=362)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	24.07	6.24	26.00	8.00	0 to 32	5
Coping	14.35	5.39	14.00	7.00	0 to 24	3
Recognition and management of symptoms	18.89	3.66	19.00	5.75	0 to 24	4
Adherence to treatment	13.12	3.18	14.00	4.00	0 to 16	5
Total score	70.44	14.39	72.00	20.00	0 to 96	4

Skewed distribution use median and IQR as measure of central tendency

Partners in health by condition

Comparisons were made by **condition**. There were 57 participants (15.75%) with developmental anomalies , 72 participants (19.89%) with diseases of the immune system , 93 participants (25.69%) with diseases of the nervous system , 29 participants (8.01%) with diseases of the skin , 86 participants (23.76%) with endocrine, nutritional or metabolic diseases , and 25 participants (6.91%) with other rare condition.

Assumptions for normality of residuals was not met, a Kruskal-Wallis test was used. Post hoc pairwise comparisons using Wilcoxon rank sum test was used to

identify the source of any differences identified in the Kruskal -Wallis test.

A Kruskal-Wallis test indicated a statistically significant difference in the **Partners in health: Knowledge scale** between groups, $\chi^2(5) = 11.38$ $p = 0.0443$. However, post hoc comparisons using the Tukey HSD test did not indicate any significant differences between groups.

A Kruskal-Wallis test indicated a statistically significant difference in the **Partners in health: Coping** scale between groups, $\chi^2(5) = 12.86$ $p = 0.0247$.

The largest significant difference was between participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 15.00, IQR = 6.00), and participants in the Diseases of the skin subgroup (median = 11.00, IQR = 6.00, $p = 0.0160$).

A Kruskal-Wallis test indicated a statistically significant difference in the **Partners in health: Adherence to treatment** scale between groups, $\chi^2(5) = 12.99$ $p = 0.0235$. The largest significant difference was between participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 15.00, IQR = 3.00), and participants in the Diseases of the skin subgroup (median = 12.00, IQR = 7.00, $p = 0.0097$).

A Kruskal-Wallis test indicated a statistically significant difference in the **Partners in health: Total score scale** between groups, $\chi^2(5) = 12.64$ $p = 0.0270$. The largest significant difference was between participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 73.00, IQR = 13.00), and participants in the Diseases of the skin subgroup (median = 61.00, IQR = 16.00, $p = 0.0055$).

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 the Diseases of the immune system subgroup scored higher than participants in the Diseases of the skin subgroup. This indicates that participants in the Diseases of the immune system subgroup had very good knowledge about their condition and treatments, and participants in the Diseases of the skin subgroup had good knowledge.

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 Endocrine, nutritional or metabolic diseases subgroup scored higher than participants in the Diseases of the skin subgroup. This indicates that participants in the Endocrine, nutritional or metabolic diseases subgroup were good at coping with their condition, and participants in the Diseases of the skin subgroup were average at coping.

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 the Endocrine, nutritional or metabolic diseases subgroup scored higher than participants in the Diseases of the skin subgroup. This indicates that, treatment adherence was very good for participants in the Endocrine, nutritional or metabolic diseases subgroup, and good for participants in the Diseases of the skin subgroup.

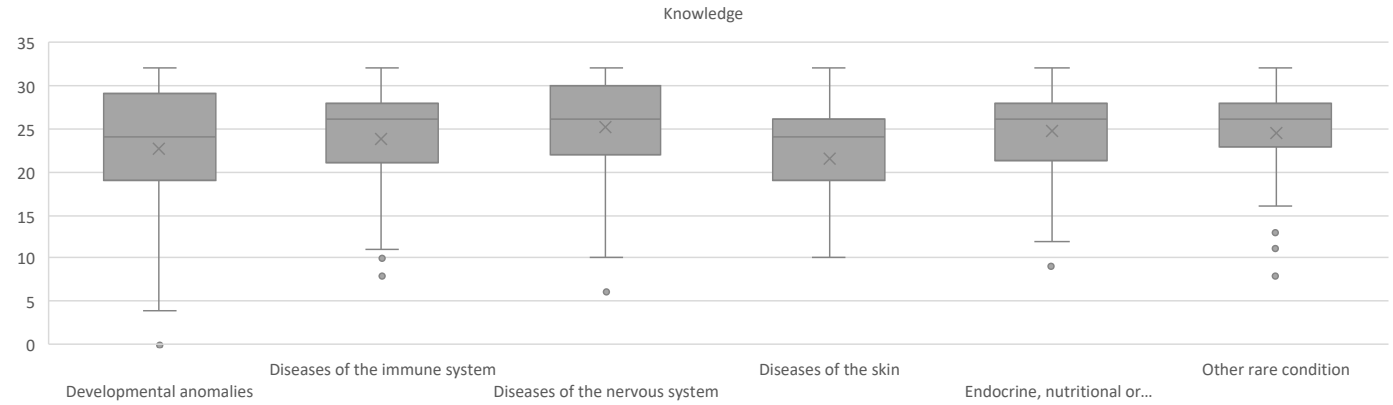
The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Endocrine, nutritional or metabolic diseases subgroup had a higher score for quality of compared to the Diseases of the skin subgroup, however, both groups had good overall knowledge, coping and confidence for managing their own health.

Table 6.16: Partners in health by condition summary statistics and Kruskal-Wallis test

SF36 scale	Group	Number (n=362)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Developmental anomalies	57	15.75	24.00	10.00	11.38	5	0.0443*
	Diseases of the immune system	72	19.89	26.00	7.00			
	Diseases of the nervous system	93	25.69	26.00	8.00			
	Diseases of the skin	29	8.01	24.00	7.00			
	Endocrine, nutritional or metabolic diseases	86	23.76	26.00	6.75			
	Other rare condition	25	6.91	26.00	5.00			
Coping	Developmental anomalies	57	15.75	15.00	7.00	12.86	5	0.0247*
	Diseases of the immune system	72	19.89	14.00	8.00			
	Diseases of the nervous system	93	25.69	15.00	7.00			
	Diseases of the skin	29	8.01	11.00	6.00			
	Endocrine, nutritional or metabolic diseases	86	23.76	15.00	6.00			
	Other rare condition	25	6.91	16.00	8.00			
Recognition and management of symptoms	Developmental anomalies	57	15.75	20.00	6.00	4.29	5	0.5082
	Diseases of the immune system	72	19.89	19.00	5.00			
	Diseases of the nervous system	93	25.69	20.00	6.00			
	Diseases of the skin	29	8.01	18.00	3.00			
	Endocrine, nutritional or metabolic diseases	86	23.76	19.00	3.00			
	Other rare condition	25	6.91	20.00	5.00			
Adherence to treatment	Developmental anomalies	57	15.75	14.00	4.00	12.99	5	0.0235*
	Diseases of the immune system	72	19.89	14.00	3.00			
	Diseases of the nervous system	93	25.69	14.00	4.00			
	Diseases of the skin	29	8.01	12.00	7.00			
	Endocrine, nutritional or metabolic diseases	86	23.76	15.00	3.00			
	Other rare condition	25	6.91	13.00	5.00			
Total score	Developmental anomalies	57	15.75	72.00	26.00	12.64	5	0.0270*
	Diseases of the immune system	72	19.89	70.00	21.25			
	Diseases of the nervous system	93	25.69	73.00	17.00			
	Diseases of the skin	29	8.01	61.00	16.00			
	Endocrine, nutritional or metabolic diseases	86	23.76	73.00	13.00			
	Other rare condition	25	6.91	72.00	18.00			

Table6.17: Care coordination by condition one-way post hoc Wilcoxon rank sum test

Partners in health scale		Developmental anomalies	Diseases of the immune system	Diseases of the nervous system	Diseases of the skin	Endocrine, nutritional or metabolic diseases
Knowledge	Diseases of the immune system	0.6780	-	-	-	-
	Diseases of the nervous system	0.1670	0.2090	-	-	-
	Diseases of the skin	0.4710	0.2660	0.0820	-	-
	Endocrine, nutritional or metabolic diseases	0.3410	0.4710	0.4710	0.1670	-
	Other rare condition	0.4710	0.5580	0.7510	0.2090	0.8650
Coping	Diseases of the immune system	0.4870	-	-	-	-
	Diseases of the nervous system	0.4870	0.8630	-	-	-
	Diseases of the skin	0.0160*	0.0560	0.0480*	-	-
	Endocrine, nutritional or metabolic diseases	0.8070	0.4870	0.5680	0.0160*	-
	Other rare condition	0.8630	0.4870	0.4870	0.0450*	0.7750
Adherence to treatment	Diseases of the immune system	0.8147	-	-	-	-
	Diseases of the nervous system	0.8905	0.8147	-	-	-
	Diseases of the skin	0.1245	0.0888	0.1245	-	-
	Endocrine, nutritional or metabolic diseases	0.2674	0.2674	0.1737	0.0097*	-
	Other rare condition	0.8147	0.7740	0.8147	0.3752	0.3752
Total score	Diseases of the immune system	0.8255	-	-	-	-
	Diseases of the nervous system	0.8255	0.7054	-	-	-
	Diseases of the skin	0.1128	0.0716	0.0189*	-	-
	Endocrine, nutritional or metabolic diseases	0.7054	0.3654	0.8255	0.0055*	-
	Other rare condition	0.8255	0.8255	0.9396	0.0716	0.8255



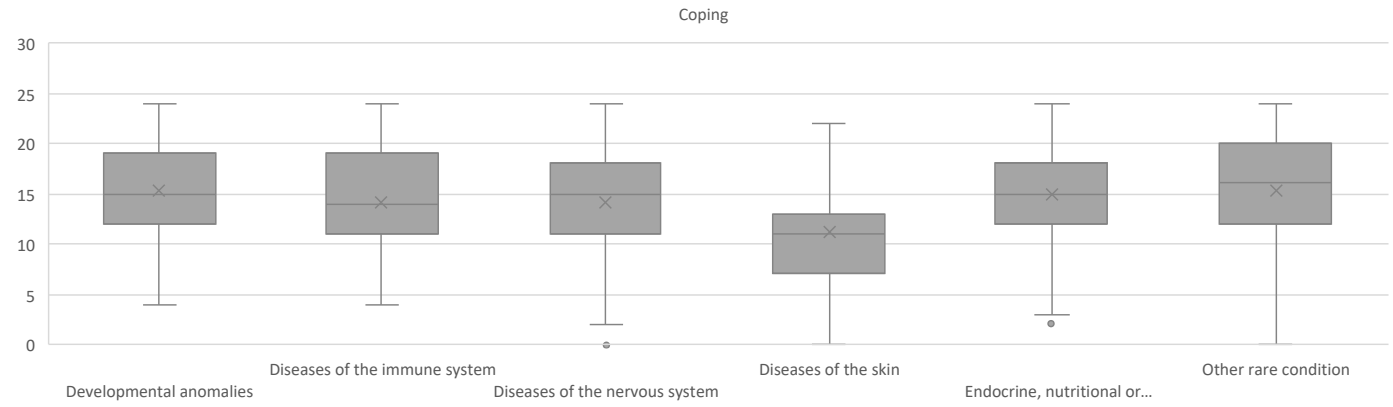


Figure 6.9: Boxplot of Partners in health: knowledge by condition

Figure 6.10: Boxplot of Partners in health: coping by condition

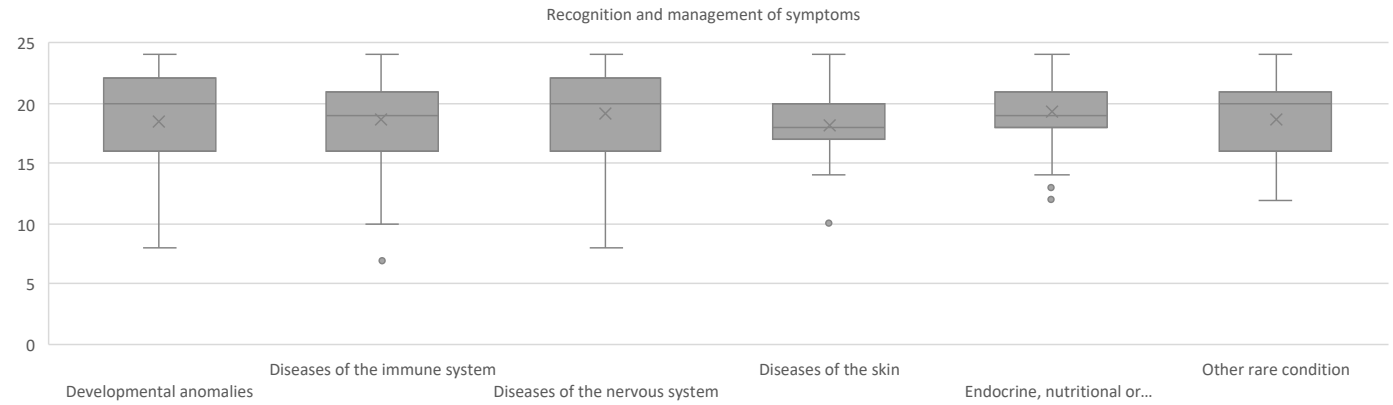


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by condition

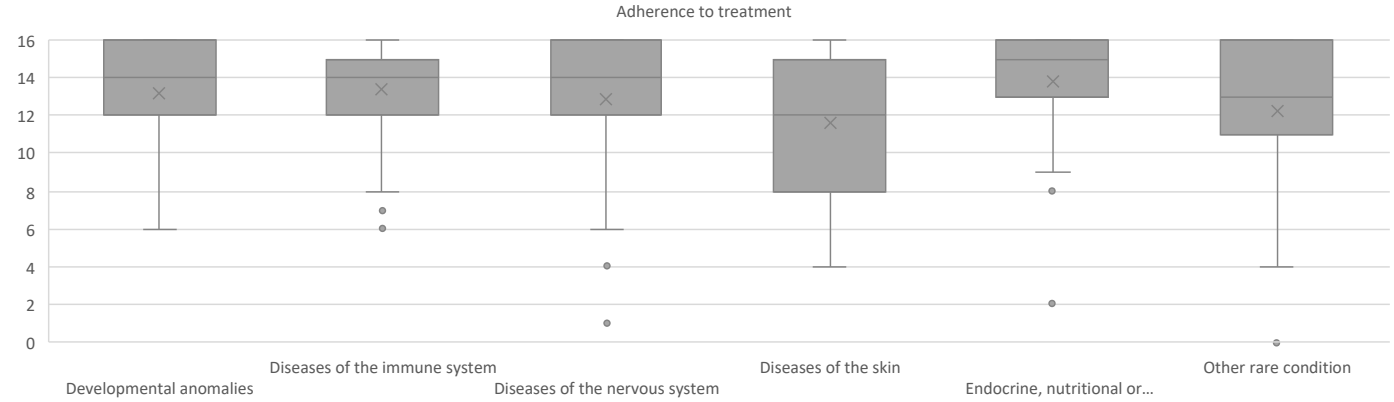


Figure 6.12: Boxplot of Partners in health: adherence to treatment by condition

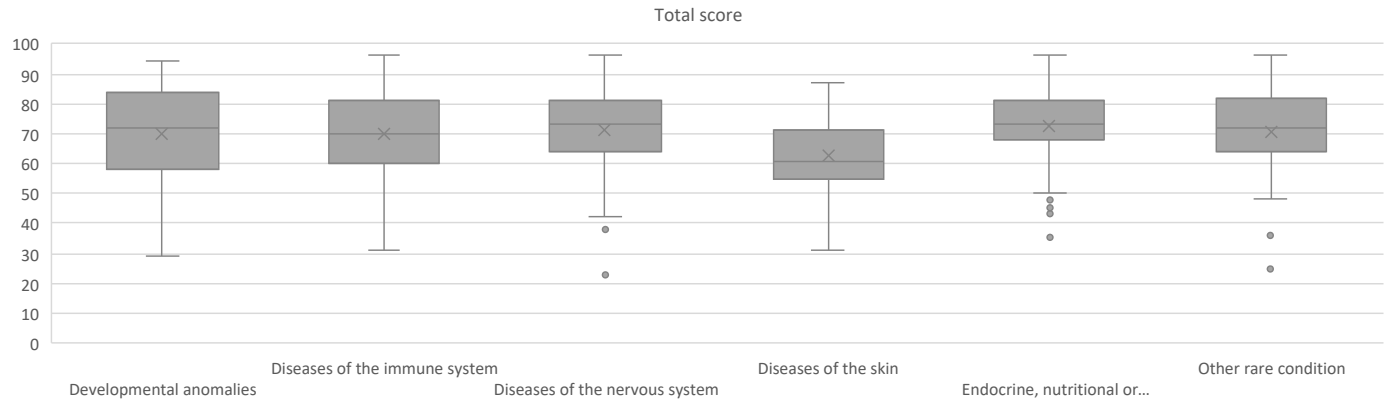


Figure 6.13: Boxplot of Partners in health Total score by condition

Partners in health by type of participant

Comparisons were made by **type of participant** there were 241 participants (66.57%) with person with condition and, 121 participants (33.43%) with carer.

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 Knowledge scale [W = 11891.00 , p = 0.0041] was significantly lower for participants in the Person with condition subgroup (Median = 25.00, IQR = 8.00) compared to participants in the Carer subgroup (Median = 27.00, IQR = 9.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Recognition and management of symptoms scale [W = 11137.00 , p = 0.0002] was significantly lower for participants in the Person with condition subgroup (Median = 19.00, IQR = 5.00) compared to participants in the Carer subgroup (Median = 20.00, IQR = 5.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Total score scale [W = 11925.00 , p = 0.0047] was significantly lower for participants in the Person with condition subgroup (Median = 71.00, IQR = 20.00) compared to participants in the Carer subgroup (Median = 75.00, IQR = 18.00.

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 the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that participants in the Carer subgroup had very good knowledge about their condition and treatments, and participants in the Person with condition subgroup had good knowledge.

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 Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that recognition and management of symptoms was very good for participants in the Carer subgroup, and good for participants in the Person with condition subgroup.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Carer subgroup had a higher score for quality of compared to the Person with condition subgroup, however, both groups had good overall knowledge, coping and confidence for managing their own health.

Table 6.18: Partners in health by type of participant summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=362)	Percent	Median	IQR	W	p-value
Knowledge	Person with condition	241	66.57	25.00	8.00	11891	0.0041*
	Carer	121	33.43	27.00	9.00		
Coping	Person with condition	241	66.57	14.00	7.00	13584	0.2876
	Carer	121	33.43	15.00	8.00		
Recognition and management of symptoms	Person with condition	241	66.57	19.00	5.00	11137	0.0002*
	Carer	121	33.43	20.00	5.00		
Adherence to treatment	Person with condition	241	66.57	14.00	4.00	13414	0.2069
	Carer	121	33.43	14.00	4.00		
Total score	Person with condition	241	66.57	71.00	20.00	11925	0.0047*
	Carer	121	33.43	75.00	18.00		

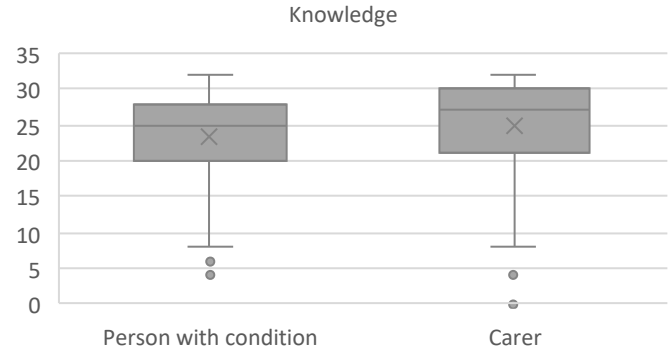


Figure 6.14: Boxplot of Partners in health: knowledge by type of participant

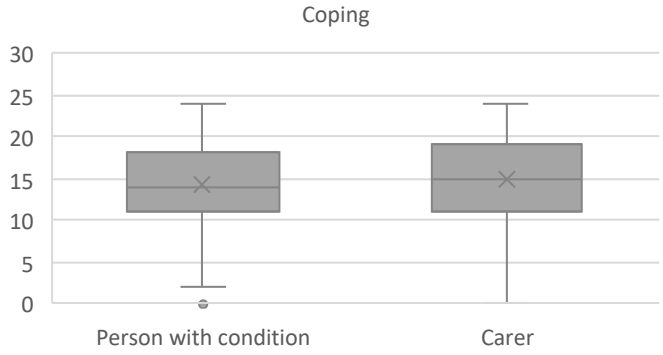


Figure 6.15: Boxplot of Partners in health: coping by type of participant

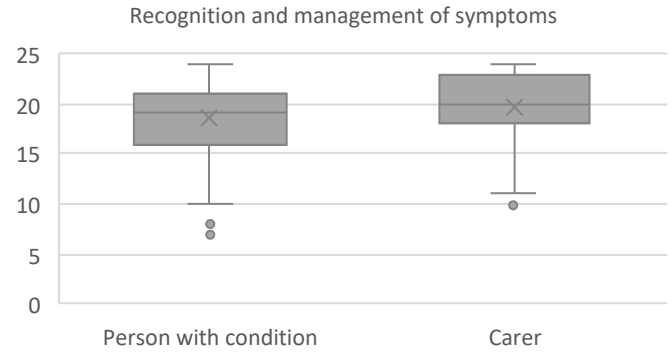


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by type of participant

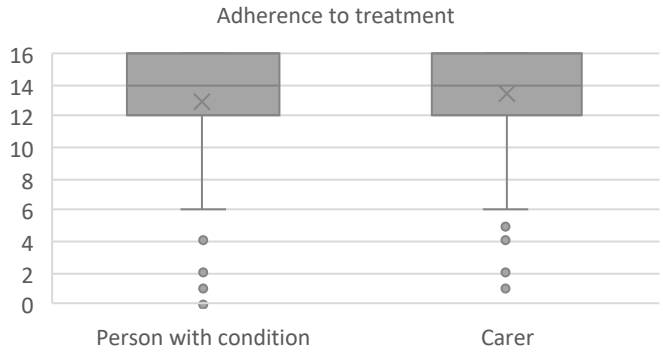


Figure 6.17: Boxplot of Partners in health: adherence to treatment by type of participant

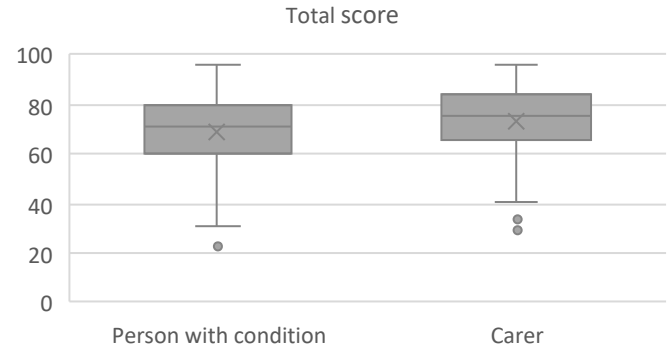


Figure 6.18: Boxplot of Partners in health Total score by type of participant

Partners in health by gender

Comparisons were made by **gender**, there were 272 female participants (75.56%), and 88 male particpants (24.44%).

Assumptions for normality and variance for a two-sample t-test 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 6.19: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=360)	Percent	Median	IQR	W	p-value
Knowledge	Female	272	75.56	25.00	8.00	11443.00	0.5357
	Male	88	24.44	26.00	6.50		
Coping	Female	272	75.56	14.00	7.00	10584.00	0.1022
	Male	88	24.44	15.50	9.00		
Recognition and management of symptoms	Female	272	75.56	19.00	5.00	11131.00	0.3219
	Male	88	24.44	20.00	5.00		
Adherence to treatment	Female	272	75.56	14.00	4.00	11056.00	0.2750
	Male	88	24.44	14.00	4.00		
Total score	Female	272	75.56	71.00	20.00	10658.00	0.1228
	Male	88	24.44	73.50	18.25		

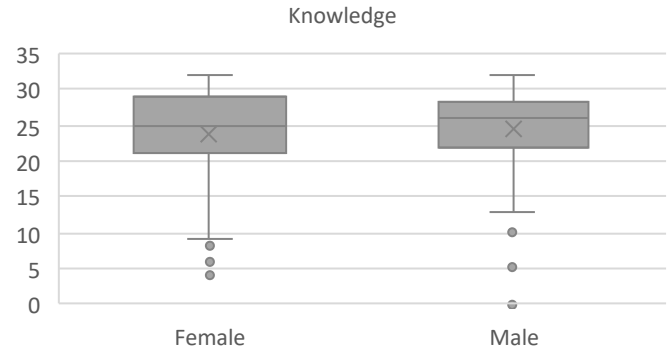


Figure 6.19: Boxplot of Partners in health: knowledge by gender

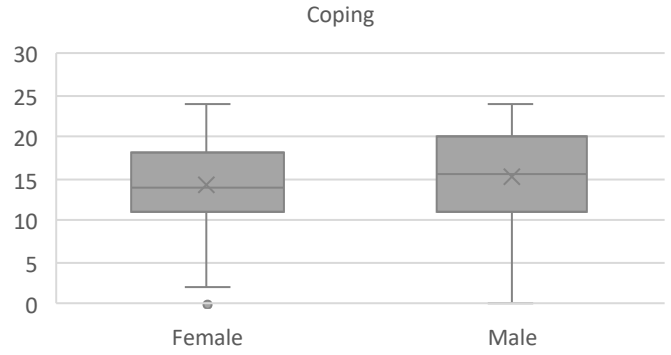


Figure 6.20: Boxplot of Partners in health: coping by gender

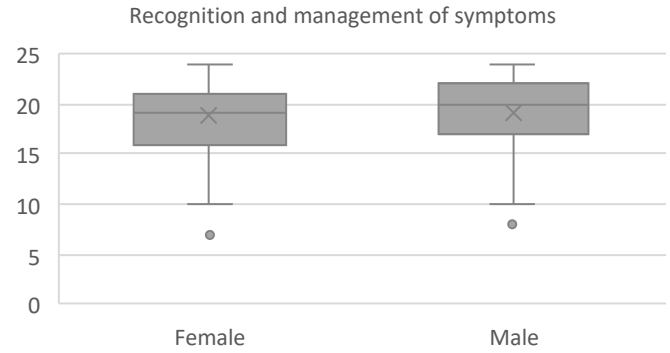


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by gender

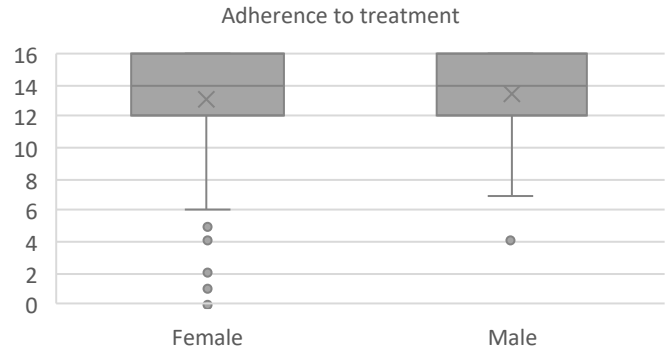


Figure 6.22: Boxplot of Partners in health: adherence to treatment by gender

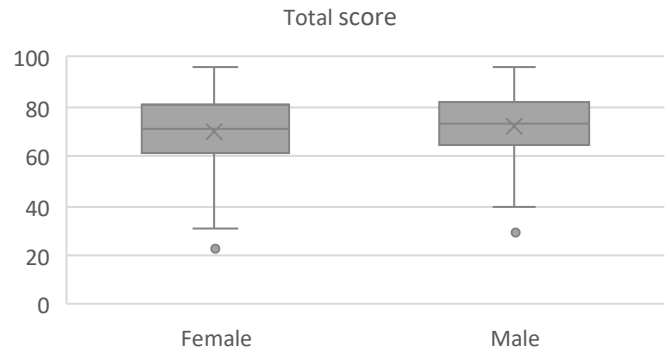


Figure 6.23: Boxplot of Partners in health Total score by gender

Partners in health by age

Comparisons were made by **age** of person with condition. There were 87 participants (24.03%) with aged under 18, 120 participants (33.15%) with aged 18 to 44, 102 participants (28.18%) with aged 45 to 64, and 53 participants (14.64%) with aged 65 or older.

Assumptions for normality of residuals was not met, a Kruskal-Wallis test was used. Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test.

A Kruskal-Wallis test indicated a statistically significant difference in the Partners in health: Knowledge scale between groups, $\chi^2(3) = 29.64$ $p<0.0001$. The largest significant difference was between Aged under 18 (median = 26, IQR = 8.5), and Aged 18 to 44 (median = 24, IQR = 8, p = <0.0001).

A Kruskal-Wallis test indicated a statistically significant difference in the Partners in health: Coping scale between groups, $\chi2(3) = 8.34$ P = 0.0394. The largest significant difference was between Aged 65 or older (median = 17, IQR = 9.25), and Aged 18 to 44 (median = 12, IQR = 6, p = 0.037).

A Kruskal-Wallis test indicated a statistically significant difference in the Partners in health: Recognition and management of symptoms scale between groups, $\chi^2(3) = 29.24$ $p<0.0001$. The largest significant difference was between Aged under 18 (median = 20, IQR = 5.5), and Aged 18 to 44 (median = 19, IQR = 5, p = <0.0001).

A Kruskal-Wallis test indicated a statistically significant difference in the Partners in health: Adherence to treatment scale between groups, $\chi^2(3) = 25.21$ $p<0.0001$. The largest significant difference was between Aged 65 or older (median = 15, IQR = 2), and Aged 18 to 44 (median = 13, IQR = 4, p = 0.0001).

A Kruskal-Wallis test indicated a statistically significant difference in the Partners in health: Total score scale between groups, $\chi^2(3) = 32.1$ $p<0.0001$. The largest significant difference was between Aged under 18 (median = 74, IQR = 20.5), and Aged 18 to 44 (median = 69, IQR = 19, p = <0.0001).

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 the Aged under 18subgroup scored higher than participants in the Aged 18 to 44subgroup. This indicates that participants in the Aged under 18subgroup had very good knowledge about their condition and treatments, and participants in the Aged 18 to 44subgroup had good knowledge.

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 Aged 65 or older subgroup scored higher than participants in the Aged 18 to 44subgroup. This indicates that participants in the Aged 65 or older subgroup were good at coping with their condition, and participants in the Aged 18 to 44subgroup 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 Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that recognition and management of symptoms was very good for

participants in the Aged under 18 subgroup, and good for participants in the Aged 18 to 44 subgroup.

The **Partners in health:adherence to 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 the Aged 65 or older subgroup had a higher total score for navigation compared to Aged 18 to 44, however both groups had very good treatment adherence.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Aged under 18subgroup had a higher score for quality of compared to the Aged 18 to 44 subgroup, however, both groups had good overall knowledge, coping and confidence for managing their own health.

Table 6.20: Partners in health by age summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=362)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Aged under 18	87	24.03	26.00	8.50	29.64	3	<0.0001*
	Aged 18 to 44	120	33.15	24.00	8.00			
	Aged 45 to 64	102	28.18	25.00	7.00			
	Aged 65 or older	53	14.64	28.00	5.25			
Coping	Aged under 18	87	24.03	16.00	7.00	8.34	3	0.0394*
	Aged 18 to 44	120	33.15	12.00	6.00			
	Aged 45 to 64	102	28.18	14.00	8.00			
	Aged 65 or older	53	14.64	17.00	9.25			
Recognition and management of symptoms	Aged under 18	87	24.03	20.00	5.50	29.24	3	<0.0001*
	Aged 18 to 44	120	33.15	19.00	5.00			
	Aged 45 to 64	102	28.18	19.00	5.00			
	Aged 65 or older	53	14.64	20.00	4.00			
Adherence to treatment	Aged under 18	87	24.03	14.00	4.00	25.21	3	<0.0001*
	Aged 18 to 44	120	33.15	13.00	4.00			
	Aged 45 to 64	102	28.18	14.00	4.00			
	Aged 65 or older	53	14.64	15.00	2.00			
Total score	Aged under 18	87	24.03	74.00	20.50	32.10	3	<0.0001*
	Aged 18 to 44	120	33.15	69.00	19.00			
	Aged 45 to 64	102	28.18	72.00	20.50			
	Aged 65 or older	53	14.64	80.00	15.75			

Table6.21: Care coordination by age one-way post hoc Wilcoxon rank sum test

Partners in health scale	Group	Aged under 18	Aged 18 to 44	Aged 45 to 64
Knowledge	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	0.0310*	0.0134	-
	Aged 65 or older	0.8293	0.0002*	0.0552
Coping	Aged 18 to 44	0.1950	-	-
	Aged 45 to 64	0.6000	0.2900	-
	Aged 65 or older	0.2900	0.0370*	0.2230
Recognition and management of symptoms	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	0.0067*	0.0245*	-
	Aged 65 or older	0.1183	0.0061*	0.3364
Adherence to treatment	Aged 18 to 44	0.0001*	-	-
	Aged 45 to 64	0.5543	0.0031*	-
	Aged 65 or older	0.4797	0.0001*	0.3661
Total score	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	0.0500*	0.0080*	-
	Aged 65 or older	0.8420	0.0001*	0.0590

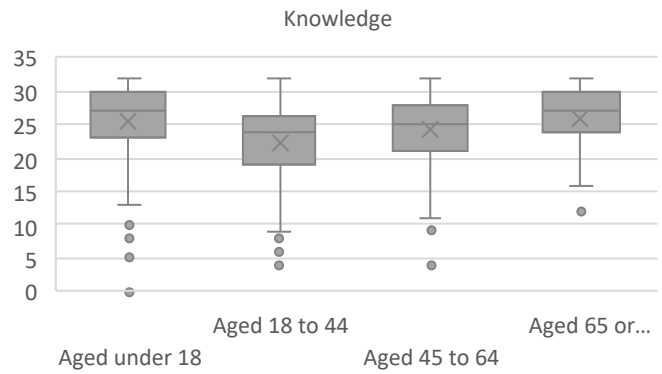


Figure 6.24: Boxplot of Partners in health: knowledge by age

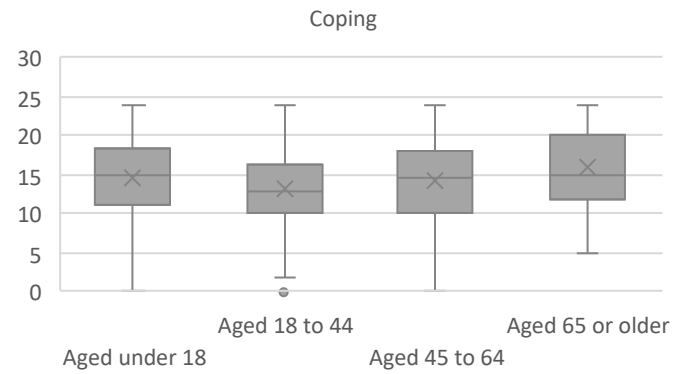


Figure 6.25: Boxplot of Partners in health: coping by age

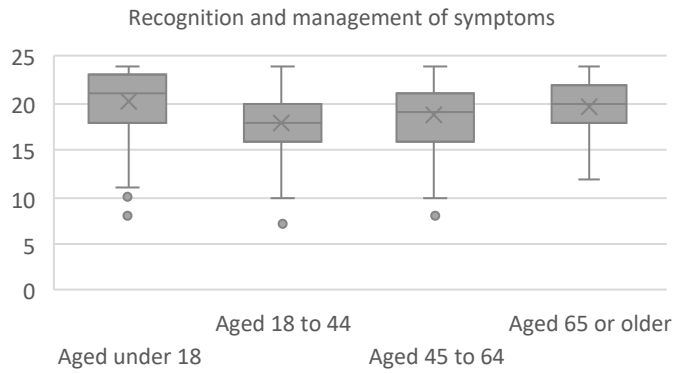


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by age

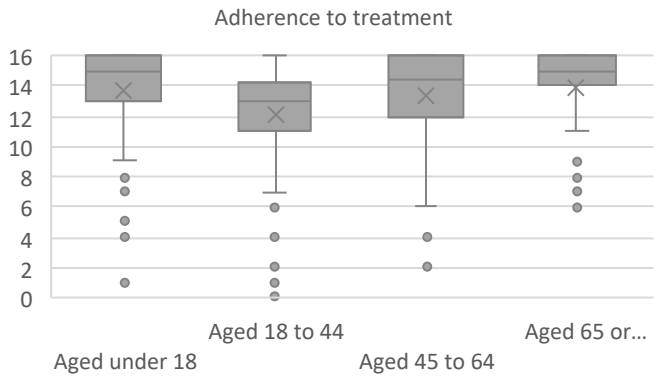


Figure 6.27: Boxplot of Partners in health: adherence to treatment by age

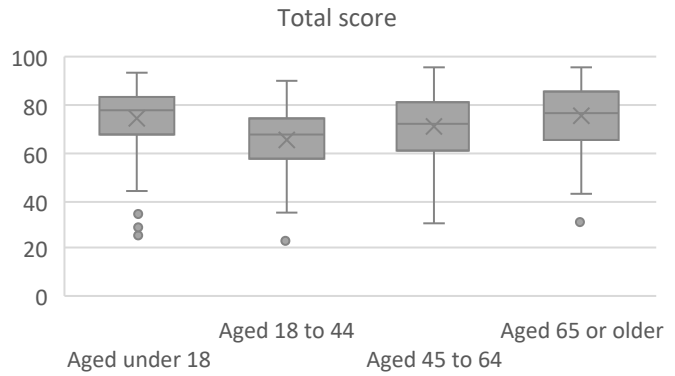


Figure 6.28: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by **education** status, between those with trade or high school qualifications (n=175, 49.44%), and those with a university qualification (n=179, 50.56%).

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

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

Table 6.22: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=354)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	175	49.44	25.00	8.50	14980.00	0.4781
	University	179	50.56	26.00	8.00		
Coping	Trade or high school	175	49.44	14.00	7.00	14682.00	0.3073
	University	179	50.56	15.00	8.00		
Recognition and management of symptoms	Trade or high school	175	49.44	19.00	6.00	15652.00	0.9917
	University	179	50.56	20.00	4.00		
Adherence to treatment	Trade or high school	175	49.44	14.00	5.00	15165.00	0.5998
	University	179	50.56	14.00	4.00		
Total score	Trade or high school	175	49.44	71.00	20.50	14452.00	0.2084
	University	179	50.56	72.00	18.00		

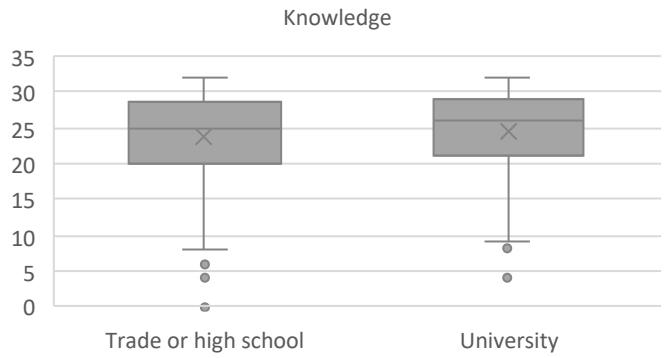


Figure 6.29: Boxplot of Partners in health: knowledge by education

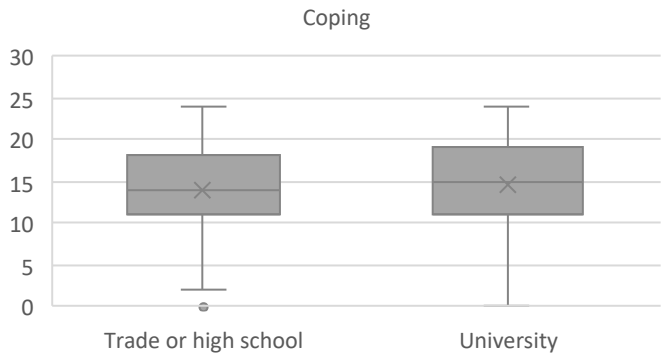


Figure 6.30: Boxplot of Partners in health: coping by education

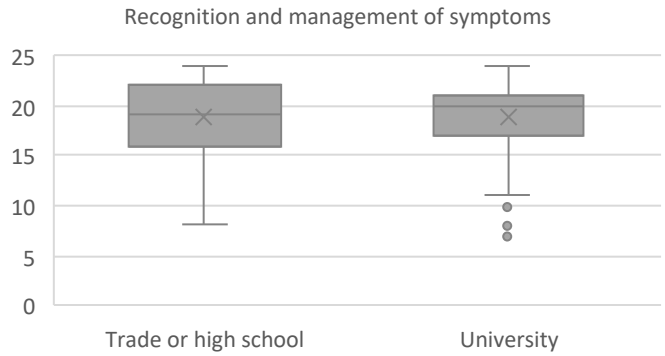


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by education

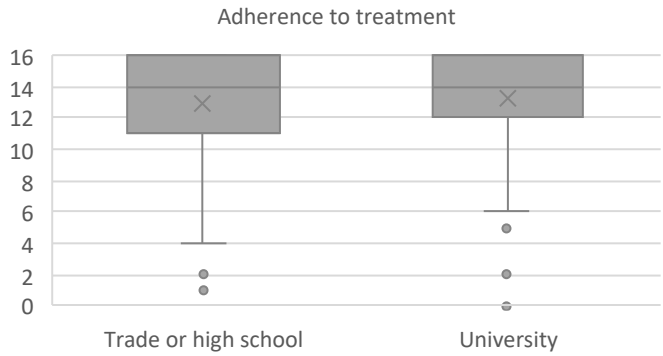


Figure 6.32: Boxplot of Partners in health: adherence to treatment by education

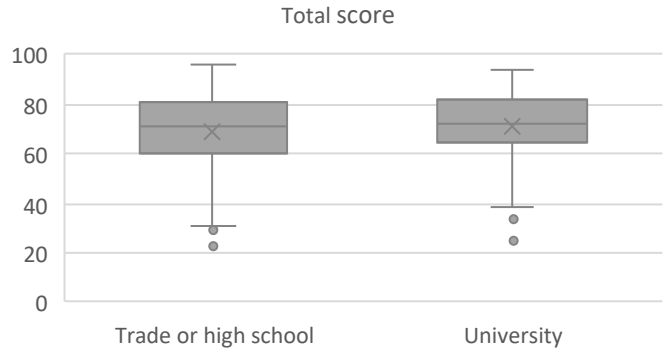


Figure 6.33: Boxplot of Partners in health Total score by education

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=103, 28.45%) were compared to those living in a metropolitan area (n=259, 71.55%).

Assumptions for normality and variance for a two-sample t-test 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 6.23: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=362)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	103	28.45	26.00	7.00	13282.00	0.9502
	Metropolitan	259	71.55	25.00	8.00		
Coping	Regional or remote	103	28.45	15.00	7.50	13535.00	0.8269
	Metropolitan	259	71.55	14.00	7.00		
Recognition and management of symptoms	Regional or remote	103	28.45	19.00	5.00	13667.00	0.7137
	Metropolitan	259	71.55	19.00	6.00		
Adherence to treatment	Regional or remote	103	28.45	14.00	4.00	14022.00	0.4399
	Metropolitan	259	71.55	14.00	4.00		
Total score	Regional or remote	103	28.45	73.00	17.50	13842.00	0.5758
	Metropolitan	259	71.55	72.00	20.50		

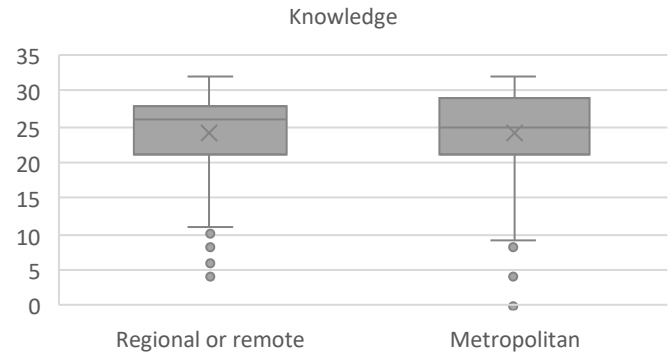


Figure 6.34: Boxplot of Partners in health: knowledge by location

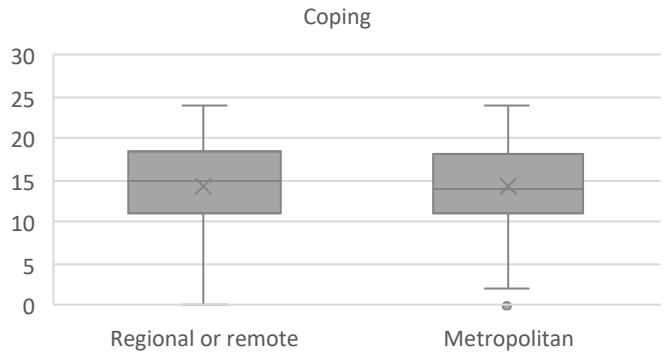


Figure 6.35: Boxplot of Partners in health: coping by location

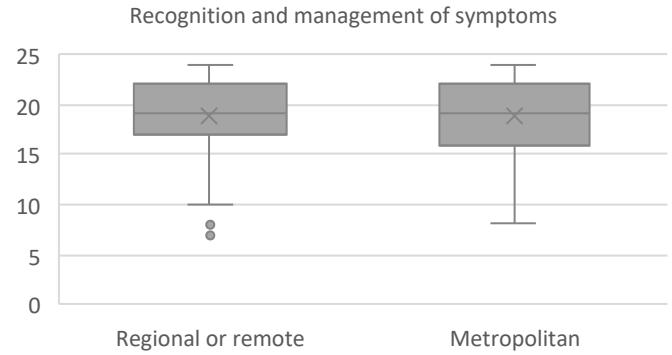


Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by location

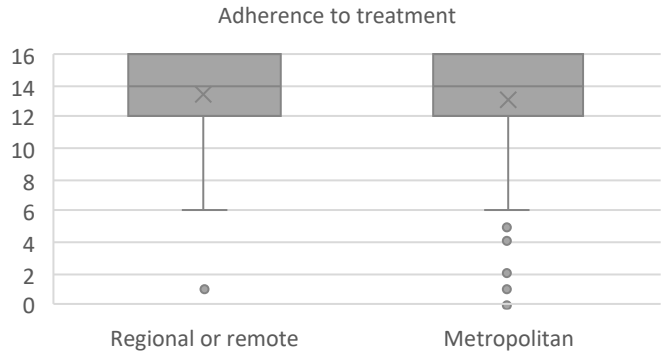


Figure 6.37: Boxplot of Partners in health: adherence to treatment by location

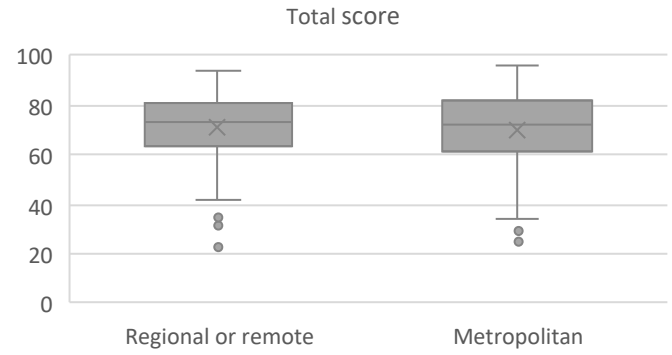


Figure 6.38: Boxplot of Partners in health Total score by location

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 (n=184, 50.83%) compared to those with a higher SEIFA score of 7-10 (n=178, 49.17%).

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 Knowledge scale [W = 14326.00 , p = 0.0390] was significantly lower for participants in the Mid to low status subgroup (Median = 25.00, IQR = 8.00) compared to participants in the **Higher status** subgroup (Median = 26.00, IQR = 7.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Recognition and management of symptoms scale [W = 14360.00 , p = 0.0420] was significantly lower for participants in the Mid to low status subgroup (Median = 19.00, IQR = 5.00) compared to participants in the Higher status subgroup (Median = 20.00, IQR = 5.00.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Total score scale [W = 14090.00 , p = 0.0216] was significantly lower for participants in the Mid to low status subgroup (Median = 71.00, IQR = 21.25) compared to participants in the Higher status subgroup (Median = 73.00, IQR = 18.00.

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 the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that participants in the Higher status subgroup had very good knowledge about their condition and treatments, and participants in the Mid to low status subgroup had good knowledge.

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 Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that recognition and management of symptoms was very good for participants in the Higher status subgroup, and good for participants in the Mid to low 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 Higher status subgroup had a higher score for quality of compared to the Mid to low status subgroup, however, both groups had good overall knowledge, coping and confidence for managing their own health.

Table 6.24: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=362)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	184	50.83	25.00	8.00	14326.00	0.03908
	Higher status	178	49.17	26.00	7.00		
Coping	Mid to low status	184	50.83	14.00	6.00	14620.00	0.07728
	Higher status	178	49.17	15.00	8.00		
Recognition and management of symptoms	Mid to low status	184	50.83	19.00	5.00	14360.00	0.04208
	Higher status	178	49.17	20.00	5.00		
Adherence to treatment	Mid to low status	184	50.83	14.00	4.00	15096.00	0.19158
	Higher status	178	49.17	14.00	4.00		
Total score	Mid to low status	184	50.83	71.00	21.25	14090.00	0.02168
	Higher status	178	49.17	73.00	18.00		

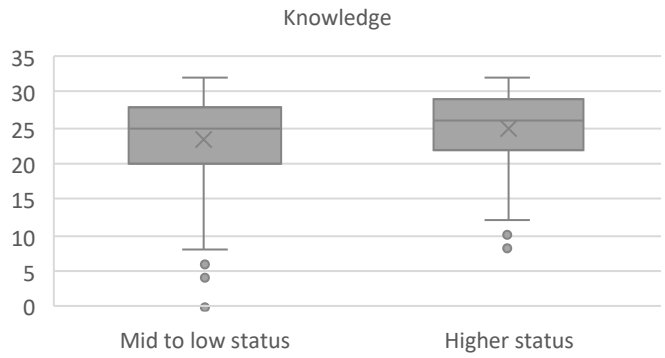


Figure 6.39: Boxplot of Partners in health: knowledge by socioeconomic status

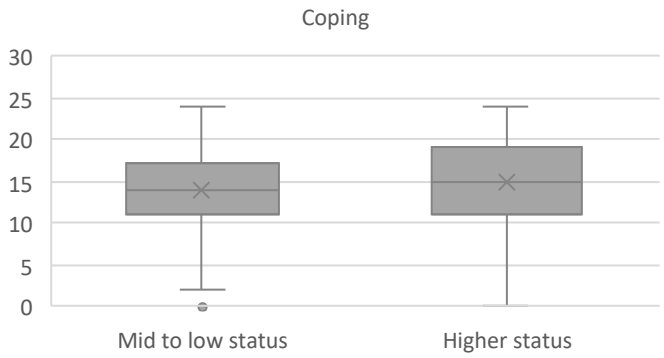


Figure 6.40: Boxplot of Partners in health: coping by socioeconomic status

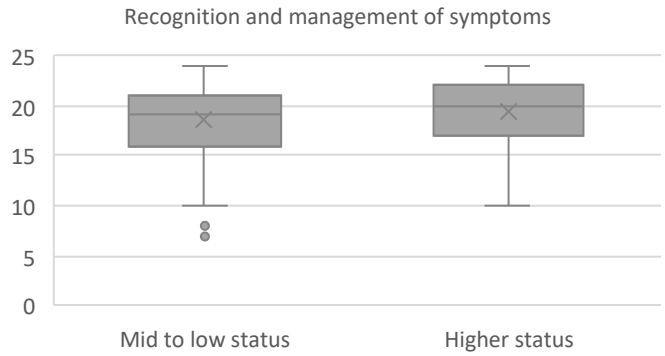


Figure 6.41: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

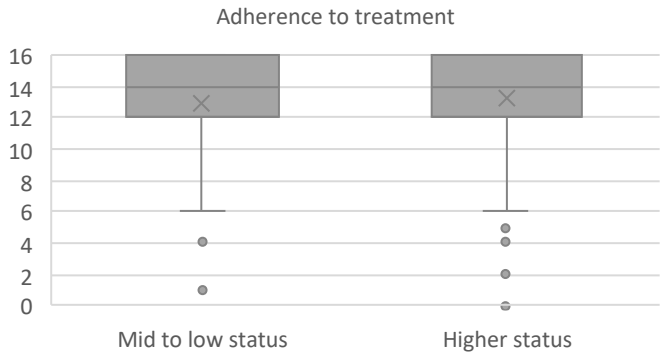


Figure 6.42: Boxplot of Partners in health: adherence to treatment by socioeconomic status

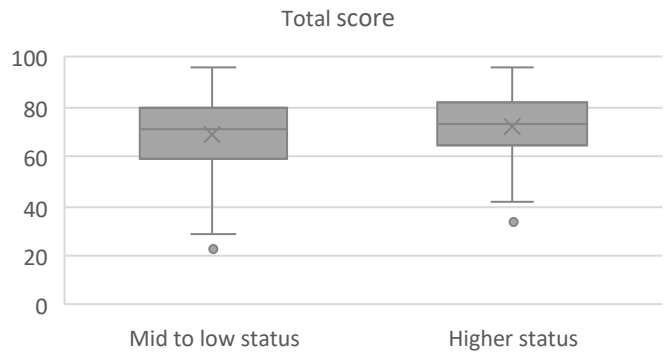


Figure 6.43: Boxplot of Partners in health Total score by socioeconomic status

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=173, 57.10%), and 120 participants (39.60%) responded that they took medicines as prescribed most of the time. There were 6 participants (1.98%) that sometimes took medicines as prescribed.

Table 6.25: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	Number (n=303)	Percent
All of the time	173	57.10
Most of the time	120	39.60
Sometimes	6	1.98
Rarely	4	1.32

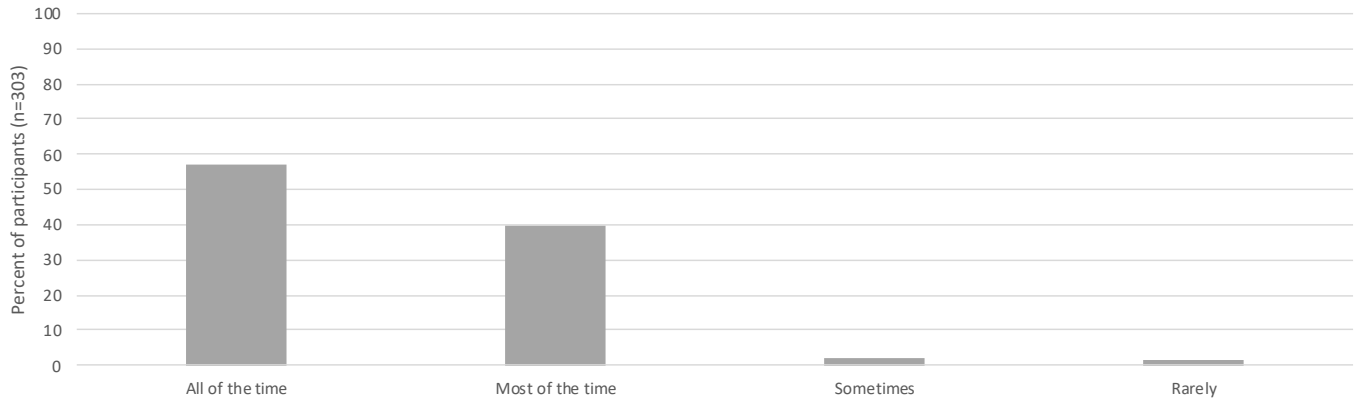


Figure 6.44: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=188, 58.02%), disease management (n=147, 45.37%), disease cause (n=119, 36.73%) and, physical activity (n=85, 26.23%) were most frequently given to participants by healthcare professionals, and, information about interpret test results (n=54, 16.67%), clinical trials (n=43, 13.27%) and, complementary therapies (n=34, 10.49%) were given least often.

Table 6.26: Information given by health professionals

Information given by health professionals	Number (n=324)	Percent
Disease Cause	119	36.73
Treatment options	188	58.02
Disease management	147	45.37
Complementary therapies	34	10.49
Interpret test results	54	16.67
Clinical trials	43	13.27
Dietary	78	24.07
Physical activity	85	26.23
Psychological/ social support	69	21.30
Hereditary considerations	76	23.46

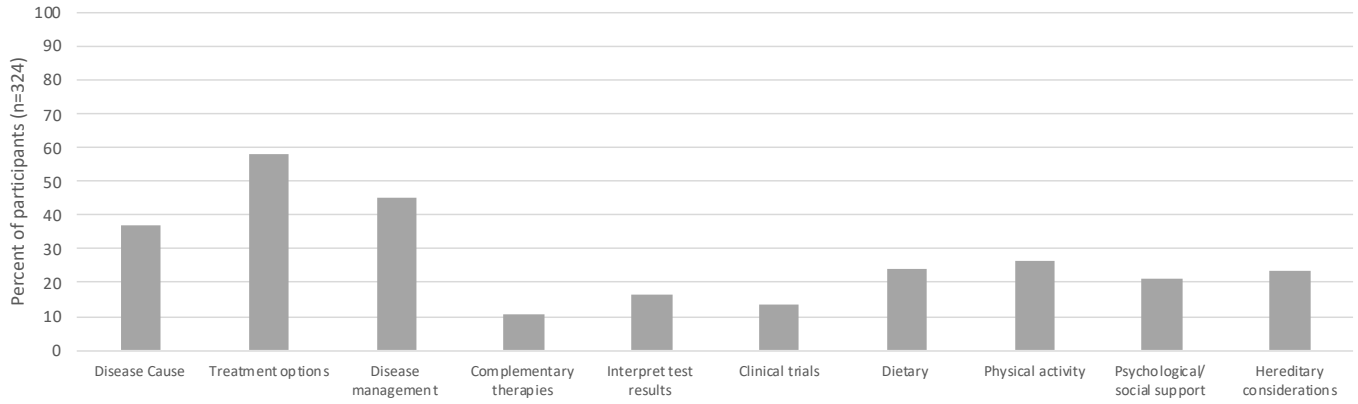


Figure 6.45: Information given by health professionals

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 management (n=212, 65.43%), treatment options (n=210, 64.81%), disease cause (n=207, 63.89%) and, complementary therapies (n=167, 51.54%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=123, 37.96%), interpret test results (n=120, 37.04%) and, hereditary considerations (n=103, 31.79%) were searched for least often.

Table 6.27: Information searched for independently

Information searched independently	Number (n=324)	Percent
Disease Cause	207	63.89
Treatment options	210	64.81
Disease management	212	65.43
Complementary therapies	167	51.54
Interpret test results	120	37.04
Clinical trials	123	37.96
Dietary	155	47.84
Physical activity	138	42.59
Psychological/ social support	136	41.98
Hereditary considerations	103	31.79

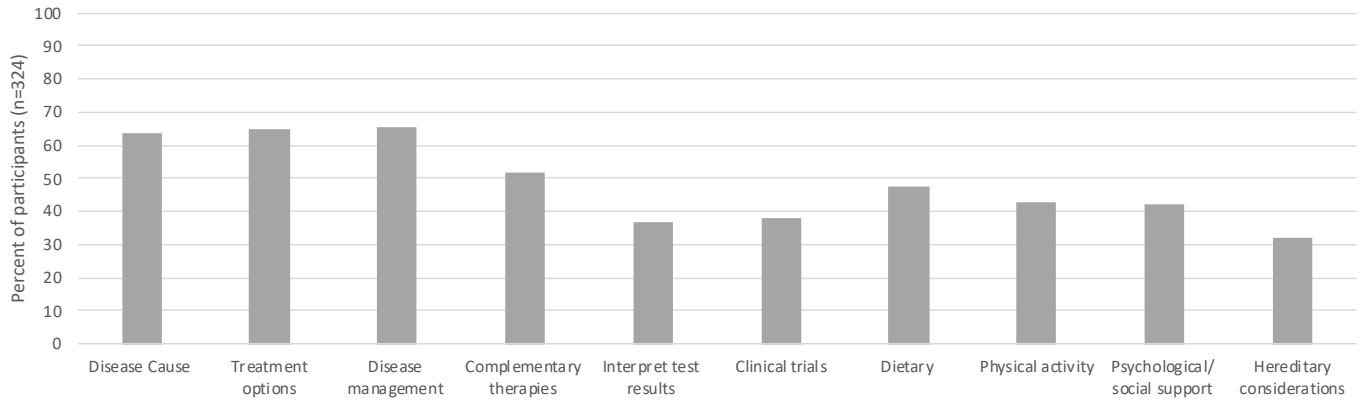


Figure 6.46: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=177, 54.63%) and interpret test results (n=172, 53.09%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=66, 20.37%) and disease cause (n=58, 17.90%).

The topics that participants were given most information from both healthcare professionals and searching independently for were disease cause (n=146, 45.06%) and complementary therapies (n=145, 44.75%).

The topics that participants searched for independently after not receiving information from healthcare professionals were treatment options (n=122, 37.65%) and disease management (n=96, 29.63%).

Table 6.28: 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=324	%	n=324	%	n=324	%	n=324	%
Disease cause	59	18.21	58	17.90	146	45.06	61	18.83
Treatment options	48	14.81	66	20.37	88	27.16	122	37.65
Disease management	61	18.83	51	15.74	116	35.80	96	29.63
Complementary therapies	145	44.75	12	3.70	145	44.75	22	6.79
How to interpret test results	172	53.09	32	9.88	98	30.25	22	6.79
Clinical trials	177	54.63	24	7.41	104	32.10	19	5.86
Dietary information	130	40.12	39	12.04	116	35.80	39	12.04
Physical activity	141	43.52	45	13.89	98	30.25	40	12.35
Psychological/social support	153	47.22	35	10.80	102	31.48	34	10.49
Hereditary considerations	169	52.16	52	16.05	79	24.38	24	7.41

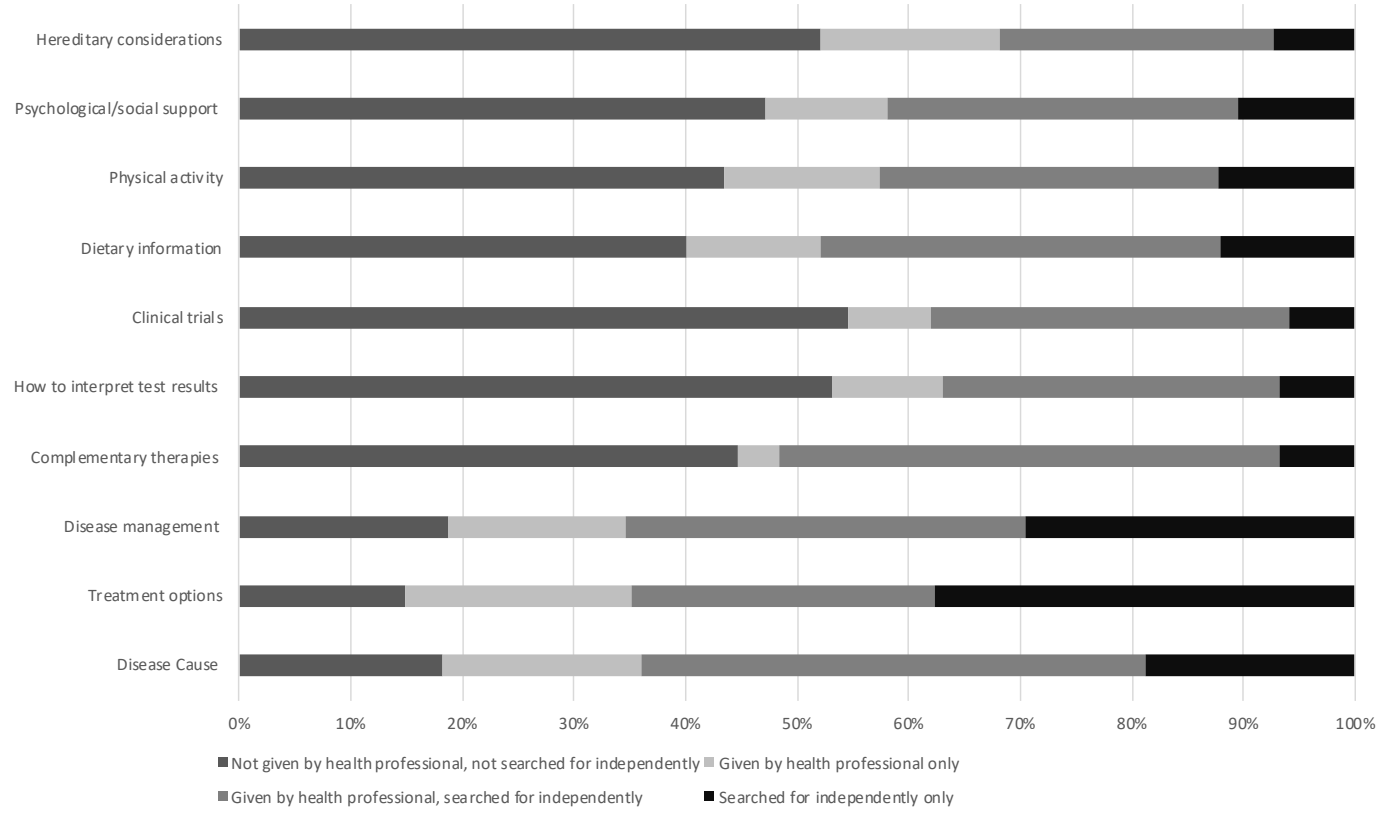


Figure 6.47: Information gaps

Most accessed information

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

Table 6.29: Most accessed information

Information source	Weighted average (n=321)
Non-profit organisations, charity or patient organisations	3.57
Government	2.45
Pharmaceutical companies	2.19
Hospital or clinic I am being treated in	3.15
Medical journals	3.34

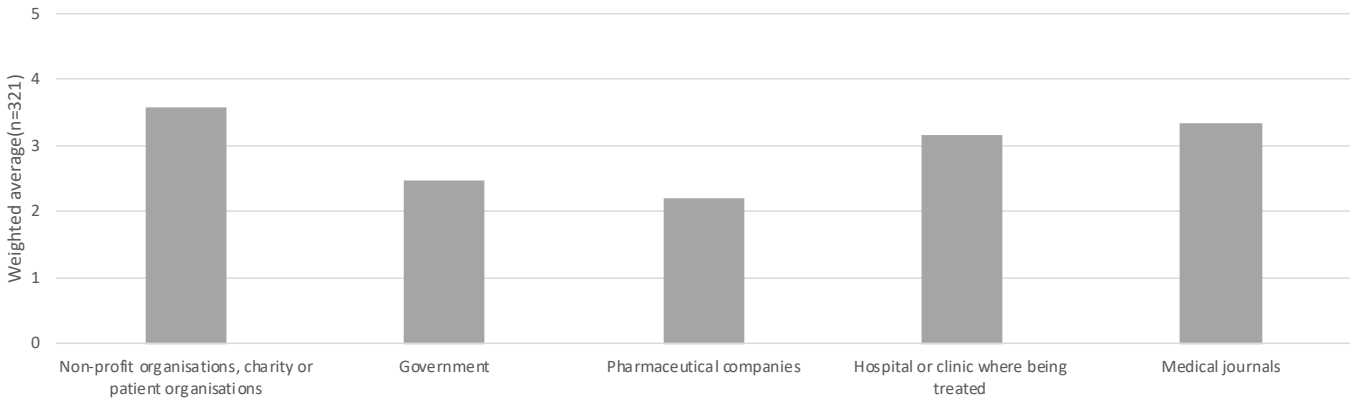


Figure 6.48: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 114 participants (39.31%) had accessed My Health Record, 176 participants (60.69%) had not.

Of those that had accessed My Health Record, there were 71 participants (62.28%) who found it to be porr or very poor, 33participants (28.95%) who found it acceptable, and 10 participants (8.77%) who found it to be good or very good.

Table 6.30: Accessed My Health Record

How useful was "My health record"	Number (n=114)	Percent
Very poor	37	32.46
Poor	34	29.82
Acceptable	33	28.95
Good	9	7.89
Very good	1	0.88

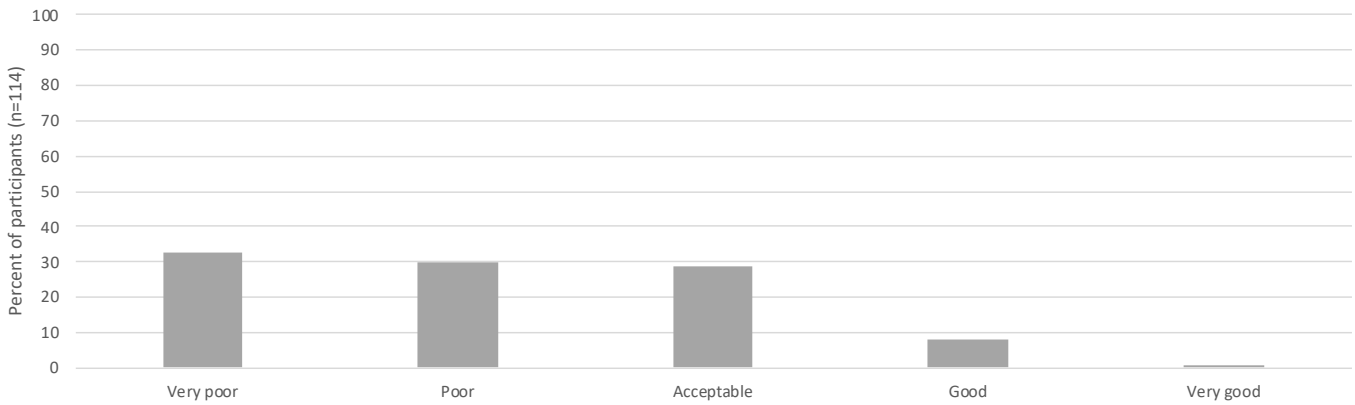


Figure 6.49: Accessed My Health Record

Table 6.31: How useful was My Health Record

Accessed "My health record"	Number (n=290)	Percent
Yes	114	39.31
No	145	50.00
Not sure	11	3.79
Doesn't know what 'My Health Record' is	20	6.90

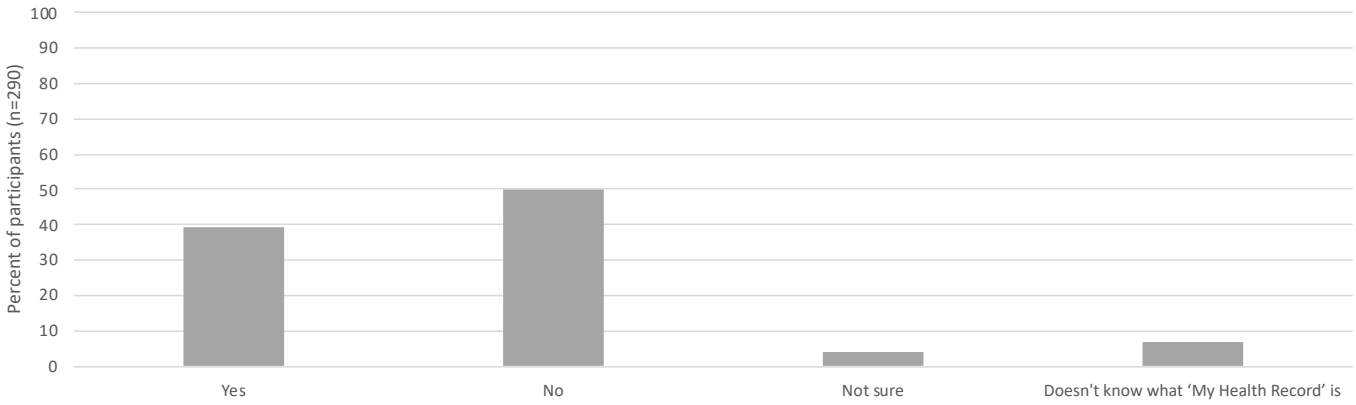


Figure 6.50: How useful was My Health Record