

Section 6 Information and communication

Section 6: Information and communication

Access to information

- The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).
- There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.
- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Almost half of the participants (n=48, 48.00%) described a preference for talking to someone. Of those that described a preference for a talking to someone 27 participants preferred this along with written or online material.

Information that was helpful

- 21 participants (21.00%) felt that was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew. There were 14 participants that described information about diet as being a useful topic and 14 participants (14.00%) that described information about other people's experience as helpful. There were 13 participants (13.00%) that described the internet being a useful source of information. Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%).
- In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

Information that was not helpful

- The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful. The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). The final theme in this section was in relation to a lack of new information (n=10, 10.00%).
- There were two sub-group variations. Participants with mild AD reported no information as being unhelpful more frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

Timing of information

- The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better. The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information.
- Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort). Participants with moderate AD reported a preference for

receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

Health professional communication

- The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general. The next most common theme was that communication was overall positive (n=32, 32.00%). There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information.
- In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

Respect shown to patients

- The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously
- In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

Knowledge and confidence

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

- Overall, the participants scored in the top quintile for, adherence to treatment, and management of symptoms, indicating very good outcomes; the overall median score for knowledge, and mean score for coping and total score were all in the second highest quintile indicating outcomes.
- Participants with very severe disease scored lower compared to all other groups in the PIH coping and PIH total score.
- There were no differences observed in PIH subscales by comorbid depression and anxiety, location and education status.

Information given by healthcare professionals and searched for independently.

- Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given least often.
- Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for.

Most trusted information sources

- Across all participants, information from the not for profit or charitable organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies. This order of trusted information source was the same for all of the subgroups (disease severity, comorbid depression and anxiety, location and education) with the exception of those with moderate disease. Those with moderate disease most trusted information from government.

Access to information

Participants were asked what information they had accessed in relation to AD. There was one key theme in relation to accessing information via the internet. The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).

There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.

Table 6.1: Access to information

Access to information	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant described accessing information through the internet in general	73	73.00	8	72.73	18	69.23	28	68.29	19	86.36
Participant described primarily accessing information through treating clinician	25	25.00	2	18.18	11	42.31	10	24.39	2	9.09
Participant describes not seeking / researching information extensively	12	12.00	3	27.27	5	19.23	4	9.76	0	0.00
Participant described primarily accessing information through other patient's experience	10	10.00	0	0.00	2	7.69	4	9.76	4	18.18
Participant described accessing information primarily through journals (research articles)	8	8.00	1	9.09	0	0.00	4	9.76	3	13.64
Participant describes receiving information from books and newsletters	8	8.00	0	0.00	1	3.85	5	12.20	2	9.09
Participant described accessing information primarily through Facebook	5	5.00	1	9.09	0	0.00	2	4.88	2	9.09
Participant describes receiving information from chemist /pharmacist	5	5.00	0	0.00	1	3.85	3	7.32	1	4.55

Expectations of health professional communication	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant described accessing information through the internet in general	30	76.92	31	75.61	42	71.19	41	70.69	32	76.19
Participant described primarily accessing information through treating clinician	10	25.64	10	24.39	15	25.42	16	27.59	9	21.43
Participant describes not seeking / researching information extensively	2	5.13	3	7.32	9	15.25	7	12.07	5	11.90
Participant described primarily accessing information through other patient's experience	4	10.26	5	12.20	5	8.47	5	8.62	5	11.90
Participant described accessing information primarily through journals (research articles)	2	5.13	3	7.32	5	8.47	6	10.34	2	4.76
Participant describes receiving information from books and newsletters	3	7.69	3	7.32	5	8.47	3	5.17	5	11.90
Participant described accessing information primarily through Facebook	3	7.69	3	7.32	2	3.39	3	5.17	2	4.76
Participant describes receiving information from chemist /pharmacist	3	7.69	3	7.32	2	3.39	2	3.45	3	7.14

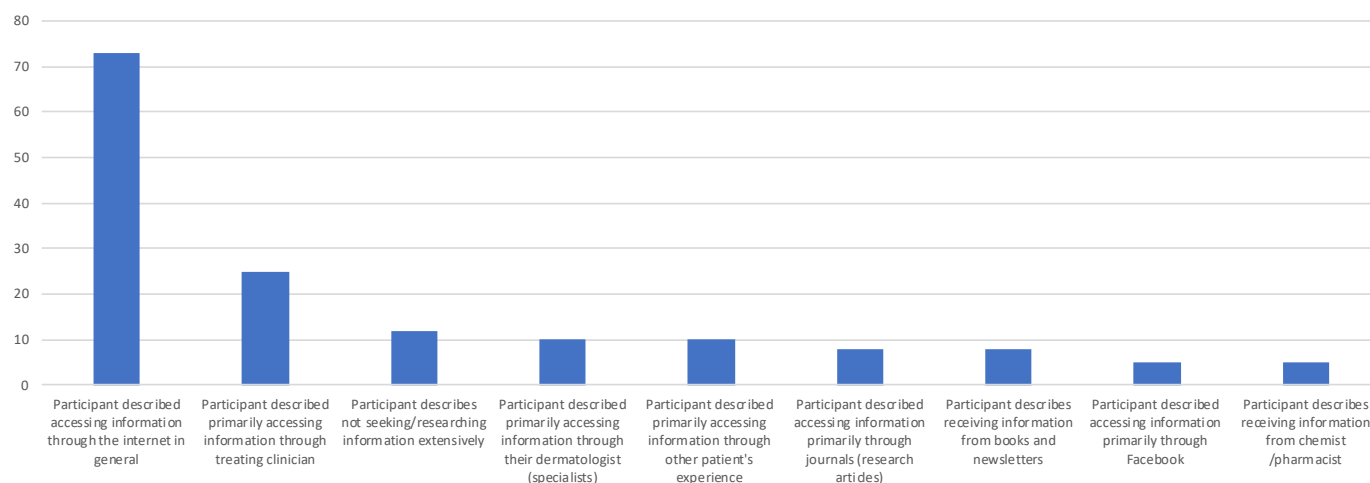


Figure 6.1: Access to information (% of all participants)

Information that was helpful

After talking about all of the information that participants had received, they were then asked what information had been helpful. There were a number of themes identified, however the main theme described by 21 participants (21.00%) was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew:

At some point, there was just following certain things like making sure when you head to showers you put on your moisturizer and those sort of things. But I haven't really been able to find a specific, anything really that has been helpful, or that I would have gone to the doctor and said, "Can you look at this?". **Participant 45**

Not really. I mean, I've read things, and it says, you know, you really should keep your skin really moisturised; that's the best thing for eczema, and things like that. Then I; but that doesn't necessarily help me. I sort of feel, lot of things I read, that, everyone's different with their eczema. And we'll, we have different ways to, to heal it, to make us feel better. And, we all have different triggers. So, I sort of, a lot of the information is quite generic. And, I don't - ... just always the same. You've got dry skin, put, put moisturiser on it. And -... and to me, that doesn't - ... necessarily help. **Participant 60**

Not a lot, actually. Because no one can really tell me why I've got eczema. Because no one else in my family has it except myself. **Participant 84**

There were 14 participants that described information about diet as being a useful topic, particularly in

relation to understanding how diet can impact or trigger AD:

I think the most helpful thing for me have been the...to make the connection between eczema and my gut health, because I really-- over the past two years or so, I really started to eat a lot better and really-- I've been exercising a lot and looking at my diet and eating a lot of fresh healthy food, because of my eczema. Avoiding things such as dairy or gluten, because I know that they're inflammatory to eczema. I've just been looking up from a diet perspective, "What can I do?" Because from my perspective, "Steroid cream's not working, cortisol injections aren't working. What can I do in order to help myself?" But again, I haven't seen any massive improvements with that. **Participant 38**

Well, yes. I was actually walking home one day, and I crazily had the universe as my call light. I just read a book called The Eczema Diet. I was originally just sitting straight on the road. I was like, "Wow, that's strange. Picked it up, and I've just kind of been reading it like crazy. Just, I mean, the things ... That are in her book sound really helpful, and it's really well written. It's like the elimination diet as well. That's something that ... I think stuck with me. **Participant 58**

There was a book that came out ... Actually two books. And you'd be surprised, they're cook books. Which is what I do. So yeah, one was super ... Something Super Food Grain ... But before that, Super Food brand came out. It was super food ... It told you all about yeah ... Different foods that ... different nutrients and I just kind of, "Oh yeah, this is what could be a problem for me." And then same with Gluten Free cook books. They give you a big blurb about the damaging effects of gluten on your diet and on your tummy. So I've then looked into bio-immune stuff and got help. **Participant 61**

Another theme noted by 14 participants (14.00%) was that information about other people's experience was helpful. This was in relation to being able to see what other people have tried, what has worked and what has not worked:

Probably, as I said, Doctor Google. Looking, reading other people's experiences online. What's worked for them, seeing if it works for me. Trial and error. **Participant 12**

I think that chats that people ... because we're now on the Internet, people chat and say back, like on the Facebook sites and Twitter and all that. Here are the people's stories and what they've tried. It might not help much, but it's just a journey that you realise that you're not actually the only one. And- Yeah. And perhaps someone's tried something completely stupid, and you might have suspected it was completely stupid, but now they've told you it didn't work. And so you go, "No, I'll put a nail in it." **Participant 32**

I think the real life stories because I've been in the same situation myself. And they've had success or something, then that's what I find helpful. **Participant 51**

There were 13 participants (13.00%) that described the internet being a useful source of information, particularly because of its convenience and wide range of information:

The first time I got information for it, the doctor gave me an information from the Better Health channel. So, that was descriptive. And then later on I found the eczema remedy type of thing. It was just tips, a guide or something like that. And then on a Juvie website I think it was, and then another similar Better Health channel. It was like a health guide type of thing. I think it was more like a dermatologist website or something- ... And then it shows what not to use and what to use. That type of thing, yeah. **Participant 21**

Yes, I believe it is good because nowadays it's so easy to have access to information through the internet. It's not everything that you can trust because I've tried so many different treatments and it just got worse like, "It's good for your skin to find some coconut oil." It's a lie because of all your blogs, your skin should breathe and information like blood. Once you collate and the oil blocks. I got such a bad inflammation at that time. I had to be careful with what I read and with what I try in my body. **Participant 57**

I found the internet to be really helpful just because you get access to a wide variety of voices and you can really

get both sides of whether it works for someone or doesn't work for someone. You can kind of balance that but, it's a huge wealth of information that you can access. My GP, they haven't been a huge help. All they do is prescribe me steroid cream, that's it. So, they haven't been wonderful. Yeah, I'm going to say the internet because that's where I read up on a few coping mechanisms and a few things to try that have actually worked for me so, I'll say that that's been the best resource. **Participant 66**

Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%):

Participant describes information about specific treatments as being useful

Well, obviously, consumer information for medications. If I'm prescribed anything, I always check it out for consumer information that's relevant. It's always helpful to some point, sometimes it's alarming because it tells you all the things that could go wrong. But that's important to know anyway. **Participant 20**

What's been helpful? Probably information on antihistamines, and managing the allergy sides of things, to then cope with the eczema. Yeah, knowing about the side effects, for example the steroids I'd have to take, so I could try and put things in place and just know what was coming up beforehand. **Participant 34**

The medical information and recently the consumer information. **Participant 40**

Participant describes information about allergies/potential triggers as useful

Here, I have to say, that not a lot of that has been helpful because probably I don't know that my eczema severe enough. It's probably been more helpful around links back with other things, like my allergies. That's probably where I've found information that's been very helpful. Yeah. **Participant 8**

Yeah, it was. I was probably more helpful, again, because it was something I could control myself. It took a bit of time to do because it's quite different ... Like, it's not hard but, again, it's something to try and you commit through the day. That you try and maintain what you're eating all the time and that that's the good stuff. And, usually it's not particularly exciting food, it's relatively bland. And, things like, I suppose, what I'm wearing. So, I only wear cotton clothes. I don't wear

*synthetics. And, things like in my room, I'm always vacuuming dust. So about maintaining my home lifestyle as well. Just reading about, need to know irritants like that can effect you, even though it doesn't effect that. **Participant 18***

*What's been helpful? Probably information on antihistamines, and managing the allergy sides of things, to then cope with the eczema. **Participant 34***

In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

Table 6.2: Information that was helpful

Information that has been helpful	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes no or very limited information has been helpful	21	21.00	3	27.27	3	11.54	9	21.95	6	27.27
Participant describes dietary information being helpful	14	14.00	4	36.36	2	7.69	6	14.63	2	9.09
Participant describes being able to read or learn about other patient's experience as helpful (Knowing they aren't alone)	14	14.00	1	9.09	5	19.23	5	12.20	3	13.64
Participant describes information from internet which was helpful	13	13.00	0	0.00	4	15.38	5	12.20	4	18.18
Participant describes information about specific treatments as being useful	10	10.00	0	0.00	4	15.38	3	7.32	3	13.64
Participant describes information about allergies/potential triggers as useful	9	9.00	1	9.09	2	7.69	4	9.76	2	9.09
Participant describes information from GP or specialist as being helpful	9	9.00	1	9.09	5	19.23	3	7.32	0	0.00
Participant describes information about alternatives to corticosteroids as being helpful	8	8.00	0	0.00	1	3.85	4	9.76	3	13.64
Participant describes information about the underlying cause of AD as being helpful	7	7.00	1	9.09	1	3.85	1	2.44	4	18.18
Participant describes all information as helpful	6	6.00	0	0.00	3	11.54	2	4.88	1	4.55

Information that has been helpful	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes no or very limited information has been helpful	8	20.51	8	19.51	13	22.03	10	17.24	11	26.19
Participant describes dietary information being helpful	5	12.82	4	9.76	10	16.95	7	12.07	7	16.67
Participant describes being able to read or learn about other patient's experience as helpful (Knowing they aren't alone)	5	12.82	8	19.51	6	10.17	9	15.52	5	11.90
Participant describes information from internet which was helpful	5	12.82	7	17.07	6	10.17	5	8.62	8	19.05
Participant describes information about specific treatments as being useful	4	10.26	3	7.32	7	11.86	6	10.34	4	9.52
Participant describes information about allergies/potential triggers as useful	4	10.26	3	7.32	6	10.17	4	6.90	5	11.90
Participant describes information from GP or specialist as being helpful	3	7.69	2	4.88	7	11.86	7	12.07	2	4.76
Participant describes information about alternatives to corticosteroids as being helpful	3	7.69	4	9.76	4	6.78	7	12.07	1	2.38
Participant describes information about the underlying cause of AD as being helpful	3	7.69	2	4.88	5	8.47	3	5.17	4	9.52
Participant describes all information as helpful	2	5.13	0	0.00	6	10.17	4	6.90	2	4.76

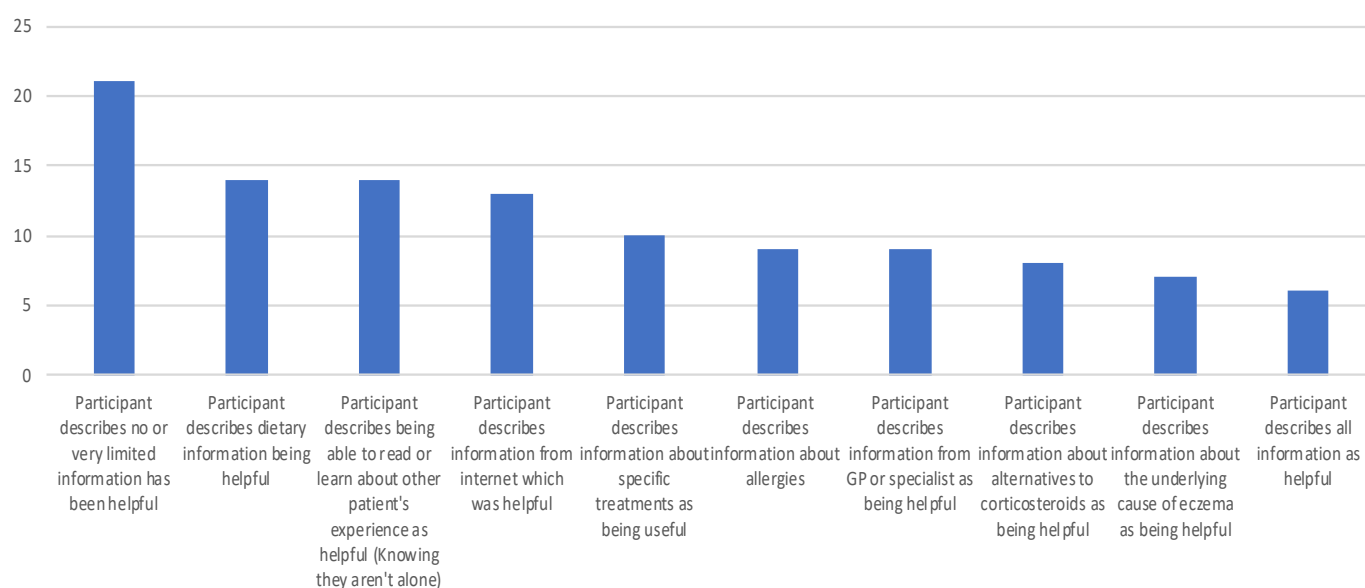


Figure 6.2: Information that was helpful

Information that was not helpful

Participants were asked whether there was any information they had come across that was not helpful. The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). Within this theme, participants spoke about their openness to new information, driven by the willingness to try new things to manage their AD:

*I'm not too sure I could say with that one, either, because pretty much everything I come across, I'm willing to give it a go. **Participant 3***

*I suppose that, no, because it's all learning. Everything that I tried, and I thought come to a bit like a woman going ... I feel like it got me where I am now. Because I feel maybe it's not something that I found useful, but it could be for someone else. **Participant 58***

*I've found all sorts of sites. Nothing is really not been helpful. I've tried every therapy or alternate therapy that there has been. Now, I'm about to go into the acupuncture and hypnosis to see if I can stop scratching. **Participant 89***

There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful:

*No, no. But I'm smart enough about my health to realise that there are things I control and not to do, like, eat less dairy and so on, and don't get hot unnecessarily. And wear your clothes that's all cotton, not synthetic, all that. If I was really struggling, I'd be mindful, but I'm not struggling in my eczema. **Participant 30***

*I don't know about that. No, I don't know that I have come across information that isn't helpful ... apart from, I guess you could say, rubbish users. All that woman's day rubbish. None of that's helpful to anybody. Yeah, and all that marketing for goat's milk cream or ... You know. Yeah. None of that I feel is helpful, but I don't pay much attention to it. But I suspect in the wider community, if you weren't educated, you might spend a lot of money trying a lot of products that weren't helpful. But no, I'm not interested. **Participant 32***

You read a lot of shit out there. Yeah, there's a lot of good stuff published, and there's a lot of rubbish as well. But you've got to read them all, try other things and decide for yourself if it works for you or not. And then you decide if well that was good information or it wasn't. And as I said, what is bad information for me

*might be good information for someone else because it'll work for them but it won't work for me. That's the problem with eczema. So everything is different. People react to one thing like pet dander. And others won't. But to look at the two people side by side without their clothes on they've still got the same thing. One will enter into the room, one person will freak and the other person will start petting it. So yeah, so there's good and bad out there. As I said, you don't know it's good until you try it, you don't know it's bad until you try it. **Participant 95***

The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Within this theme there was a sense of fatigue in relation to being told what worked for other people, particularly if they did not really understand the potential severity of AD:

*More of anecdotal things that a random old lady or something will tell you. They don't do any harm, but it won't do any good either. They probably work for very mild eczema. **Participant 42***

*Probably the most unhelpful is, maybe, the people that tell you something that worked for ... Or gave you for eczema that was there for, like, a week. I don't know how to explain it. **Participant 51***

*I think people's personal stories are not usually helpful. If someone else had eczema or I used this, it's really great and cleared up my eczema in three days. I think other people's personal journeys and how their eczema has been cleared doesn't really help someone else in the same situation. Not everyone's experience has been the same. Like I said, you give things a try because other people recommend them but it doesn't necessarily mean that their information helpful to you whatsoever. **Participant 55***

Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). Participants described frustration in the lack of information provided, particularly in relation to treatment options:

*Plenty of information hasn't been helpful. Just from doctors, I just don't feel like they really understand my condition or what they can do for me or what-- any alternatives are. I just don't feel like the information or lack thereof. What they give me is really helpful, I don't think it is, because they'll just say, "You've got this for life. You've just got a used steroid creams" or something like that. That's not helpful. **Participant 38***

Anyone who says, don't itch. [laughs]The information that I receive from the dermatologist has not been helpful. Those huge things like I said all for an appointment they'll say, "You have this mirror. Here's some steroid cream. Put it on for two weeks twice a day and then taper off." That's about as much as they say and they don't give much more advice than that. That's really unhelpful to receive basic information about medication which is actually really strong, those medications really strong. It screwed up like my whole endocrine system. It's not something that should have been taken lightly and in the way that they talk about it, the way they move you in and out of an appointment in 15 minutes. It makes you feel like actually the medication's fine, there's nothing, it's no big deal and funny now that we know that to go through this process that it's really mucked up everything. I'd have to say that insufficient information given about steroids and their side effects. **Participant 80**

Just the information from my doctors, basically. Just saying that there's nothing I can do. **Participant 98**

The final theme in this section was in relation to a lack of new information (n=10, 10.00%). Participants spoke about the repetitive nature of information provided that gave no new advice or treatment options:

I'm not sure. Maybe just the repetitive things, so when you ... Generally, when doctors talk to you about treatment, they say wet dressings, steroid creams. It's quite repetitive, there doesn't seem to be any new information coming up. So, probably that's been unhelpful because it's stuff I know anyway. **Participant 34**

Basically information that just tells me to keep doing what I'm doing, or information that's so general and basic that it doesn't tell me anything about why what I'm doing is not working, or why my body's responding the way it is to a certain treatment. **Participant 92**

Well, I don't think I've tried anything that's been a disaster. I haven't read anything or seen anything and tried it and it's just been the doctor that set me on some track. But I think it's the lack of information. Just the lack of information that you're given through doctors, or through sources where you go to seek what you would think is kind of expert advice on something. They just don't give you any helpful information. Just giving you the cortisone cream. They're saying that that's going to help. That hasn't been helpful because it hasn't actually really worked. It's hard to say because I don't think I've really found anything terribly helpful but on

the opposite unhelpful because I haven't really found much that's helpful. **Participant 99**

There were two sub-group variations. Participants with mild AD reported no information as being unhelpful less frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

Table 6.3: Information that was not helpful

Information that has not been helpful	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes no information as being unhelpful	28	28.00	6	54.55	7	26.92	12	29.27	3	13.64
Participant describes feeling confident in deciding if something is not helpful (or not credible)	15	15.00	1	9.09	2	7.69	7	17.07	5	22.73
Participant describes experiences and suggestions of other people as being unhelpful	13	13.00	1	9.09	2	7.69	6	14.63	4	18.18
Participant describes the GP/specialist as being unhelpful	12	12.00	0	0.00	6	23.08	2	4.88	4	18.18
Participant describes lack of new information as unhelpful	10	10.00	0	0.00	1	3.85	4	9.76	5	22.73
Participant describes conflicting information as not helpful	4	4.00	2	18.18	1	3.85	0	0.00	1	4.55
Participant describes complementary therapies as being unhelpful	4	4.00	1	9.09	2	7.69	1	2.44	0	0.00

Information that has not been helpful	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes no information as being unhelpful	12	30.77	4	9.76	24	40.68	13	22.41	15	35.71
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	17.95	9	21.95	6	10.17	9	15.52	6	14.29
Participant describes experiences and suggestions of other people as being unhelpful	3	7.69	9	21.95	4	6.78	9	15.52	4	9.52
Participant describes the GP/specialist as being unhelpful	7	17.95	6	14.63	6	10.17	7	12.07	5	11.90
Participant describes lack of new information as unhelpful	3	7.69	6	14.63	4	6.78	4	6.90	6	14.29
Participant describes conflicting information as not helpful	2	5.13	2	4.88	2	3.39	2	3.45	2	4.76
Participant describes complementary therapies as being unhelpful	1	2.56	2	4.88	2	3.39	3	5.17	1	2.38

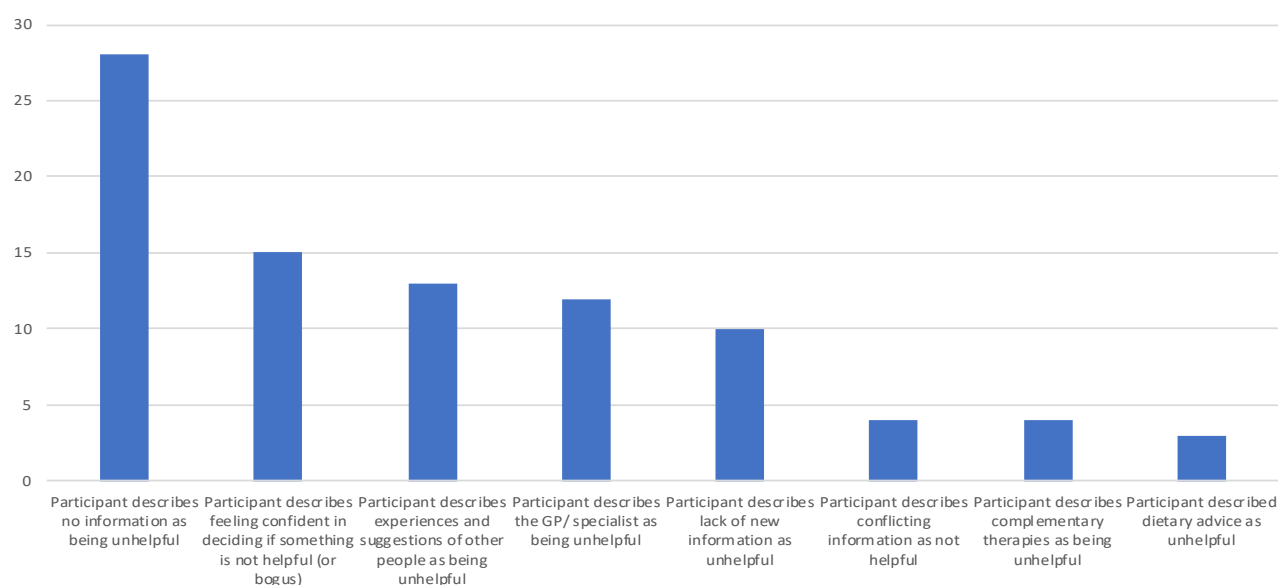


Figure 6.3: Information that was not helpful (% of all participants)

Information preferences (Format of information)

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Almost half of the participants (n=48, 48.00%) described a preference for talking to someone. Of those that described a preference for a talking to someone 27 participants preferred this along with written or online material.

The second most common theme was accessing information online (n=35, 35.00%). Written information was preferred by 4 participants (4.00%) and phone apps by 3 participants (3.00%)

In relation to talking to someone, patients also described the preference of talking to someone as it is easier to show someone their skin and discuss it, so that they are not dismissed:

If someone does thingslike if someone doesn't know what they are talking about, I prefer in person because I can show them the way my skin is like that has been the dermatologist that was really good. But I was like, "I prefer to go in person and talk and show them".
Participant 57

I think in-- When it gets really that bad to the point where I'm so badly scratching my hands and bleeding every day, I want to talk to somebody face-to-face. To be able to probably just show them how severe it's getting as well. I think sometimes when you just say eczema, dermatitis or something like that people go, "Yes." They just think of a couple of little spots of red rash and then that's it. I find when it's really bad, it's just better to talk to somebody face-to-face because you can actually show them how bad things are getting.
Participant 63

Talking to someone. Well, you're the first person that I've talked to. I thought about this. You're the first person I've talked to about eczema for a very, very long time. Very long time. I cannot remember when I last had a proper chat.
Participant 32

The preference for online information was primarily related to ease in which it can be accessed and also the breadth of information available:

My preference is online. Yeah. Yeah, purely for convenience. I can sit down and have my lunch, and I can search something out and do a bit of reading on it while I have lunch or the kids are quiet. Yeah, purely for convenience. I can sit down and have my lunch, and I can search something out and do a bit of reading on it while I have lunch or the kids are quiet.
Participant 2

I think online, or an app, or whatever, would be fine. I think it's pretty hard to actually get to talk to somebody. And I think this interview today would be the first time I've spoken with anybody at this length about it. It's tended to be something to figure outthe snippets that you get, and they're from the specialists, you can find online.
Participant 62

Online for me works best because I can access it anywhere. I've done a little bit of research myself or what I can get access to. That's just convenient as I can read it on the bus or I can read at home, I can read it, probably not work. That's probably not good. How about possibly wouldn't like that? I can read in my time.
Participant 83

Table 6.4: Information preferences (Format)

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a preference for talking to someone	48	48.00	4	36.36	13	50.00	20	48.78	11	50.00
Of those that described a preference for a talking to someone along - these participants preferred this along with written or online material	27	27.00	3	27.27	5	19.23	10	24.39	9	40.91
Participant describes a preference for online information	35	35.00	5	45.45	10	38.46	12	29.27	8	36.36
Participant describes a preference for written information (newsletters, booklets, pamphlets)	11	11.00	0	0.00	5	19.23	5	12.20	1	4.55
Participant describes a preference for a phone app	7	7.00	1	9.09	1	3.85	4	9.76	1	4.55

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a preference for talking to someone	20	51.28	23	56.10	25	42.37	27	46.55	21	50.00
Of those that described a preference for a talking to someone along - these participants preferred this along with written or online material	12	30.77	10	24.39	17	28.81	14	24.14	13	30.95
Participant describes a preference for online information	12	30.77	13	31.71	22	37.29	23	39.66	12	28.57
Participant describes a preference for written information (newsletters, booklets, pamphlets)	4	10.26	3	7.32	8	13.56	6	10.34	5	11.90
Participant describes a preference for a phone app	3	7.69	3	7.32	4	6.78	5	8.62	2	4.76

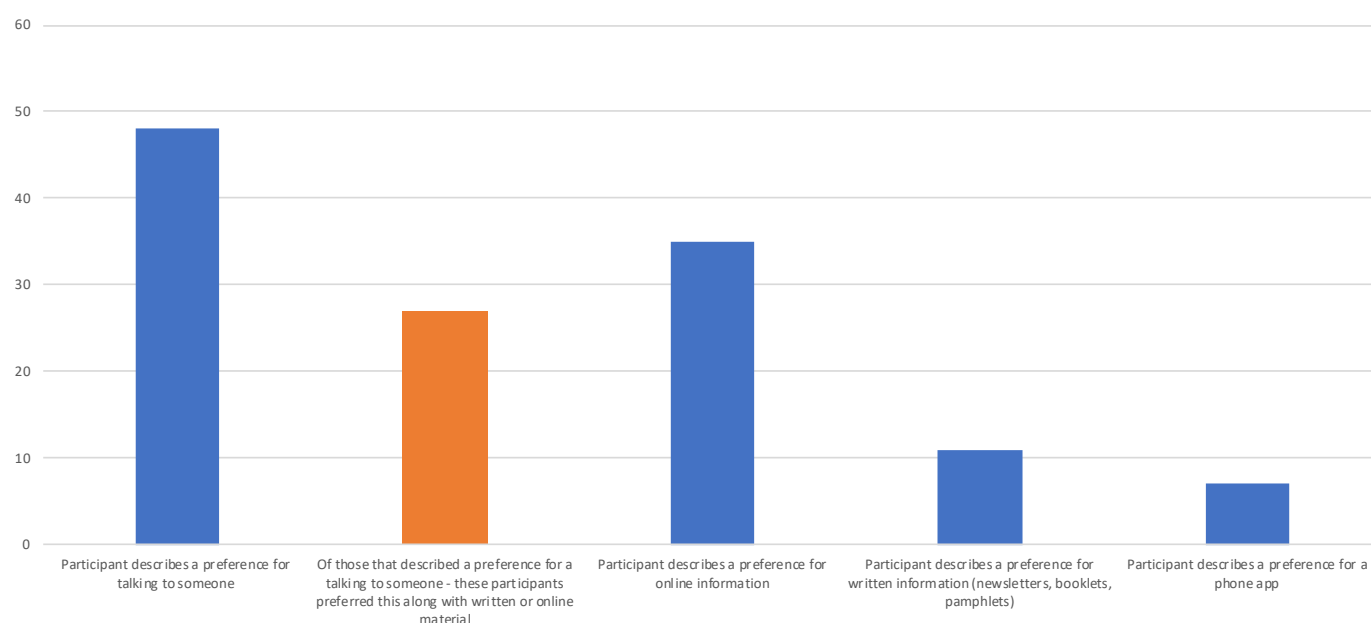


Figure 6.4: Information preferences – Format (% of all participants)

Information preferences (Timing of information)

Participants were asked to reflect on their experience and think about when they were most receptive to receiving information, not when they actually received the information, but when they felt they could take it all in. There was a wide range of responses across six key themes.

The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better.

Participant describes a preference for receiving information when their eczema has become worse (Flare)

Probably when the eczema's bad then you would probably look back at it. So, yeah not straight away, if you just get you probably wouldn't when its bad then you'd go and look at it again. Or re read it, or reuse it or whatever. Participant 27

I think for me, personally, it would depend on why I thought the flare up occurred. If it was due to stress, and those sorts of things, then I would be looking at how to alleviate the stress, as well as how to deal with the eczema. So, I'd probably want the information then. I don't think after the fact would help me, because I'd want the information to help get the flare up under control. As opposed to ... Well, I guess it depends on what sort of the information was. Whether it was how to stop it happening again, or an ongoing treatment plan. If it was an ongoing treatment plan, then I'd want it at the time of the flare up. Whereas if it was sort of how to stop it occurring again, or how to lessen the flare up in the first place, then sort of after the event would be okay. Participant 37

It's usually when I'm at a low point, and so when you're physically low so you're just suffering from all this inflammation, your brain, you can't function, you can't sleep. It's usually those times when you start to ... When you say receive information, it's like you're not receiving any information unless you're looking for it, so you don't have someone trying to tell you about this, that and the other and you should try this and you should try that, unless you're participating in those conversations or in those groups, so I guess it would be when you're really looking for it, which is when I'm really low physically and then that becomes obviously a mental and emotional low as well as the result. Yeah and for me it's usually when I'm having a really bad flare. Participant 91

Participant describes having no real preference for the timing of information

Look, I don't think there is a most-- if I make sense of I had some conversations with the dermatologists that had been fruitful in the sense of my understanding. Usually, it's only one or two points which are significant but otherwise, I would probably, apart from those occasions, I would probably get those from internet sources. Participant 20

I normally jump in without thinking, if it's something I think - I'm not someone who has to research something to the hilt before they start it. Like if I get A sniff of the information and thing 'Geez wow', let's go and I'll just go and buy the thing or do it or whatever. Typically, if I think that there is some merit to it, it's fine. Participant 39

Really any time. There will be times I'll sit down and I'll just read through and go through all these sites and read everybody's experiences and things like that. So I'm sort of open to that all the time. Participant 95

The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information:

Probably, when it's cleared up. If it's all infected and awful, you just want it rid of. But if there's clear skin, which I do have now, it's a lot easier. You're rested. You're not worrying about the itch and you're not-- all of that stuff. Participant 16

I think when the crisis is over. When you can look back on it and go, "Yes, I understand what they were saying now. Or if their information is really helpful." Now hopefully I can move on with that and it won't happen again. Participant 55

After my treatments. After I've started to improve or get past being at the worst point. Because yeah, I can reflect on what works for me or maybe try it different or using the symptoms I've had to compare stuff. Participant 73

The final theme in this section was that participants absorbed information when they were a teen or adult (n=8, 8.00%). In this theme participants spoke about this being the time when they took an active interest in/need to managing their AD:

*When you're a bit younger, you either ignore it or you don't want to listen to your mother. [laughs] As I've gotten older, I've gone out into the world. It affects how you look and your day-to-day life. **Participant 12***

*Yes, it was probably in the last year or so. When I've turned 22. I've just matured a little bit more and decided to take more responsibility for my health. If that makes sense? **Participant 29***

*Yes. Look, I think, probably, it started in the mid-teen years for me. I think, as a child-- as a kid, you just follow what your parents recommend. I think, I hit about 14 or so, and from there, it's just been pretty consistent, in terms of being receptive to info. I'm now 24. Good ten years of learning. **Participant 46***

Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort.) Participants with moderate AD reported a preference for receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

Table 6.5: Information preferences (Timing)

	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a preference for receiving information when their AD has become worse (Flare)	22	22.00	5	45.45	5	19.23	7	17.07	5	22.73
Participant describes having no real preference for the timing of information	22	22.00	1	9.09	5	19.23	10	24.39	6	27.27
Participant describes a preference for receiving information at times when they are well, not too busy with life in general and can take the information.	17	17.00	1	9.09	8	30.77	7	17.07	1	4.55
Participant describes being more receptive to information as a teen or adult	8	8.00	0	0.00	1	3.85	4	9.76	3	13.64

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a preference for receiving information when their AD has become worse (Flare)	7	17.95	3	7.32	19	32.20	15	25.86	7	16.67
Participant describes having no real preference for the timing of information	11	28.21	9	21.95	13	22.03	13	22.41	9	21.43
Participant describes a preference for receiving information at times when they are well, not too busy with life in general and can take the information.	6	15.38	10	24.39	7	11.86	10	17.24	7	16.67
Participant describes being more receptive to information as a teen or adult	5	12.82	4	9.76	4	6.78	4	6.90	4	9.52

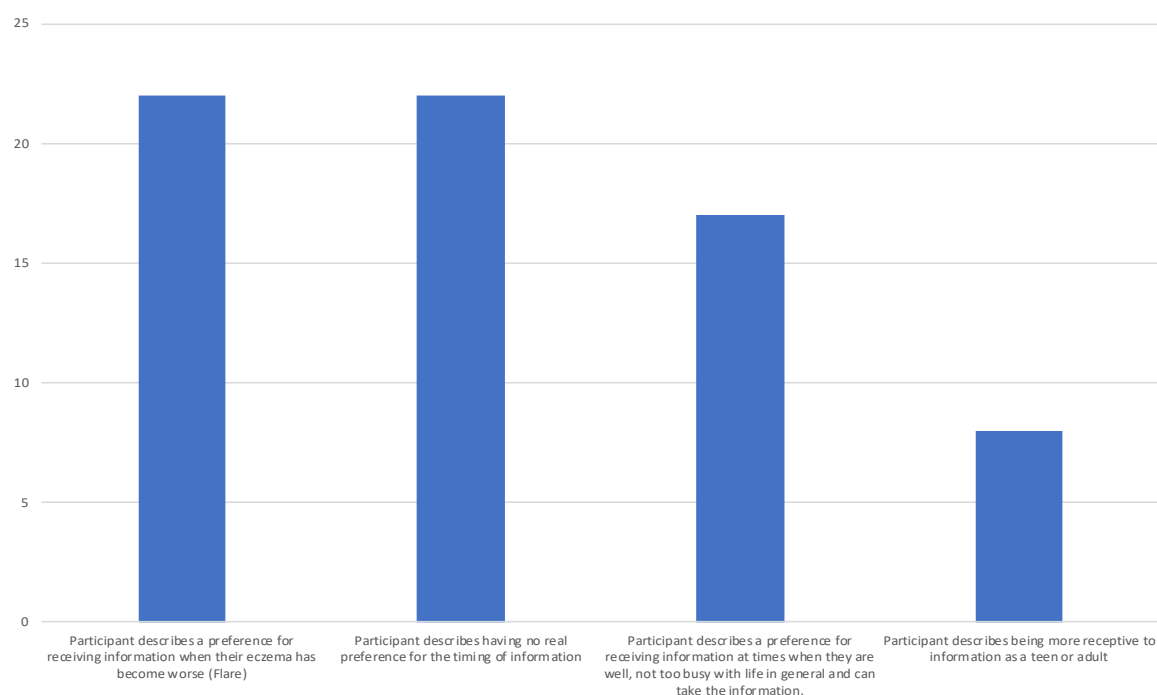


Figure 6.5: Information preferences – Timing (% of all participants)

Communication with health professionals

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general:

Minimal and dismissive. It's pretty much just, "Here's the prescription, go away". **Participant 1**

They kind of just say like, "Do this, do that." I don't know whether my GP I go to. They're pretty busy, at times, to try and get you in, do it, get you out. The ones I spoke to, a couple hundred bucks try this cream really. Again, that was all about five years ago. They might change now, but I just gave up after that and thought "Buggar it, I'll just look after it myself". **Participant 12**

The only healthcare professional that's really helped me is my GP that was able to give me the hydrocortisone and cortisone creams. Skin specialists, I've seen so many skin specialists in my life, and they just look at me and say "There's nothing we can do." There's no magic pill. **Participant 28**

Then she put me onto another GP in her clinic who I started to see. She was really unhelpful, was not willing to talk about options, was not willing to do anything other than prescribe steroids for me. Just said, in the end well after a year of meeting her periodically, we just basically had a personality clash and she said, "I think you should probably see one of the other GP's in the clinic." I said, "Well, I was going to offer you that same thing today." [laughs] **Participant 47**

She just tells me, "You've got to do this, you can't do that". I'm not really, really happy about it, what she ... She doesn't do a lot for me. When I go to the doctor, she never says anything, all she says is "Stop scratching." That's the doctor. She wouldn't say "Have you tried this?", or "Have you been back to the specialist?" No, she doesn't say a word. I don't get a lot of help. You don't get a lot of help, you're on your own, really. You're on your own to really try and help yourself. **Participant 93**

The next most common theme was that communication was overall positive (n32, 32.00%). Where communication was positive, this was often because a two-way conversation, where options had been provided, was held:

They are all pretty good. There's been tons. It's because I've had it for years, I can tell when doctors know the

stuff or not know the stuff or maybe it's more around having to care for the patient. If the experience I felt that, "Yes. The doctor didn't care or she didn't care." Then I wouldn't go back to that professional, because you can get that vibe. Their lack of knowledge, I can accept that. Yes. If I'm happy with the service or the information that was there or the treatment-- not treatment, advice. Then, yes, I'd just take my business elsewhere or get a second opinion. Yes, I'm one of those people that, if I didn't like what heard or wasn't completely happy or second guessing what they said, then I go get a second opinion. **Participant 15**

My GP is quite up to date ... Well, I assume is quite up to date with her suggestions. She'll sort of have a look through my file and go, "Okay, well this is what worked last time. Are we gonna try that again? Or are you looking to try something new?" I guess I'm very much, "Well, this worked last time, let's try this again." I guess, A, because I'm comfortable with just applying a lotion. I know it's not ... Or a cream, or whatever, it's probably not the best way to do it. I probably should look a bit further into my diet and things. But, yeah. She's quite happy to ask me what I think, and then sort of say, "Yeah, I think you're on the right track", or, "I think we should try something new." Or those sorts of things. Whether it be for eczema, or whether it be for the celiac disease, or asthma, or whatever. So I'm acutely aware that sort of all our body systems are all incredibly interactive ... Interlaced, and just dealing with eczema in isolation, probably isn't gonna fix the problem. That it's got to do with my diet, that it's got to do with my lifestyle, and my environment, and all the rest of it. There's no point in just going, "Here's the cream, that'll fix it." Sometimes it is if I just come into contact with wool, or whatever, and I just need something to stop a flare up. But then other times I sort of struggle to find the reason why it's flared up. And it might even be that I've been stressed about something, but I haven't realised exactly how stressed I've been about it. Yeah, very much so. It's only when you sort of look back at it in hindsight you kinda go, "Oh, that's probably why that happened" sort of thing. My GP, as far as my eczema's concerned. But I'm also lucky, I've got a fabulous physio, for sports injuries and things, which happens on a fairly regular basis. **Participant 37**

It's always been pretty good. [laughs] My GP is really, really good with me. He gets me to try new things and whatever. We've got a new cream or this or that. I'm a creature of habit, I like the cream that works. That's what I stick to. I don't generally. I don't like to be looking scabby and red and horrible. **Participant 64**

There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information:

Some of them, they didn't have as much information or the information they're telling me doesn't correspond to the-- some of the stuff I may have already read up on or already know about my condition. Then some of them-- I don't know. Maybe their job, I can sense from them that they just want to get me out of there quick like, "Get over it." Yes. Get the appointment over with..

Participant 15

So I think there's definitely a lack of understanding, lack of knowledge on their part about information, about information that eczema, none of them can really explain to me what eczema is, none of them can really explain to me even just basic stuff, basic information about side effects on steroid creams, side effects on oral steroids. No one mentioned anything about side effects so very little knowledge, very little education to the patient, very disappointing and unwillingness to even just listen really. **Participant 67**

The first time I went and seen a new doctor. He, actually, told me I had scabies. I refused to see that doctor ever again. It's quite difficult because I don't like to show my eczema because I am very embarrassed by it. It is hard for me to go and see someone and discuss my eczema with somebody. **Participant 84**

In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

Table 6.6: Communication with health professionals

Communication with health professionals	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes a healthcare professional being dismissive about AD and about exploring treatment options ('Nothing we can do'/One way conversation)	47	47.00	4	36.36	9	34.62	22	53.66	12	54.55
Participant describes overall positive communication (holistic, two way conversations)	32	32.00	5	45.45	12	46.15	11	26.83	4	18.18
Participant describes that healthcare professionals don't understand AD	15	15.00	0	0.00	4	15.38	5	12.20	6	27.27
Participant describes feeling as though healthcare professionals don't have a lot of time for them	10	10.00	0	0.00	4	15.38	5	12.20	1	4.55
Participant describes negative communication	6	6.00	0	0.00	2	7.69	3	7.32	1	4.55
Participant does not regularly speak to a healthcare professional about their AD	5	5.00	1	9.09	2	7.69	2	4.88	0	0.00

Communication with health professionals	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a healthcare professional being dismissive about AD and about exploring treatment options ('Nothing we can do'/One way conversation)	19	48.72	15	36.59	32	54.24	25	43.10	22	52.38
Participant describes overall positive communication (holistic, two way conversations)	15	38.46	14	34.15	18	30.51	22	37.93	10	23.81
Participant describes that healthcare professionals don't understand AD	3	7.69	8	19.51	7	11.86	10	17.24	5	11.90
Participant describes feeling as though healthcare professionals don't have a lot of time for them	4	10.26	3	7.32	7	11.86	7	12.07	3	7.14
Participant describes negative communication	4	10.26	1	2.44	5	8.47	4	6.90	2	4.76
Participant does not regularly speak to a healthcare professional about their AD	0	0.00	3	7.32	2	3.39	3	5.17	2	4.76

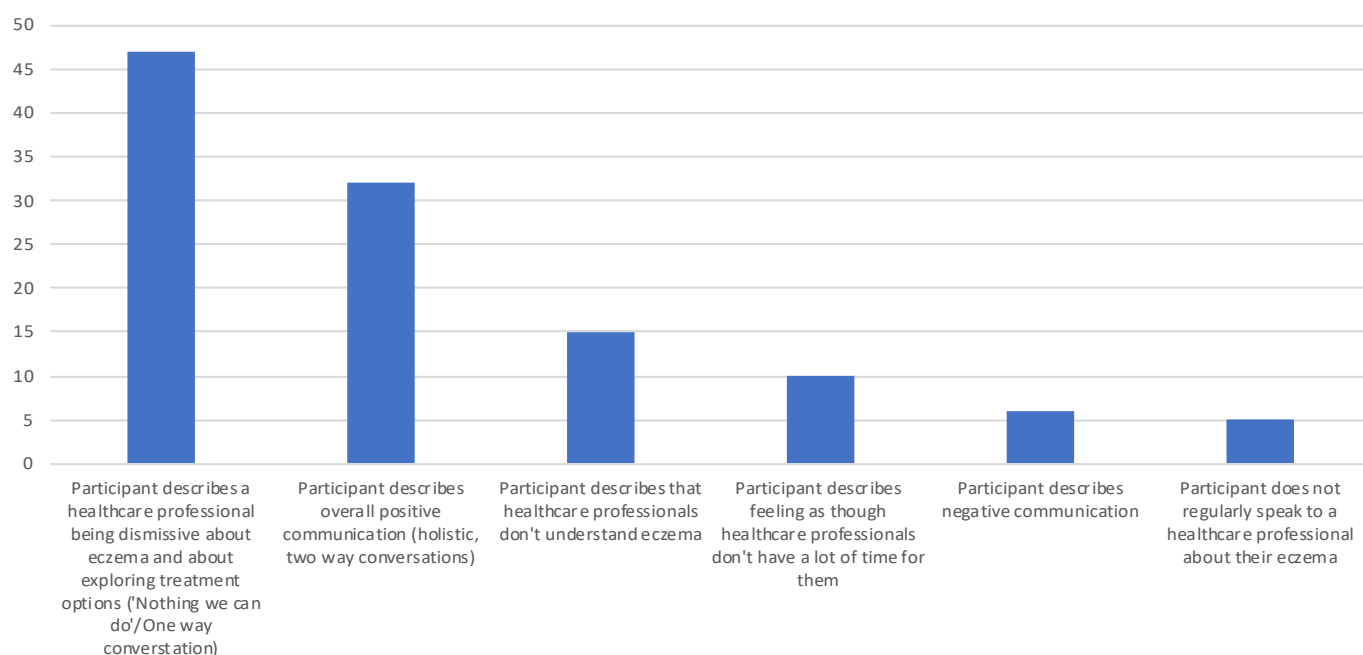


Figure 6.6 : Communication with health professionals (% of all participants)

Who patients talk to about their condition

Participants were asked who they talk to the most about their condition. The majority of participants reported that they mostly speak to their general practitioner (n=42, 42.00%) followed by their dermatologist (n=29, 29.00%). There were also 12

(12.00%) participants that described not having a regular health professional that they spoke to about their AD and ten (10.00%) participants that described not having a preference or not speaking to any, one health professional in particular.

Table 6.7: Who patients talk to

Who patients talk to about treatment	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes trusting their General Practitioner	42	42.00	6	54.55	13	50.00	14	34.15	9	40.91
Participant describes trusting their dermatologist	29	29.00	1	9.09	7	26.92	14	34.15	7	31.82
Participant describes not having a regular health professional that they talk to.	12	12.00	0	0.00	2	7.69	6	14.63	4	18.18
Participant describes trusting a different healthcare professional (Psychiatrist, pharmacist, chiropractor, naturopath, immunologist, nurse)	10	10.00	1	9.09	4	15.38	4	9.76	1	4.55
Participant describes trusting all/no specific healthcare professional	10	10.00	0	0.00	3	11.54	5	12.20	2	9.09

Who patients talk to about treatment	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes trusting their General Practitioner	18	46.15	18	43.90	24	40.68	19	32.76	23	54.76
Participant describes trusting their dermatologist	10	25.64	15	36.59	14	23.73	21	36.21	8	19.05
Participant describes not having a regular health professional that they talk to.	7	17.95	4	9.76	8	13.56	9	15.52	3	7.14
Participant describes trusting a different healthcare professional (Psychiatrist, pharmacist, chiropractor, naturopath, immunologist, nurse)	3	7.69	2	4.88	8	13.56	5	8.62	5	11.90
Participant describes trusting all/no specific healthcare professional	4	10.26	5	12.20	5	8.47	6	10.34	4	9.52

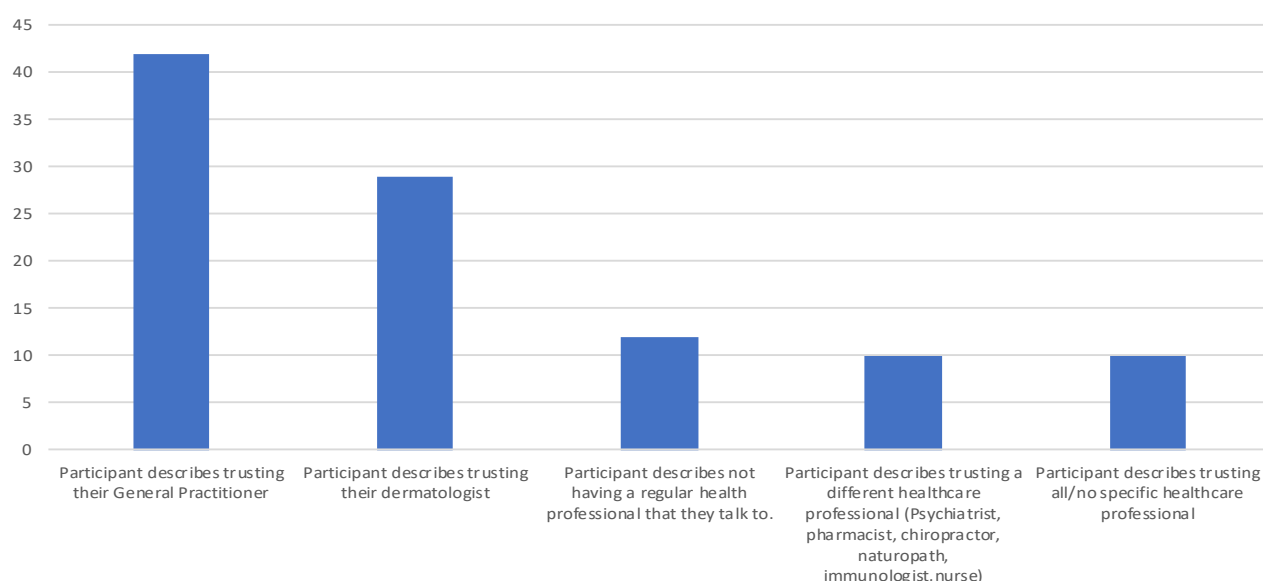


Figure 6.7: Who patients talk to (% of all participants)

Respect shown to patients in the health system

Participants were asked whether they had been treated with respect throughout their experience in the health system. The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously:

I think it's both. I think they dismiss Eczema as the real problem, like you said. I think they dismiss me as a person, because I'm quiet. I'm a young girl. Participant 38

For the most part. The only thing that's a bit bothersome is, sometimes, you just feel rushed when they're just like, "Yes, eczema." They just prescribe you anything. I understand that doctors are very time-poor. Participant 42

Most of the time, yes. I have had instances where I felt, "Buddy, you don't know what you're talking about"

kind of things. But it's more of, I feel with some of the GP's, I've had this my whole life, so I know more than they know. Participant 43

Not all the time. Sometimes, some of the doctors didn't understand my knowledge of it already, and just treat me like it was something new to me, when it's apparently not. Participant 51

In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

Table 6.8: Respect shown to patients

Respect shown to patients	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes being treated respectfully	51	51.00	8	72.73	13	50.00	23	56.10	7	31.82
Participant describes being treated respectfully however at the same time being dismissed, not heard or feeling like there was a lack of knowledge about AD	35	35.00	2	18.18	9	34.62	14	34.15	10	45.45
Participant describes not being treated respectfully	11	11.00	1	9.09	3	11.54	2	4.88	5	22.73

Respect shown to patients	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes being treated respectfully	22	56.41	24	58.54	27	45.76	31	53.45	20	47.62
Participant describes being treated respectfully however at the same time being dismissed, not heard or feeling like there was a lack of knowledge about AD	12	30.77	12	29.27	23	38.98	17	29.31	18	42.86
Participant describes not being treated respectfully	3	7.69	5	12.20	6	10.17	7	12.07	4	9.52

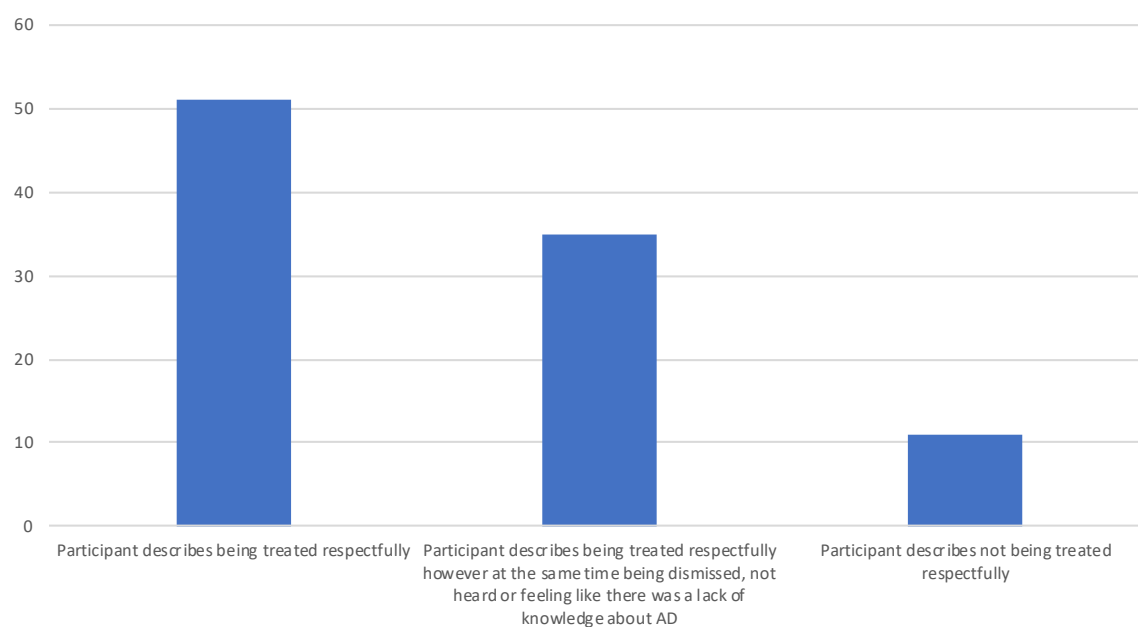


Figure 6.8: Respect shown to patients (% of all participants)

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, treatment, symptoms and coping. A higher score denotes a better outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.9. Overall, the participants scored in the top quintile for adherence to treatment (Median=14.00, IQR =4.00), management of symptoms (Median=20.00, IQR = 4.00), indicating very good outcomes. The scores for knowledge (Median=25.00, IQR = 7.00), coping (Mean=17.00, sd = 7.25) and total score

(Median=76.00, IQR = 18.25) were all in the second highest quintile indicating good outcomes.

Box plots display each of the Partners in Health sub-scales by disease severity, comorbid depression and anxiety, location of participants, and education status (Figures 6.9 – 6.28)

Comparisons of PIH global and sub scales have been made based on disease severity (Figures 6.9 to 6.13, Tables 6.10 to 6.14), comorbid depression and anxiety (Figures 6.14 to 6.18, Table 6.15), location (Figures 6.19 to 6.23, Table 6.16), and education status (Figures 6.24 to 6.28, Table 6.17).

Table 6.9: Summary statistics all participants Partners in Health

Scale	Median	IQR	Possible range
Knowledge	25.00	7.00	0-32
Adherence to treatment	14.00	4.00	0-16
Management of symptoms	20.00	4.00	0-24
Coping*	17.00	7.25	0-24
Total score*	76.00	18.25	0-96

*Normal distribution, Mean and SD reported

Comparisons of PIH sub scales by disease severity

Comparisons of PIH subscales were made disease severity. Summary statistics are listed in Tables 6.10 and 6.13. A one-way ANOVA test was used when assumptions for normality and variance were met (Table 6.11), or when assumptions for normality and variance were not met, a Kruskal-Wallis test sum correction test was used (Table 6.13).

A one way ANOVA test indicated a significant difference in the PIH coping scale between groups [$F(3,96) = 18.36, p < 0.0001$] (Table 6.11). Post hoc

comparisons using the Tukey HSD test indicated that the mean score for those with very severe disease was significantly lower than any other group (Table 6.12).

A Kruskal-Wallis test was indicated a significant difference between severity for the PIH total score, $X^2(3) = 18.31, p = 0.0004$ (Table 6.13). Post hoc pairwise comparisons using Wilcoxon rank sum test indicated that the median coping score was significantly lower for the very severe group compared to all other groups (Table 6.14).

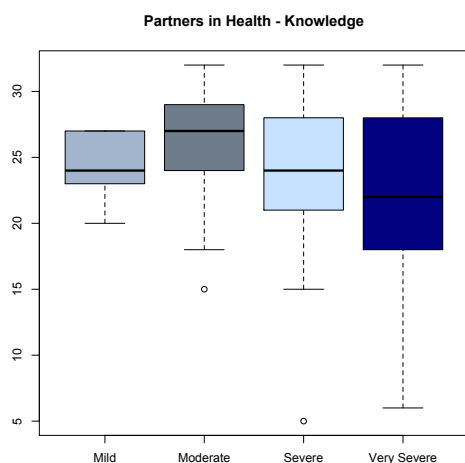


Figure 6.9: Boxplot of PIH knowledge by disease severity

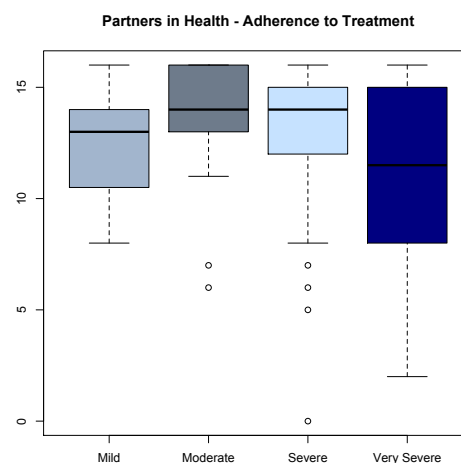


Figure 6.10: Boxplot of PIH adherence to treatment by disease severity

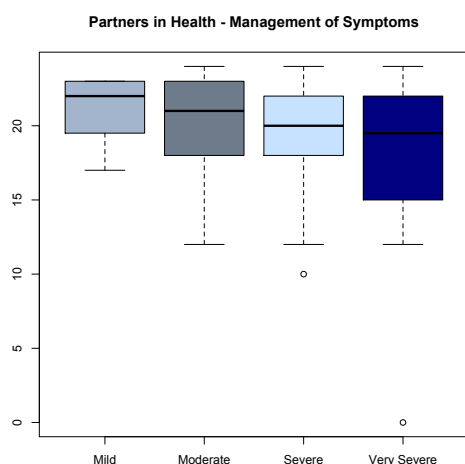


Figure 6.11: Boxplot of PIH management of symptoms by disease severity

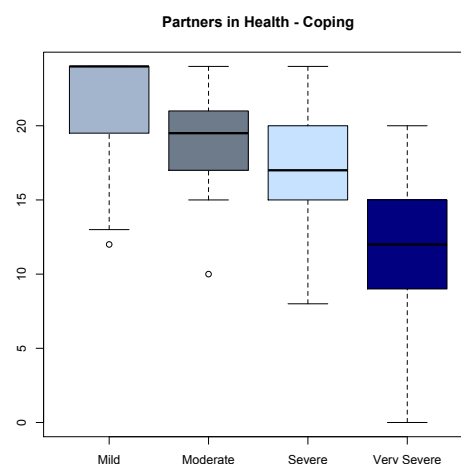


Figure 6.12: Boxplot of PIH coping by disease severity

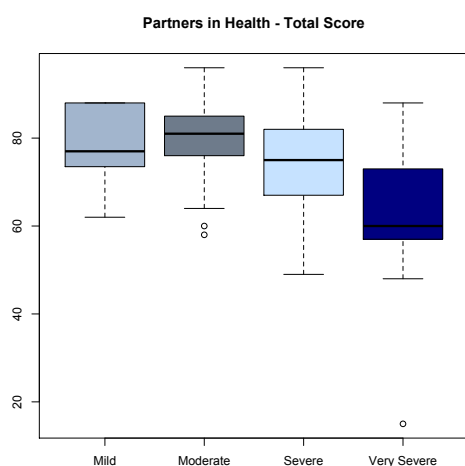


Figure 6.13: Boxplot of PIH total score by disease severity

Table 6.10: Summary statistics PIH coping scale by disease severity

PIH Scale	Group	Count	Mean	Sd
Coping	Mild	11	20.80	4.51
	Moderate	26	19.20	3.23
	Severe	41	17.40	4.04
	Very severe	22	11.60	4.82

Table 6.11: ANOVA table for PIH coping scale by disease severity

PIH Scale		Sum of squares	Df	Mean square	F	P
Coping	Between Groups	920	3	306.66	18.36	<0.0001*
	Within Groups	1604	96	16.71		
	Total	2524	99			

* Statistically significant at $p < 0.05$

Table 6.12: Post hoc Tuckey HSD test for PIH coping scale by disease severity

PIH Scale	Comparison	Mean difference	Lower	Upper	P adjusted
Coping	Moderate -Mild	-1.66	-5.51	2.18	0.6707
	Severe-Mild	-3.43	-7.06	0.20	0.0712
	Very severe – Mild	-9.18	-13.13	-5.24	<0.0001*
	Severe-Moderate	-1.76	-4.44	0.92	0.3185
	Very Severe-Moderate	-7.52	-10.61	-4.42	<0.0001*
	Very Severe-Severe	-5.75	-8.58	-2.93	<0.0001*

* Statistically significant at $p < 0.05$

Table 6.13: Summary statistics and Kruskal-Wallis rank sum test by disease severity

PIH Scale	Group	Count	Median	IQR	X ²	Df	P
Knowledge	Mild	11	24.00	4.00	4.45	3	0.2170
	Moderate	26	27.00	4.75			
	Severe	41	24.00	7.00			
	Very severe	22	22.00	20.00			
Adherence to Treatment	Mild	11	13.00	3.50	4.70	3	0.1949
	Moderate	26	14.00	2.75			
	Severe	41	14.00	3.00			
	Very severe	22	11.50	6.75			
Management of symptoms	Mild	11	22.00	3.50	4.34	3	0.2268
	Moderate	26	21.00	5.00			
	Severe	41	20.00	4.00			
	Very severe	22	19.50	6.50			
Total Score	Mild	11	77.00	14.50	18.31	3	0.0004*
	Moderate	26	81.00	8.50			
	Severe	41	75.00	15.00			
	Very severe	22	60.00	15.50			

* Statistically significant at $p < 0.05$

Table 6.14 **Post hoc** pairwise comparisons using Wilcoxon rank sum test, p-values

PIH scale	Group	Mild	Moderate	Severe
Total score	Moderate	0.8678		
	Severe	0.2267	0.0811	
	Very severe	0.0069*	0.0009*	0.0122*

* Statistically significant at $p < 0.05$

Comparisons of PIH sub scales by depression and anxiety status

Comparisons of PIH sub scales were made between participants comparing those with comorbid depression and anxiety and those that do not. Boxplots are displayed in Figures 6.14 to 6.18. Two sample t-test assumptions for normality and variance were not met,

a Wilcoxon rank sum test with continuity correction was used (Table 6.15). No statistically significant differences were observed between these two groups for any PIH sub scale (Tables 6.15).

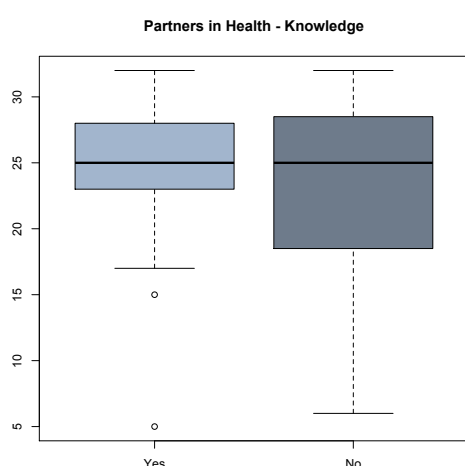


Figure 6.14: Boxplot of PIH knowledge by depression and anxiety status

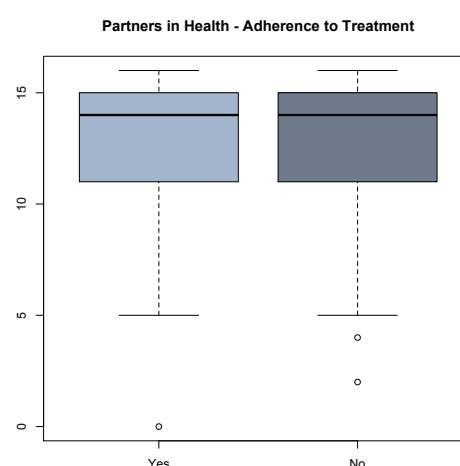


Figure 6.15: Boxplot of PIH adherence to treatment by depression and anxiety status

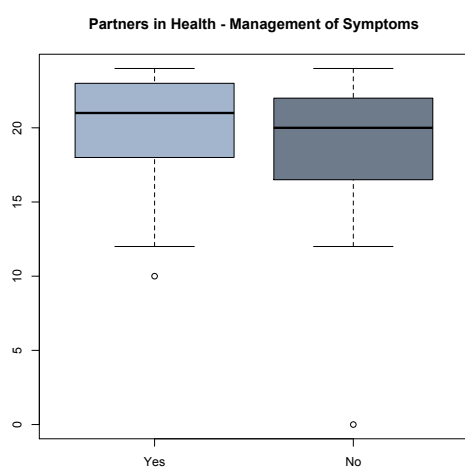


Figure 6.16: Boxplot of PIH management of symptoms by depression and anxiety status

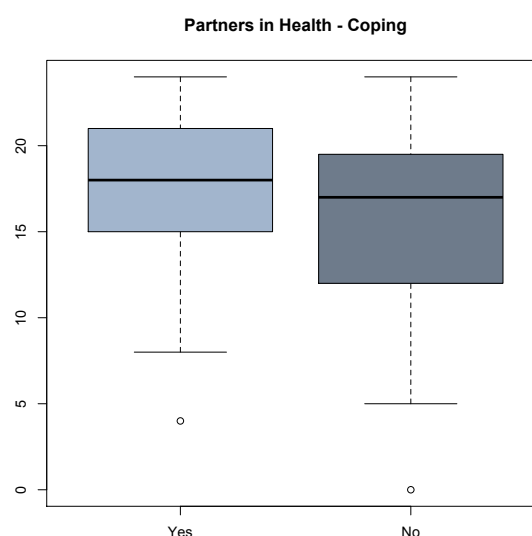


Figure 6.17: Boxplot of PIH coping by depression and anxiety status

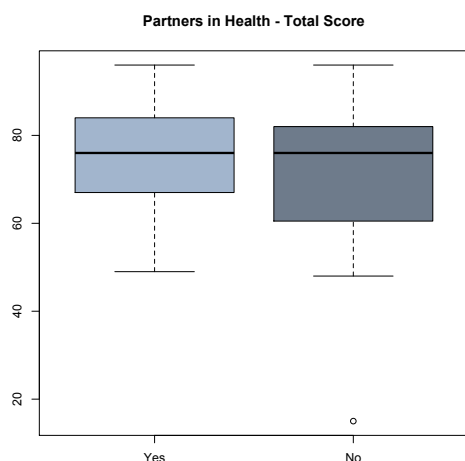


Figure 6.18: Boxplot of PIH total score by depression and anxiety status

Table 6.15: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by comorbid depression and anxiety

PIH subscale	Both depression and anxiety	Count	Median	IQR	W	P
Knowledge	No	61	25.00	5.00	1266.00	0.5899
	Yes	39	25.00	10.00		
Adherence to treatment	No	61	14.00	4.00	1172.50	0.9060
	Yes	39	14.00	4.00		
Management of symptoms	No	61	21.00	5.00	1301.50	0.4279
	Yes	39	20.00	5.50		
Coping	No	61	18.00	6.00	1380.00	0.1780
	Yes	39	17.00	7.50		
Total score	No	61	76.00	17.00	1340.5	0.2871
	Yes	39	76.00	21.50		

Comparisons of PIH sub scales by location

Comparisons of PIH sub scales were made between participants between those that live in metropolitan areas and those that live in regional or rural areas. Boxplots are displayed in Figures 6.19 to 6.23 . Two

sample t-test assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). No statistically significant differences were observed between these two groups for any PIH sub scale (Table 6.17).

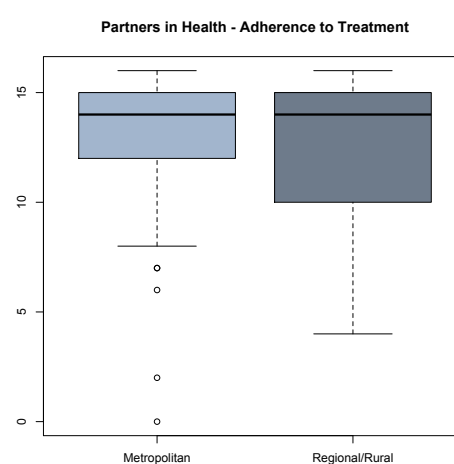
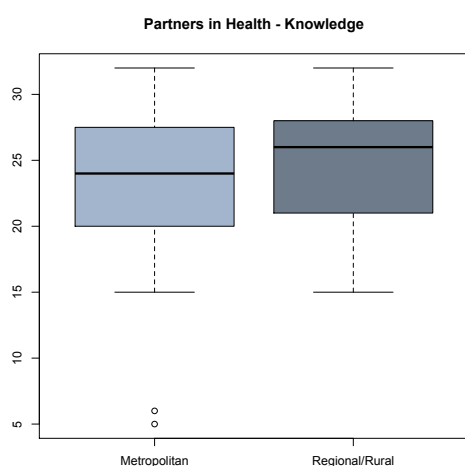


Figure 6.19: Boxplot of PIH knowledge by location

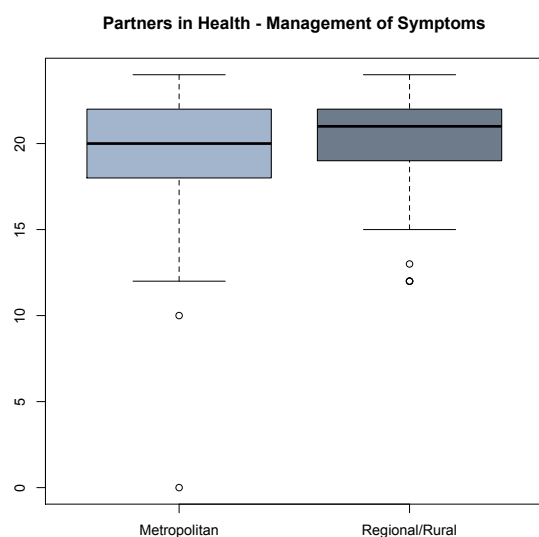


Figure 6.20: Boxplot of PIH adherence to treatment by location

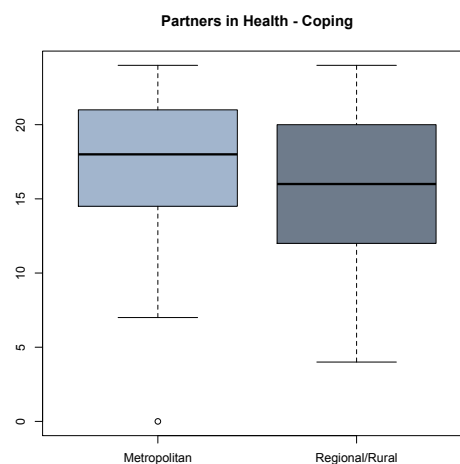


Figure 6.21: Boxplot of PIH symptoms by location

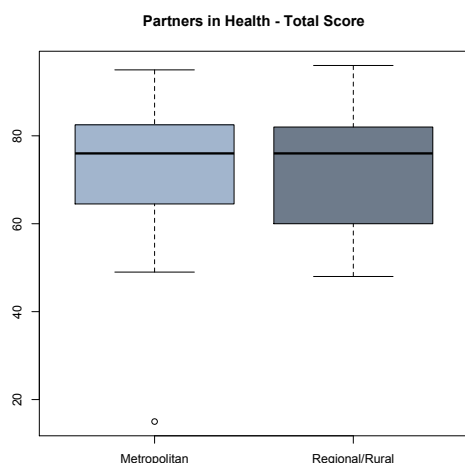


Figure 6.22: Boxplot of PIH coping by location

Figure 6.23: Boxplot of PIH total score by location

Table 6.16: Summary statistics Wilcoxon rank sum test with continuity correction PIH subscales by location

PIH subscale	Location	Count	Median	IQR	W	p
Knowledge	Metropolitan	59	24.00	7.50	1063.00	0.3045
	Regional/Remote	41	26.00	7.00		
Adherence to treatment	Metropolitan	59	14.00	3.00	1286.50	0.5870
	Regional/Remote	41	14.00	5.00		
Management of symptoms	Metropolitan	59	20.00	4.00	1047.50	0.2548
	Regional/Remote	41	21.00	3.00		
Coping	Metropolitan	59	18.00	6.50	1400.00	0.1816
	Regional/Remote	41	16.00	8.00		
Total score	Metropolitan	59	76.00	18.00	1209.05	1.000
	Regional/Remote	41	76.00	22.00		

Comparisons of PIH sub scales by Education

Comparisons of PIH sub scales were made between participants based on highest education levels obtained; high school/trade or university. Boxplots are displayed in Figures 6.24 to 6.28. Two sample t-test

assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17). No statistically significant differences were observed between these two groups for any PIH sub scale (Tables 6.17).

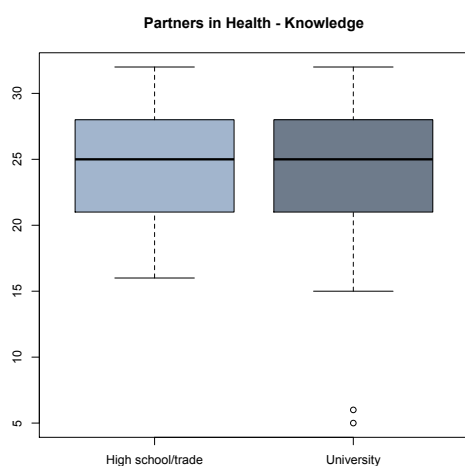


Figure 6.24: Boxplot of PIH knowledge by education status

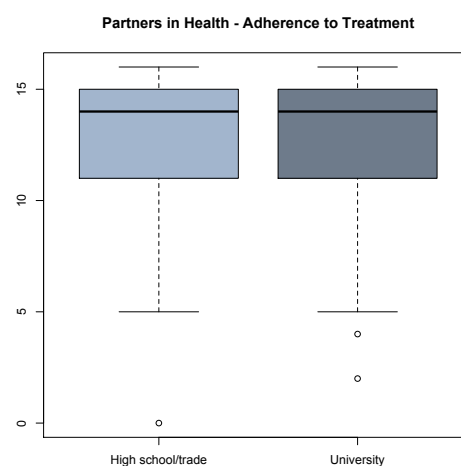


Figure 6.25: Boxplot of PIH adherence to treatment by education status

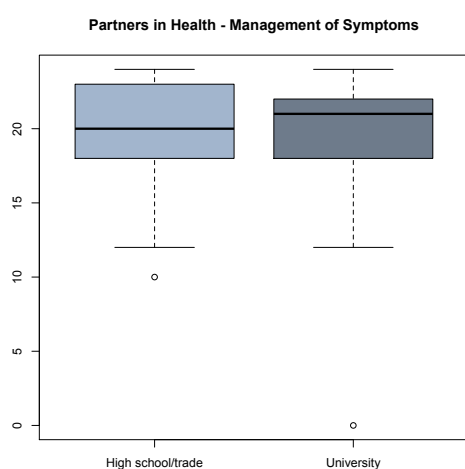


Figure 6.26: Boxplot of PIH symptoms by education status

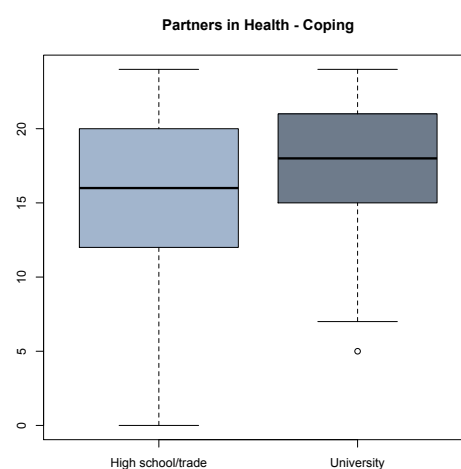


Figure 6.27: Boxplot of PIH coping by education status

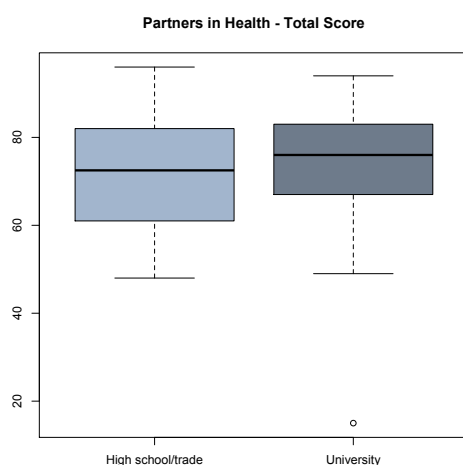


Figure 6.28: Boxplot of PIH total score by education status

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

PIH subscale	Group	Count	Median	IQR	W	P
Knowledge	Trade or high school	42	25.00	7.00	1235	0.9079
	University	58	25.00	7.00		
Adherence to treatment	Trade or high school	42	14.00	4.00	1206	0.9351
	University	58	14.00	4.00		
Management of symptoms	Trade or high school	42	20.00	4.75	1081.50	0.3392
	University	58	21.00	4.00		
Coping	Trade or high school	42	16.00	8.00	1037.5	0.2073
	University	58	18.00	6.00		
Total score	Trade or high school	42	72.50	20.20	1087	0.3616
	University	58	76.00	15.80		

Information given by healthcare professionals and searched for independently.

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given

least often (Figure 6.29). Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for (Figure 6.30). Information given to participants by was similar for by disease severity, comorbid depression and anxiety, location and education. (Figures 6.31 and 6.38). Information given and searched for independently was generally similar for all subgroups (Figures 6.31 and 6.38).

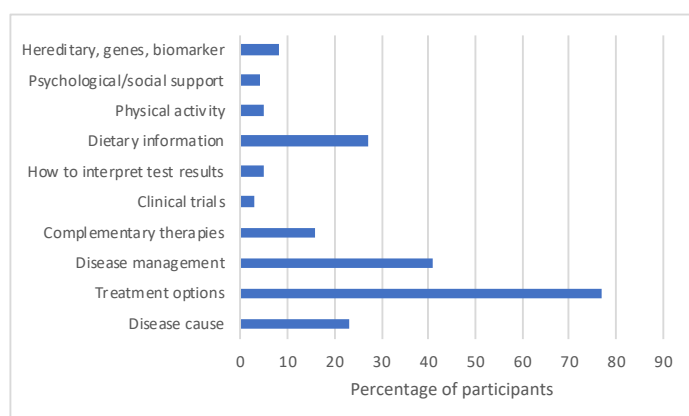


Figure 6.29: Information given by healthcare professionals: all participants

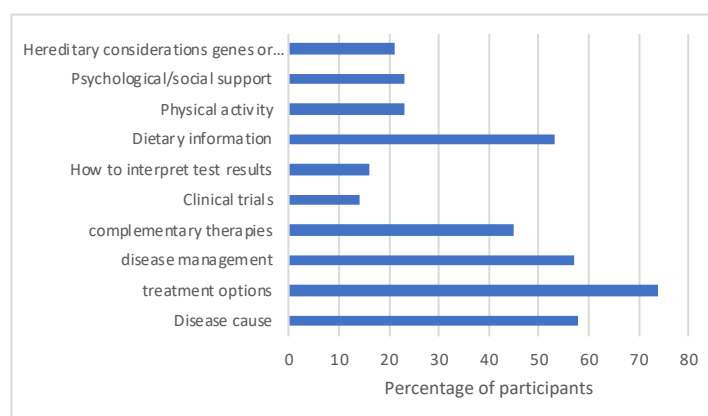


Figure 6.30: Information searched for independently: all participants

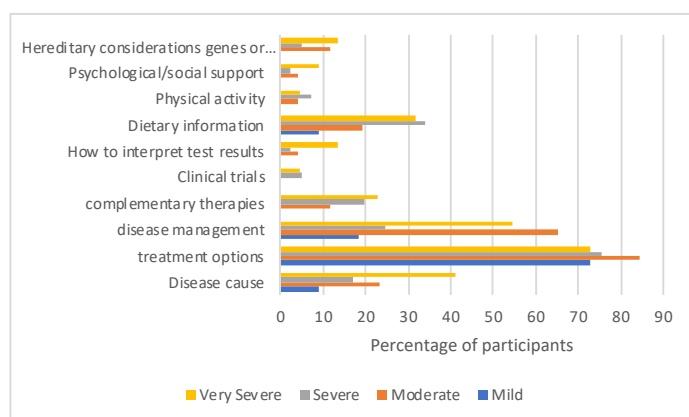


Figure 6.31: Information given by healthcare professionals by disease severity

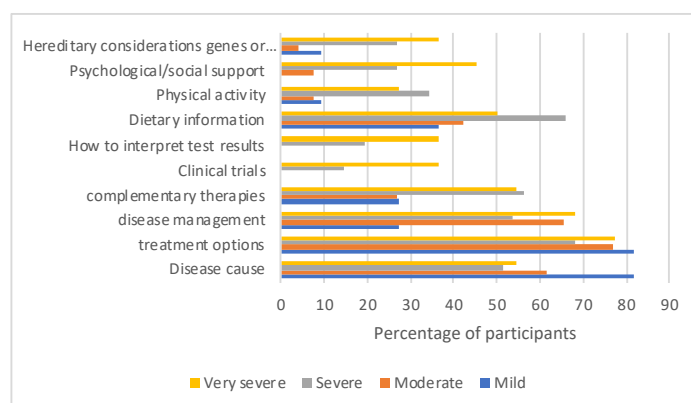


Figure 6.32: Information searched for independently by disease severity

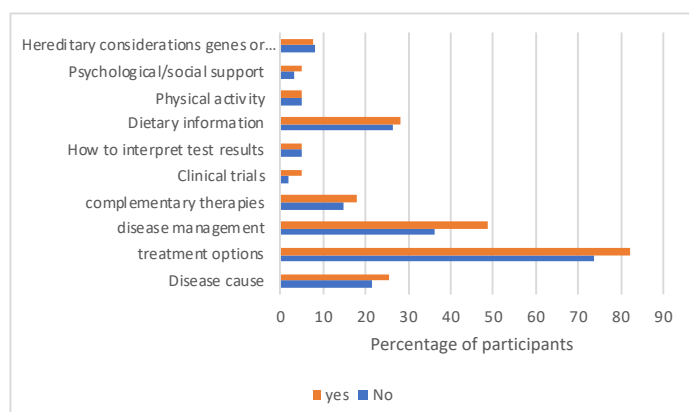


Figure 6.33: Information given by healthcare professionals by comorbid depression and anxiety

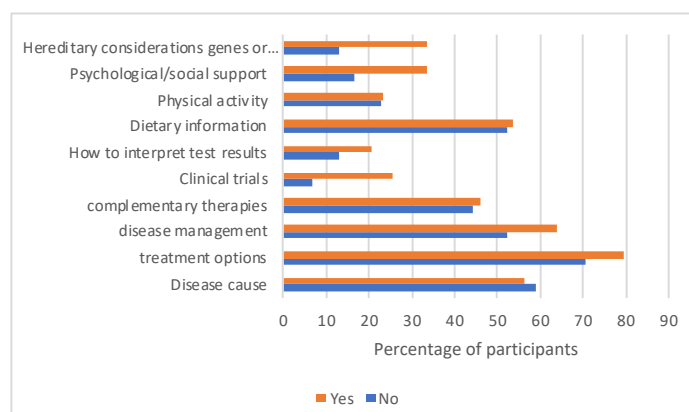


Figure 6.34: Information searched for independently by comorbid depression and anxiety

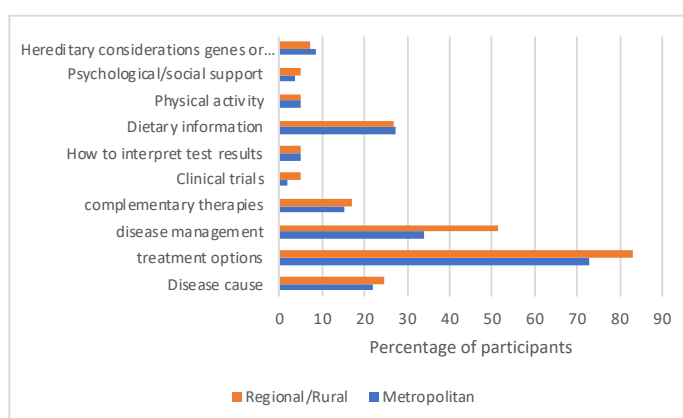


Figure 6.35: Information given by healthcare professionals by location

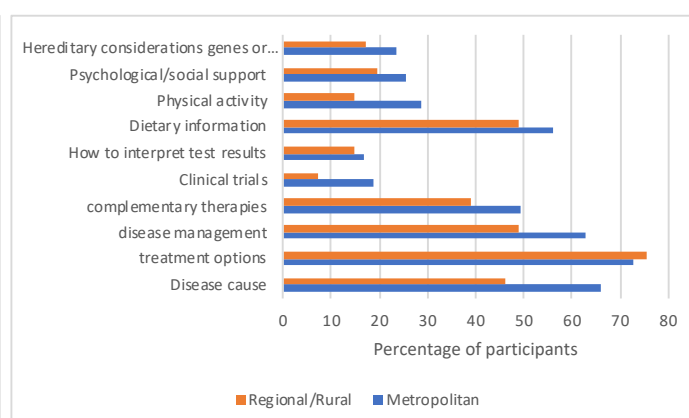


Figure 6.36: Information searched for independently by location

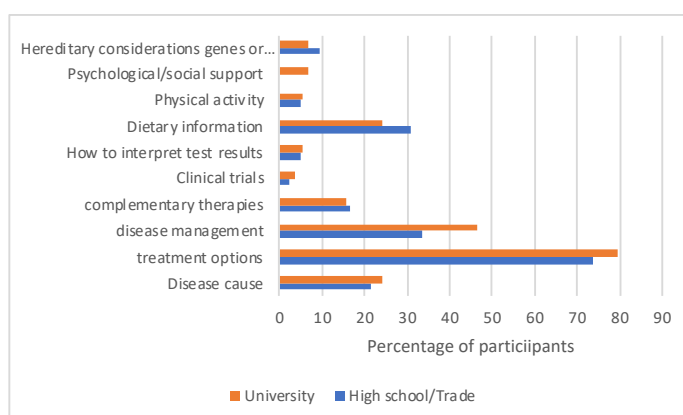


Figure 6.37: Information given by healthcare professionals by education

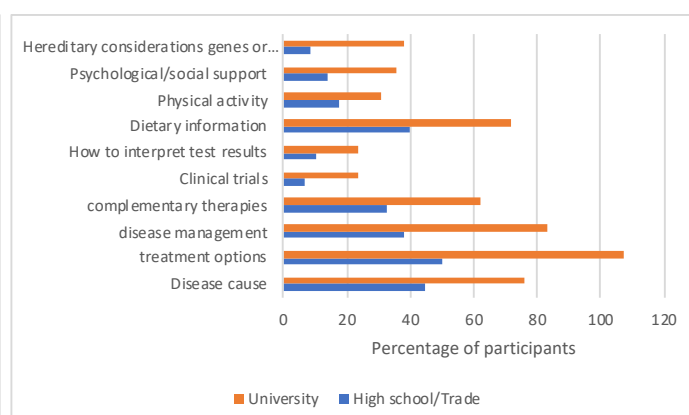


Figure 6.38: Information searched for independently by education

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials (85.00%), how to interpret test results (80.00%), physical activities (75.00%), and psychological/social support (75.00%)

(Figure 6.39). Participants were given most information either from healthcare professionals or independently for treatment options (91.00%) and disease cause (72.00%) (Figure 6.39). Disease cause was the topic that was most searched for independently following no information from health professionals (49.00%) (Figure 39).

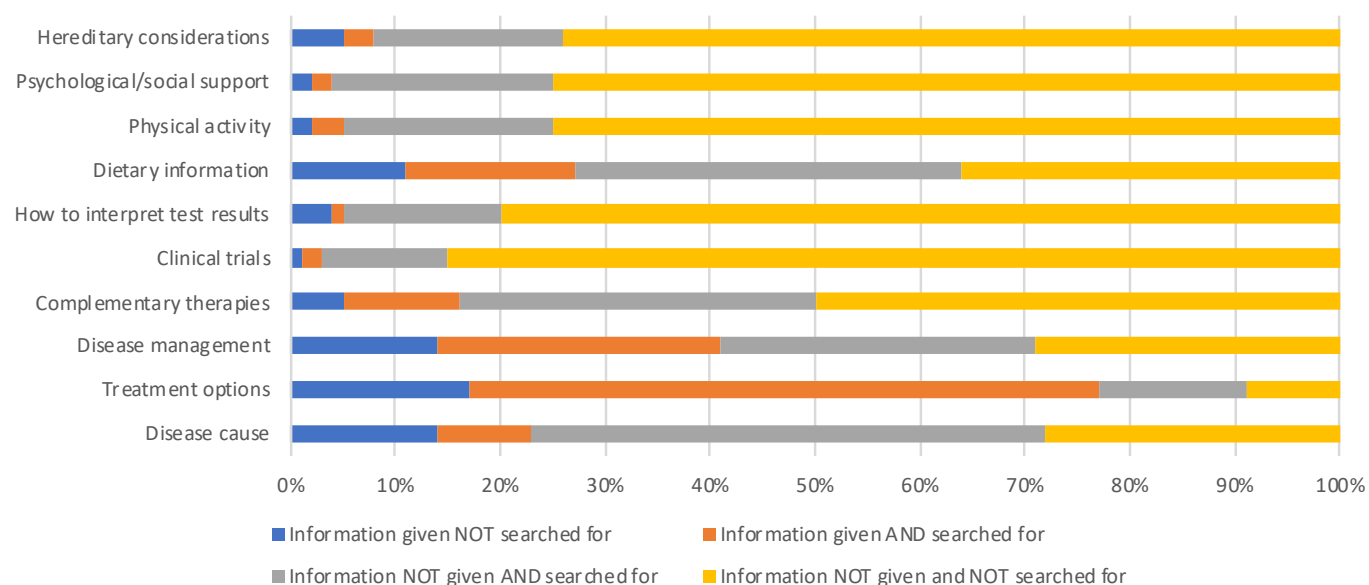


Figure 6.39: Proportion of information given by health care professionals and searched for independently.

Most trusted information sources

Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Figure 6.40. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from the not for profit or charitable

organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies (Figure 6.40). This order of preference was the same for all sub-groups with the exception of those with moderate disease that trusted information from participants' hospital or clinic, the from not for profit or charitable organisations (Figures 6.41 – 6.4

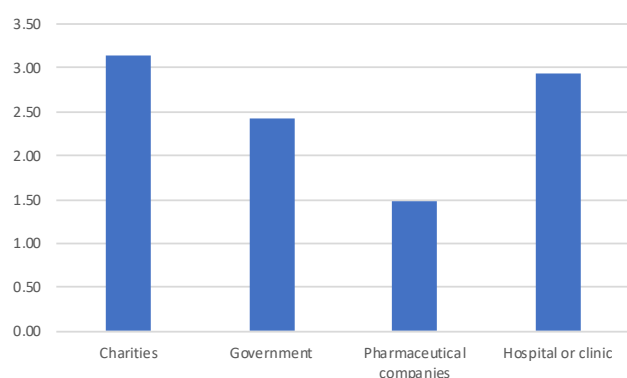


Figure 6.40: Most trusted information sources

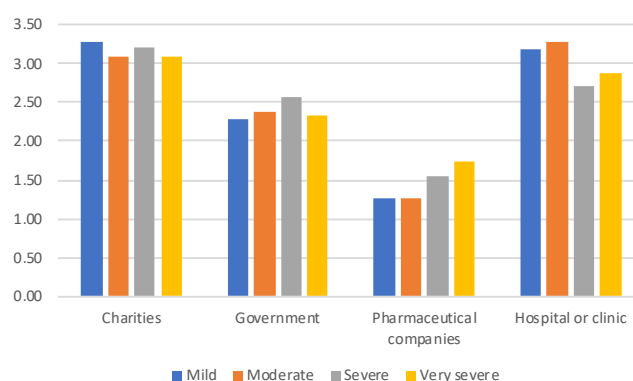


Figure 6.41: Most trusted information sources by disease severity

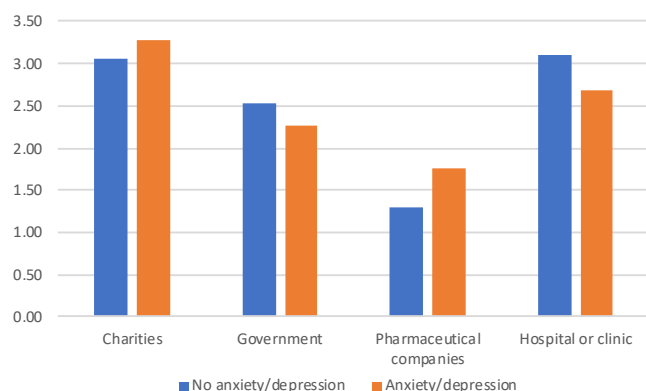


Figure 6.42: Most trusted information sources by comorbid depression and anxiety

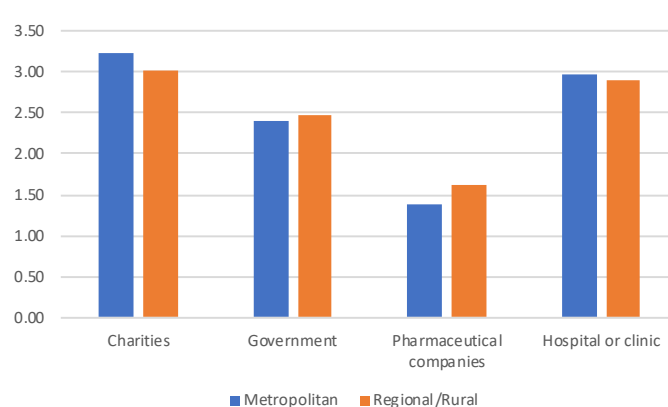


Figure 6.43: Most trusted information sources by location

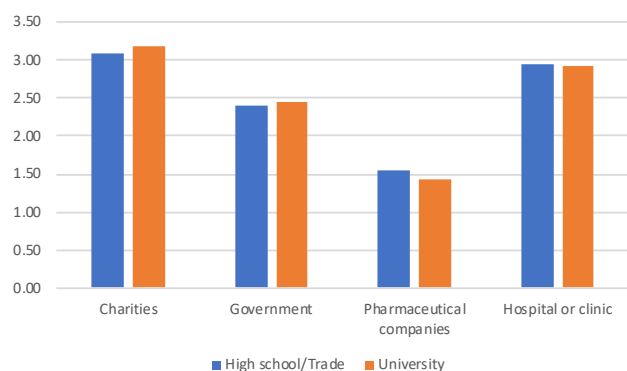


Figure 6.44: Most trusted information sources by education