

## **Section 6**

### **Information and communication**

## **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 type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

## **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 type of information found to be helpful by seven participants (38.89%) was other peoples experiences.

## **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 no information was not helpful (n=6, 33.33%)

## **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. Overall, the most common theme was online information (n=5, 27.78%).

### **Information preferences: Rationale**

The most common theme reason for their information preference was due to being able to digest information at their own pace (n=7, 38.89%).

## **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 that participants described being receptive to receiving information was from the beginning (diagnosis) (n=7, 38.89%), and participants describing being receptive to information after a specific amount of time had passed (n=7, 38.89%).

## **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 experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

### **Healthcare professional communication: Reasons for experience**

There were eight participants (44.44%) that described health professional communication as limited in relation to their understanding of the condition. Where participants described a positive experience, this related to communication being holistic (two way, supportive and comprehensive conversations) (n=5, 27.78%).

## **Partners in health**

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

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

### **Information given by health professionals**

Participants were asked about what type of information they were given by healthcare professionals. Participants with NMOSD were most commonly given information about treatment options (n=10, 55.56%), and disease management (n=6, 33.33%). There were five participants (27.78%) that received very little information from healthcare professionals.

### **Information searched independently**

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. Participants with NMOSD most commonly searched for information about disease management (n=16, 88.89%), disease cause (n=15, 83.33%), treatment options (n=12, 66.67%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants looked for information about how to interpret test results, dietary information, and psychological/social support (n=9, 50.00%).

### **Information gaps: participants with NMOSD**

The topic most often given to participants by healthcare professionals and not searched for independently was about treatment options (n = 5, 27.78%).

The topics most commonly given to participants by healthcare professionals and searched for independently were disease management (n=5, 27.78%), and treatment options (n=5, 27.78%).

Topics most often not given by health professional and not searched for independently were clinical trials (n=12, 66.67%), hereditary considerations (n=10, 55.56%), and dietary information (n=9, 50.00%).

The most common topics that were searched for and not given by a healthcare professional were disease cause (n=13, 72.22%), disease management (n=11, 61.11%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants searched for how to interpret test results, and dietary information without receiving information from healthcare professionals (n=9, 50.00%).

### **Most accessed information**

Participants were asked to rank which information source that they accessed most often. Participants with NMOSD accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often

## **My Health Record**

My Health Record is an online summary of key health information, an initiative of the Australian Government. Participants were asked if they had accessed it, and if they had accessed it, how useful it was. There were nine participants with NMOSD (50.00%) that had accessed My Health Record, seven participants (38.89%) that had not. There was one participant (5.56%) that wasn't sure, and one participant (5.56%) that's did not know what it is.

Of those that had accessed My Health Record, there were three participants (33.33%) that thought the usefulness was very poor, two participants (22.22%) that thought it was poor, and four participants (44.44%) found it acceptable)

## 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 type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

### 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 NMO\_002*

*Pretty much just the internet and I've joined some Facebook groups of people that have it. Participant NMO\_008*

*Goodness. Pretty much YouTube, Google. There wasn't really that much at that particular time. Just watching I suppose YouTube more so, I got more things out of, but still wasn't that great at that time. Participant NMO\_012*

### Participant describes accessing information primarily through Facebook

*The biggest one was to get onto the support page, their NMO 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 NMO\_009*

*Most of my information comes through Facebook, on the NMO Australia site and anything related to that, like they'll put up studies and anything that's going ahead. Participant NMO\_011*

*I'm on the Facebook page, the NMO Australian website. There's a lot of people with NMO who are on there. Participant NMO\_015*

### Participant describes accessing information from a specific health charity: Guthy-Jackson foundation

*I sought out some information from the Guthy-Jackson Charitable Foundation. I don't know if you've heard of them. They're pretty big. Participant NMO\_002*

*It was purely while I was in hospital, I happened to find the Guthy Jackson. Participant NMO\_006*

*Mostly the Guthy-Jackson Foundation in the States we could say were the first NMO-- Anyone in the world that was like a foundation for NMO. Participant NMO\_016*

### Participant describes accessing information primarily through journals (research articles)

*Medical journal, NMO support group. Back then I haven't had to sign up but I never really read anything because I didn't want to read too much and then think too much. Participant NMO\_001*

*I try my best to read-- It takes me a while with my eyes, but to read like research articles from medical journals. Participant NMO\_005*

*More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO\_010*

### Participant describes primarily accessing information through treating clinician

*The general information that I've mainly got is through my MS specialist, and on the internet, and the Guthy-Jackson Foundation, actually. Participant NMO\_004*

*When I was first diagnosed, I looked for information everywhere, my neurologist, my GP, online, and there really wasn't anything available. Participant NMO\_010*

*My neuro immunologist and neurologist gave me really good information and they sat me down a few times for a few hours and just basically went through everything, but it's the nurses when I went to have any infusions, so they were really good in the department. Participant MOG\_006*

Participant describes primarily accessing information through other patient's experience

*I'm also in a group on Facebook where people write about themselves, or any treatments, or anything new that's coming up, so it's mostly all been from me looking on-- I guess, on the internet. Participant NMO\_005*

*The biggest one was to get onto the support page, their NMO 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 NMO\_009*

*More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO\_010*

**Table 6.1: Access to information**

Information accessed	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes accessing information through the internet in general	15	83.33	8	88.89	7	77.78	8	100.00	7	70.00	6	66.67	9	100.00
Participant describes accessing information primarily through Facebook	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	3	33.33	5	55.56
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	2	22.22	4	44.44	3	37.50	3	30.00	4	44.44	2	22.22
Participant describes accessing information primarily through journals (research articles)	4	22.22	3	33.33	1	11.11	3	37.50	1	10.00	1	11.11	3	33.33
Participant describes primarily accessing information through treating clinician	3	16.67	3	33.33	0	0.00	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes primarily accessing information through other patient's experience	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	1	11.11	2	22.22

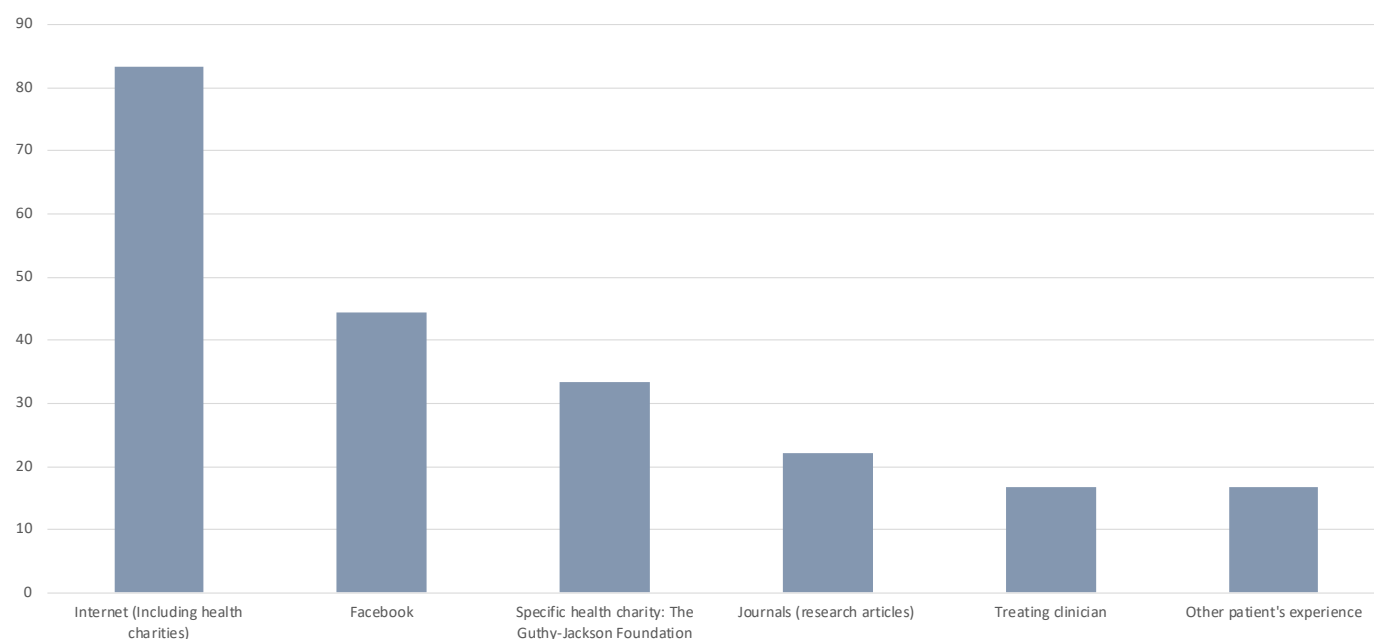
Information accessed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes accessing information through the internet in general	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	6	42.86	9	81.82
Participant describes accessing information primarily through Facebook	8	44.44	4	40.00	4	50.00	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	3	14.29	3	27.27
Participant describes accessing information primarily through journals (research articles)	4	22.22	0	0.00	4	50.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes primarily accessing information through treating clinician	3	16.67	1	10.00	2	25.00	0	0.00	3	25.00	1	42.86	2	18.18
Participant describes primarily accessing information through other patient's experience	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	28.57	1	9.09

Information accessed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes accessing information through the internet in general	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	6	42.86	9	81.82
Participant describes accessing information primarily through Facebook	8	44.44	4	40.00	4	50.00	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	3	14.29	3	27.27
Participant describes accessing information primarily through journals (research articles)	4	22.22	0	0.00	4	50.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes primarily accessing information through treating clinician	3	16.67	1	10.00	2	25.00	0	0.00	3	25.00	1	42.86	2	18.18
Participant describes primarily accessing information through other patient's experience	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	28.57	1	9.09

**Table 6.2: Access to information (Subgroup variations)**

Information accessed	More frequent	Less frequent
Participant describes accessing information through the internet in general	Low to moderate fear Good to very good physical function	High to very high fear Moderate to very poor physical function Aged 18 to 44
Participant describes accessing information primarily through Facebook	More relapses Good to very good physical function	Fewer relapses Moderate to very poor physical function
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	More relapses Moderate to very poor physical function Mid to low socioeconomic status	Fewer relapses Good to very good physical function Aged 18 to 44



**Figure 6.1: Access to information**

### 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 type of information found to be helpful by seven participants (38.89%) was other people's experiences.

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

*Knowing that there's somebody else with it was quite good. That was the best thing for me initially. I suppose it was knowing that people don't die from it. Some people have died from it but it's not the predominant type thing. That there is other people that have been in this situation and it was good to speak to them. That there are some things to do for bladder and for bowels and stuff like that, that other people have written about because it had already happened to them. Participant NMO\_006*

*Putting your mind at ease that you're not alone. That's probably been the biggest one, also certain treatments, some treatments work for some people, I know it doesn't work for others it doesn't yes, but it just gives you peace mind where you can go and research and then see what other treatment's been done and what I might be able to suggest to a neurologist and yes, things like that. Participant NMO\_009*

*Usually the other patients. Participant NMO\_014*

### Participant describes talking to their doctor or specialist as helpful

*I think the most helpful was, to be honest, probably first would have been my MS specialist and then second was the Australian Facebook Group. Participant NMO\_004*

*I went and saw, actually I did go and see a neurologist in LOCATION METROPOLITAN. The information that he sent back through was the most informative about my condition. Participant NMO\_008*

*Probably the most helpful would be my old neurologist. He was exceptionally good. He would sit down and discuss with me if I have a query or anything that was not right. Participant NMO\_013*

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

*More management plans. Knowing about the different types of NMO, what are the effects, whether is a one-off thing, whether it's relapsing form and management plan. What sensation will come up and that kind of stuff, yes the symptoms? 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 NMO\_001*

Probably, I just think sometimes NAME DOCTOR puts up webinars explaining in layman's terms how the water channel works and how this works and that. I find that good because you're seeing it and people can ask questions. I guess once you've got the diagnosis, you've got the treatment, and you're

fine, there's not much more. Unless there's new research coming out, there's not a lot of changes, I guess. Participant NMO\_015

I think it's the one explaining the NMO and what could happen. Participant NMOCA\_006

Table 6.3: Information that was helpful

Information that has been helpful	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes other people’s experiences as helpful (Peer-to-peer)	7	38.89	3	33.33	4	44.44	2	25.00	5	50.00	5	55.56	2	22.22
Participant describes talking to their doctor or specialist as helpful	4	22.22	2	22.22	2	22.22	2	25.00	2	20.00	3	33.33	1	11.11
Participant describes information specific to their condition (and sub-types) as helpful	3	16.67	3	33.33	0	0.00	2	25.00	1	10.00	1	11.11	2	22.22

Information that has been helpful	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes other people’s experiences as helpful (Peer-to-peer)	7	38.89	6	60.00	1	12.50	4	66.67	3	25.00	2	28.57	5	45.45
Participant describes talking to their doctor or specialist as helpful	4	22.22	3	30.00	1	12.50	1	16.67	3	25.00	0	0.00	4	36.36
Participant describes information specific to their condition (and sub-types) as helpful	3	16.67	0	0.00	3	37.50	1	16.67	2	16.67	1	14.29	2	18.18

Information that has been helpful	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes other people’s experiences as helpful (Peer-to-peer)	7	38.89	3	37.50	10	38.46	7	70.00	5	31.25	2	100.00	2	66.67	5	33.33
Participant describes talking to their doctor or specialist as helpful	4	22.22	2	25.00	6	23.08	1	10.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes information specific to their condition (and sub-types) as helpful	3	16.67	2	25.00	5	19.23	3	30.00	3	18.75	0	0.00	0	0.00	3	20.00

Table 6.4: Information that was helpful (Subgroup variation)

Information that has been helpful	More frequent	Less frequent
Participant describes other people’s experiences as helpful (Peer-to-peer)	High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Low to moderate fear Good to very good physical function University

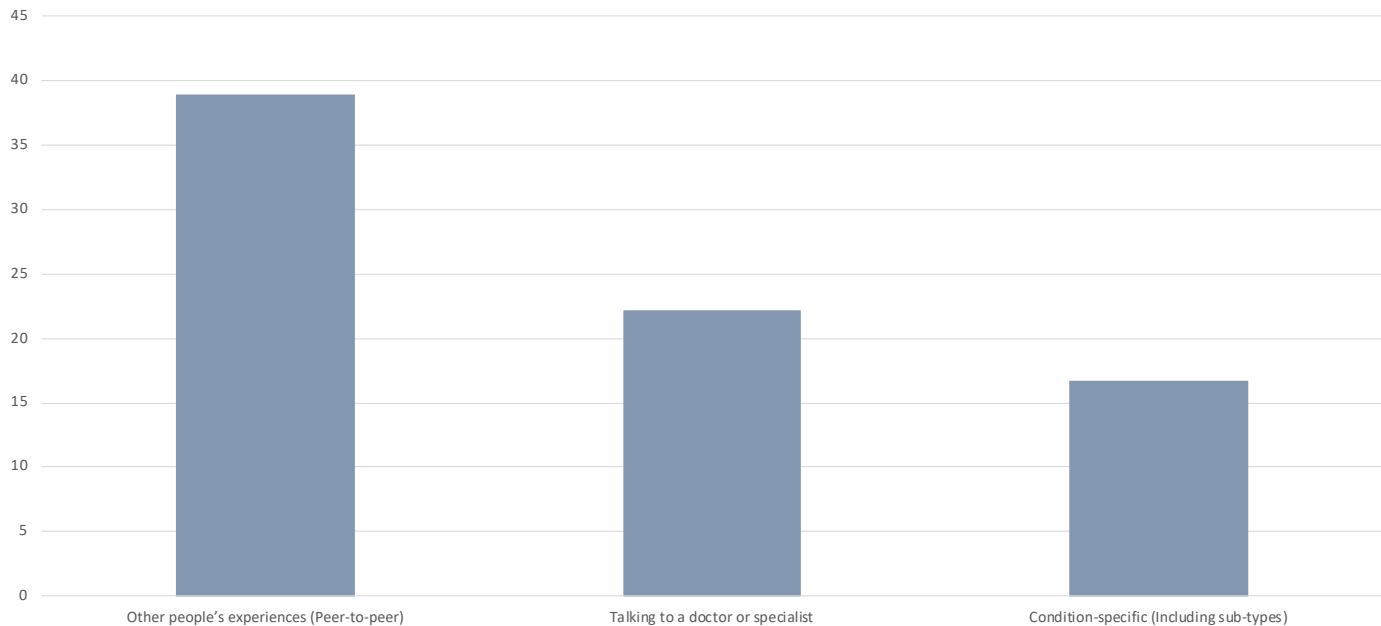


Figure 6.2: Information that was helpful



## 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 no information was not helpful (n=6, 33.33%)

### Participant describes no information being not helpful

*No, not really, because a lot of people have different symptoms or different side effects. Some people get it in their spine and so far, touch wood, I've only had it in my eye. Participant NMO\_007*

*No, not really, especially the Facebook page that everything's positive, I think it's run by two nurses on there as the admin and they watch what everyone says, but yes, everything's been good.. Participant NMO\_009*

*No, not really. Participant NMOCA\_006*

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

*I've avoided those things. If I found something, especially in the early days, if I found something that was quite negative, then I would not continue reading that because I wasn't going to allow myself to get into a situation of the doom of it because there was no point, because there was no option. I'm that kind of way inclined and online there are some very upsetting situations and when you're early diagnosed, it's good to avoid that. I think that-- I don't know. I think I'm somebody who would-- I take the positives out of just about most of the things I can find rather than the negatives. Participant NMO\_006*

*No, not really. Yes, not really. I think probably with Facebook pages, people put up their stories, their experiences, and ask questions. Maybe, I don't know, I think you need to take what you can from that. Participant NMO\_015*

*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 NMOCA\_004*

**Table 6.5: Information that was not helpful**

Information that has not been helpful	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes no information being not helpful	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	2	22.22	4	44.44
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	1	11.11	1	11.11

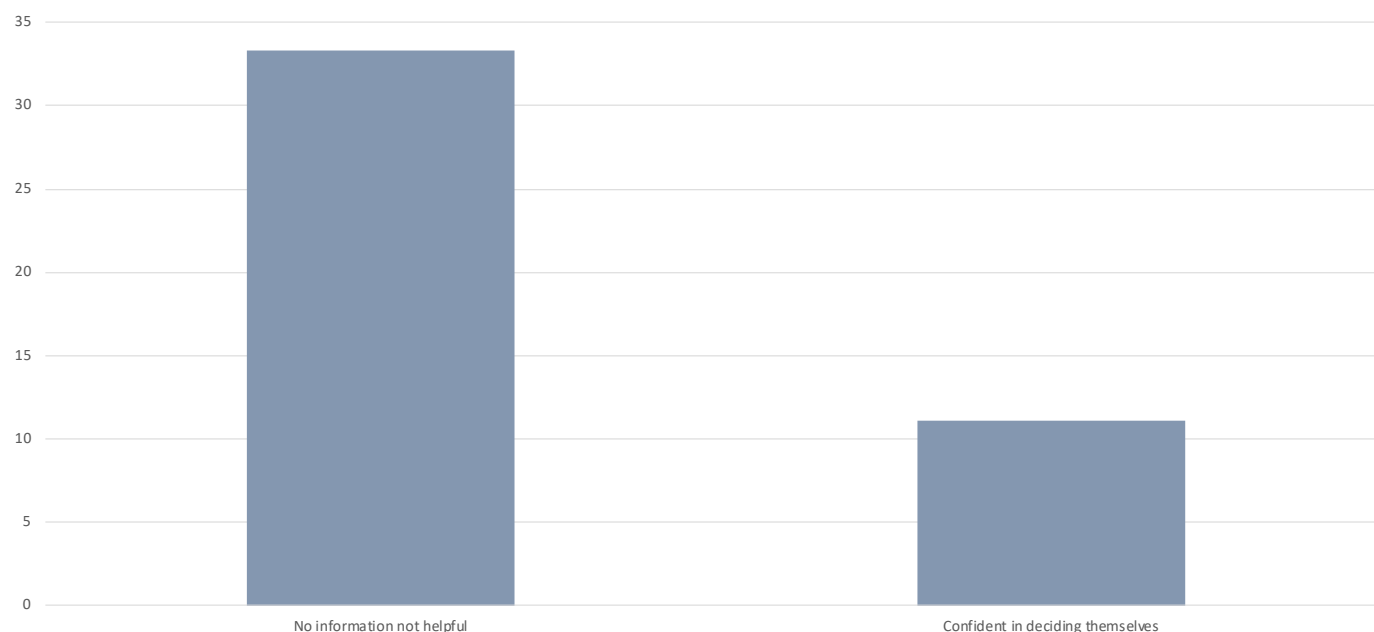
Information that has not been helpful	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes no information being not helpful	6	33.33	4	40.00	2	25.00	3	50.00	3	25.00	1	14.29	5	45.45
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	28.57	1	9.09

Information that has not been helpful	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes no information being not helpful	6	33.33	3	37.50	9	34.62	2	20.00	4	25.00	2	100.00	2	66.67	4	26.67
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	2	25.00	4	15.38	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

**Table 6.6: Information that was not helpful (Subgroup variations)**

Information that has not been helpful	More frequent	Less frequent
Participant describes no information being not helpful	Good to very good physical function Mid to low socioeconomic status Aged 45 or older	Moderate to very poor physical function Aged 18 to 44



**Figure 6.3: Information that was not helpful**

### 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. Overall, the most common theme was online information (n=5, 27.78%).

#### Online information as main preference

*I think online is good because you can read it at your leisure. Participant NMO\_002*

*I like to read online because I like to do it in my own time where I can take breaks and stuff if I'm upset by something. I haven't had a lot of good experiences talking to my specialists or doctors about NMO, but I don't really get much information on it. Participant NMO\_010*

*I think online because then I can just read it and ingest it and go back. Participant NMO\_015*

#### Talking to someone plus online information as main preference

*Okay, online, and talking to someone. Participant NMO\_001*

*Online is brilliant if you can read it and print it out and just have readily access to it. Then to improve on that would beg the ability to contact someone and discuss that with them. Participant NMO\_014*

*I think online is good because you can access it at any time, but I still think human contact and that personal conversations with people is very valuable as well, and especially when it's another person with the disease, not necessarily a medical field. I don't think I would be interested in having my doctors just on phone, I'd rather see them in person. I think there's value in actually reading a person's face and your social cues and things like that. The online information is good especially if you're researching anything, it's good. Participant NMO\_017*

#### Talking to someone as main preference

*Look, because I'm a peer support volunteer, I think there's nothing better than talking one-on-one with a person that understands because the symptoms are so weird that often, it's only the people that have gone through that, that can really relate. Participant NMO\_004*

*It would be speaking to a neurologist and listening to them, it would be number one, yes. Participant NMO\_009*

*Talking to people I love, actually. Face-to-face when we go to groups, just because of your experience, and what happened to you, and how did this all come about, and what have you done to help with the pain? Have you done this. Participant MOG\_006*

Table 6.7: Information preferences

Information preferences	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Online information as main preference	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	1	11.11	4	44.44
Talking to someone plus online information as main preference	3	16.67	3	33.33	0	0.00	3	37.50	0	0.00	1	11.11	2	22.22
Talking to someone as main preference	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	3	33.33	0	0.00

Information preferences	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Online information as main preference	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Talking to someone plus online information as main preference	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	14.29	2	18.18
Talking to someone as main preference	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	0	0.00	3	27.27

Information preferences	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Online information as main preference	5	27.78	4	50.00	9	34.62	4	40.00	5	31.25	0	0.00	0	0.00	5	33.33
Talking to someone plus online information as main preference	3	16.67	3	37.50	6	23.08	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Talking to someone as main preference	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	2	66.67	1	6.67

Table 6.8: Information preferences (Subgroup variations)

Information preferences	More frequent	Less frequent
Online information as main preference	Good to very good physical function	Moderate to very poor physical function Mid to low socioeconomic status

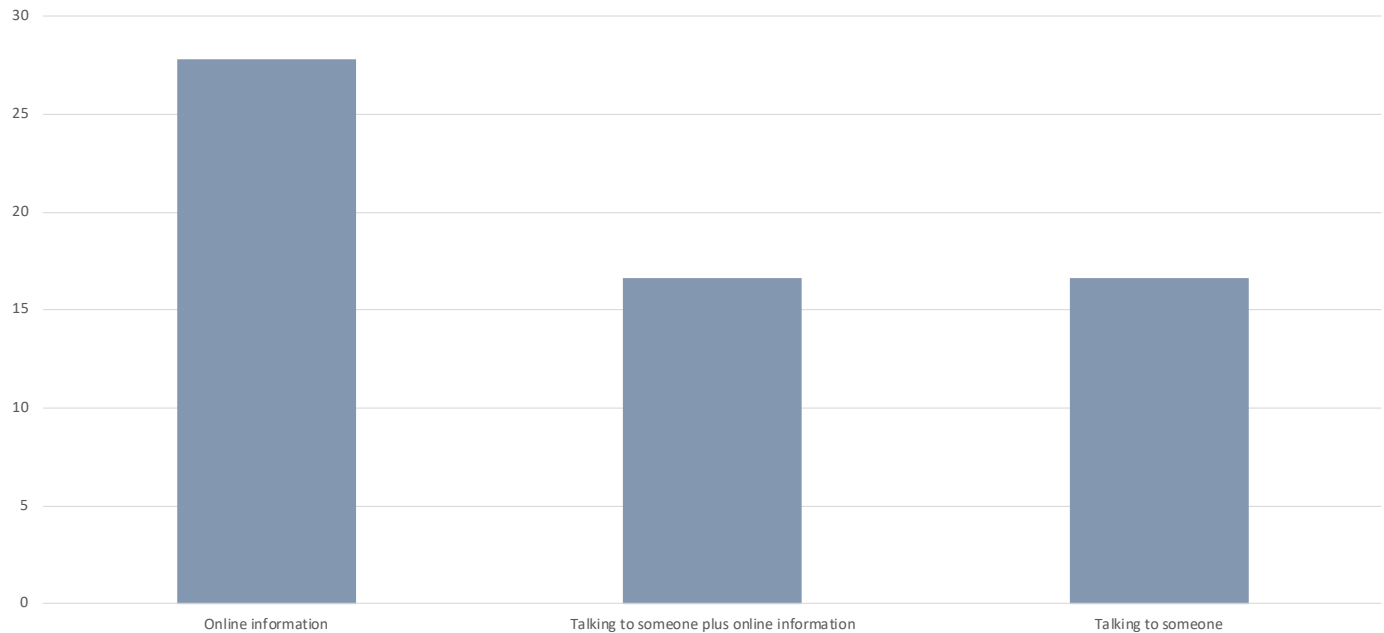


Figure 6.4: Information preferences

Information preferences: Rationale

The most common theme reason for their information preference was due to being able to digest information at their own pace (n=7, 38.89%).

Rational for preference is due to being able to digest information at their own pace

Online even if I can't remember everything, I can save the page so I can read it again whenever I want. Participant NMO\_001

I'd probably prefer booklets and stuff like that to read in my own time, just because I'm quite busy. Participant NMO\_003  
I like to read online because I like to do it in my own time where I can take breaks and stuff if I'm upset by something. Participant NMO\_010

Rationale for their preference is that it is more supportive and/or they can share experiences with peers

*I think there's nothing better than talking one-on-one with a person that understands because the symptoms are so weird that often, it's only the people that have gone through that, that can really relate. Participant NMO\_004*

*I still think human contact and that personal conversations with people is very valuable as well, and especially when it's another person with the disease, not necessarily a medical field. I don't think I would be interested in having my doctors just on phone, I'd rather see them in person. I think there's value in actually reading a person's face and your social cues and things like that. Participant NMO\_017*

*Talking to people I love, actually. Face-to-face when we go to groups, just because of your experience, and what happened to you, and how did this all come about, and what have you done to help with the pain? Have you done this? Participant MOG\_006*

Rational for preference is simply a personal preference/no strong rationale

*I don't think I have a preference. I probably would do all of them. Participant NMO\_006*

*I think online information is probably the best. As I said, NAME PERSON CARED FOR's on MOG support pages and things like that. I think that's probably what we prefer, as far as the way of doing it. Participant NMOCA\_004*

Rationale for preference is due to accessibility

*Online is brilliant if you can read it and print it out and just have readily access to it. Participant NMO\_014*

*I think online is good because you can access it at any time. Participant NMO\_017*

*The ease of online and then talking to someone just being able ask questions and get reassurance. Participant NMOCA\_002*

Rationale for their preference is there being a wider range of information available for them to choose from

*When it first happened to me, it was a very new thing and not many people knew what was going on. In America, I could get on and redo the research on it type of thing. I would write my questions down and then go to my neurologist. A lot of people, if you say NMO, they'll say, "What's that?" Then I have to tell them what it is. What I'm trying to say is, I have to tell people what I have, what I do, what treatment I have and this is what's happened to me. Participant NMO\_013*

Table 6.9: Information preferences: Rationale

Rationale for information preference	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function			
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%		
Rational for preference is due to being able to digest information at their own pace	7	38.89	3	33.33	4	44.44	4	50.00	3	30.00	2	22.22	5	55.56		
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	3	33.33	1	11.11	3	37.50	1	10.00	2	22.22	2	22.22		
Rational for preference is simply a personal preference/no strong rationale	3	16.67	1	11.11	2	22.22	0	0.00	3	30.00	3	33.33	0	0.00		
Rationale for preference is due to accessibility	2	11.11	2	22.22	0	0.00	2	25.00	0	0.00	0	0.00	2	22.22		
Rationale for information preference	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older			
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%		
Rational for preference is due to being able to digest information at their own pace	7	38.89	2	20.00	5	62.50	2	33.33	5	41.67	6	85.71	1	9.09		
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	1	10.00	3	37.50	1	16.67	3	25.00	1	14.29	3	27.27		
Rational for preference is simply a personal preference/no strong rationale	3	16.67	3	30.00	0	0.00	1	16.67	2	16.67	1	14.29	2	18.18		
Rationale for preference is due to accessibility	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	0	0.00	2	18.18		
Rationale for information preference	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Rational for preference is due to being able to digest information at their own pace	7	38.89	1	12.50	8	30.77	2	20.00	7	43.75	0	0.00	0	0.00	7	46.67
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	0	0.00	4	15.38	1	10.00	4	25.00	0	0.00	1	33.33	3	20.00
Rational for preference is simply a personal preference/no strong rationale	3	16.67	1	12.50	4	15.38	2	20.00	1	6.25	2	100.00	1	33.33	2	13.33
Rationale for preference is due to accessibility	2	11.11	1	12.50	3	11.54	3	30.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 6.10: Information preferences: Rationale (Subgroup variations)

Rationale for information preference	More frequent	Less frequent
Rational for preference is due to being able to digest information at their own pace	Low to moderate fear Good to very good physical function University Aged 18 to 44	Moderate to very poor physical function Trade or high school Aged 45 or older

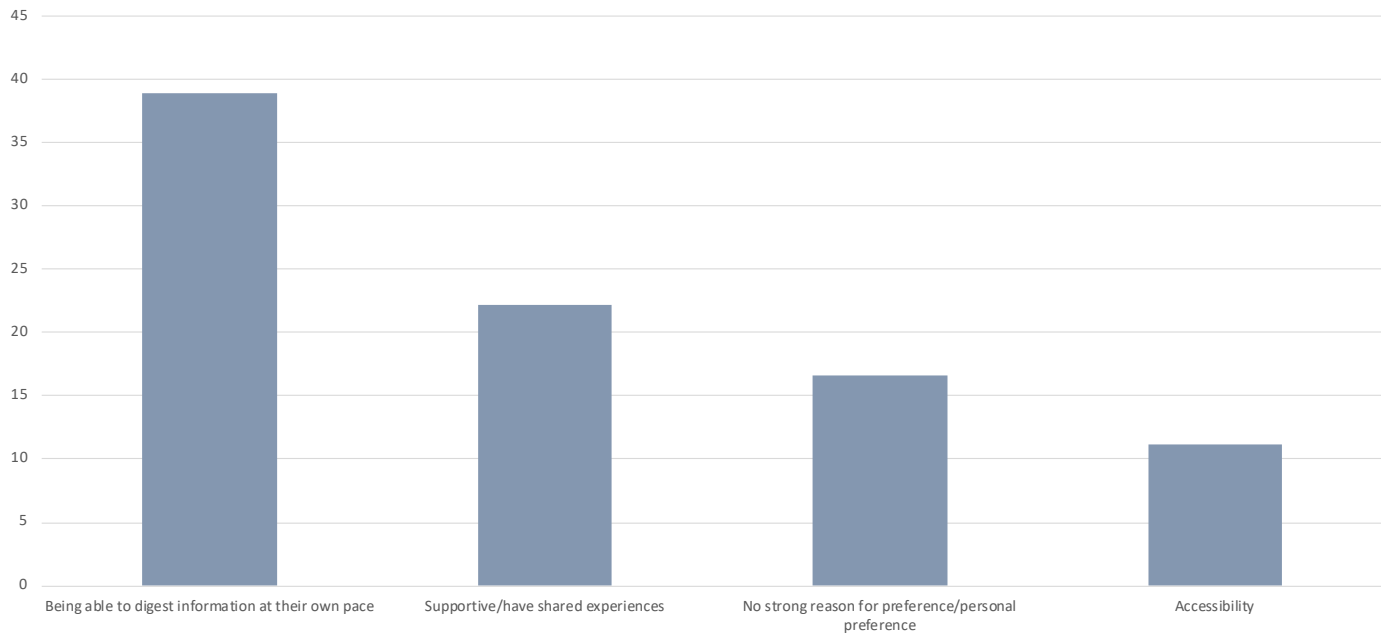


Figure 6.5: Information preferences: Rationale

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 that participants described being receptive to receiving information was from the beginning (diagnosis) (n=7, 38.89%), and participants describing being receptive to information after a specific amount of time had passed (n=7, 38.89%).

Participant describes being receptive from the beginning (diagnosis)

*I think when it was all new, because I had to get a grasp on it. I had to understand what- I think that's the medical side of me coming out- what the body was doing, how it could heal. Participant NMO\_017*

*For me, it was immediately after the diagnosis so when we went to LOCATION METROPOLITAN in April 2019. When I saw the professor told us what is false, as soon as we got home I started researching so that's when I just needed to know and that's how I've worked with everything. Participant NMOCA\_003*

*I think I would have taken information in right at the very outset. The issue was we weren't really given much information. Participant NMOCA\_007*

Participant describes being receptive to information after a specific amount of time

*At the start, it was me looking for things which I felt like I couldn't find, and then probably like halfway through, so probably after a year of being diagnosed, that's when I started to, I guess, take things more in, and think about things, and not be so overwhelmed. Whereas now, I feel like I can be really-- I can try this, this ones not a good idea. I can think about things, thinking through more. Participant NMO\_005*

*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 NMO\_001*

*I suppose four or five months after the diagnosis and after everything had probably slowed down a bit and calmed down 'then' because then I would absolutely read it in a clear mind. Participant MOG\_006*

Table 6.11: Timing of information

Timing of information	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	4	44.44	3	33.33	4	50.00	3	30.00	2	22.22	5	55.56
Participant describes being receptive to information after a specific amount of time	7	38.89	3	33.33	4	44.44	3	37.50	4	40.00	5	55.56	2	22.22

Timing of information	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	3	30.00	4	50.00	3	50.00	4	33.33	1	14.29	6	54.55
Participant describes being receptive to information after a specific amount of time	7	38.89	5	50.00	2	25.00	2	33.33	5	41.67	3	42.86	4	36.36

Timing of information	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	3	37.50	10	38.46	4	40.00	6	37.50	1	50.00	1	33.33	6	40.00
Participant describes being receptive to information after a specific amount of time	7	38.89	2	25.00	9	34.62	3	30.00	6	37.50	1	50.00	2	66.67	5	33.33

Table 6.12: Timing of information

Timing of information	More frequent	Less frequent
Participant describes being receptive from the beginning (diagnosis)	Low to moderate fear Good to very good physical function University Mid to low socioeconomic status Aged 45 or older	Moderate to very poor physical function Aged 18 to 44
Participant describes being receptive to information after a specific amount of time	Moderate to very poor physical function Trade or high school	Good to very good physical function University

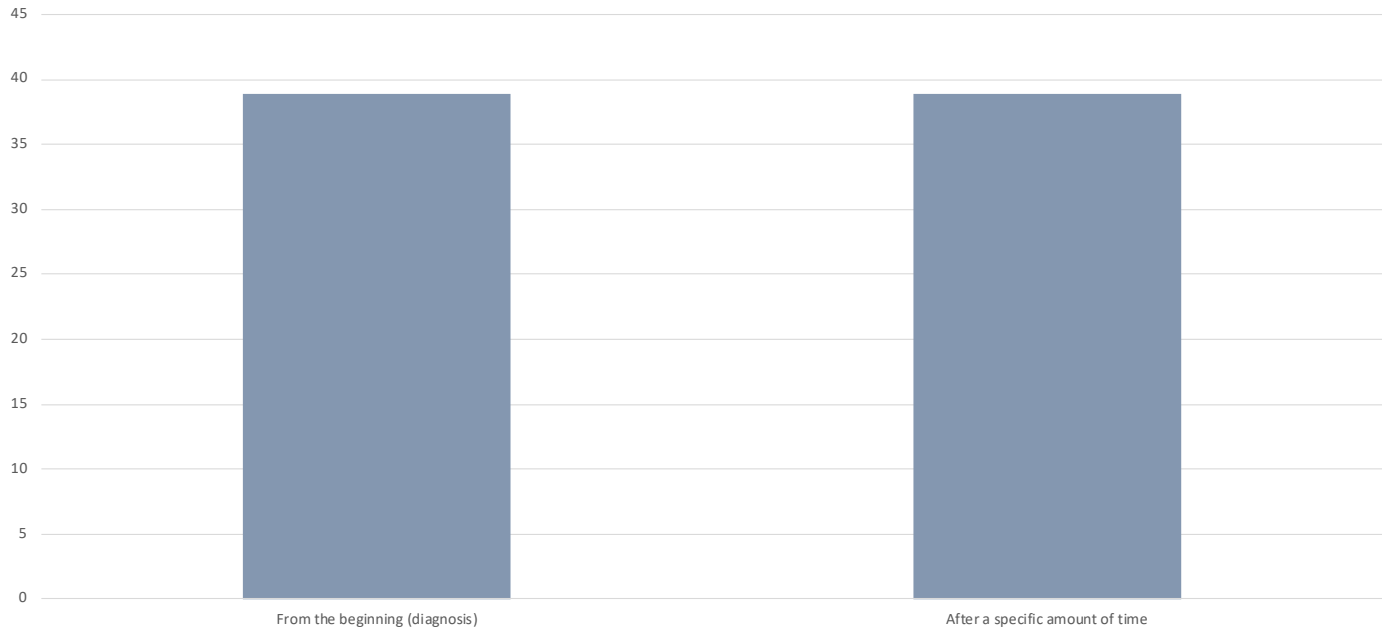


Figure 6.6: Timing of information

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 experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

Participant describes an overall negative experience with health professional communication

*Very little knowledge out there and lack of discussion more than anything. I felt like saying to my GP, "Have you actually Googled my disease and read anything about it?" Participant NMO\_014*

*Honestly, what I went through-- Well, my first attack of optic neuritis is now leaving me legally blind. I think that there has to be-- The doctors, I just don't trust them anymore, because I trusted*



*them so much, and I believed what they said, and I honestly kind of blame them for where I am at now because I feel like doctors go through like, "You have this, yes, you don't have this," and because of - From what I understand, NMO is really rare, they just didn't know what they were talking about. Participant NMO\_005*

*To be frank, not a very good one. I understand specialist are busy people and you need to see other not just us, but we haven't been given any leaflets, no information, no referrals anywhere besides just basically being told, "Okay, this is what you have." Then we've had to search, to collect information ourselves, and I'm happy to obviously do it myself sometimes, particularly at the start, it would be helpful if there was some good example of almost like a booklet or something with for dummies kind of thing, that would answer the 30 questions, I'm obviously worried and want to know is my partner going to die? Where do I find information on what happens? The options, just something basic would be really helpful. Participant NMOCA\_003*

**Participant describes an overall positive experience with health professional communication**

*Yes, yes. They're fine. Whatever I asked they were able to answer but I think neurologists is all-- Because I didn't do enough research, I didn't know what to ask sometimes. I don't know what I'm supposed to ask. Participant NMO\_001*

*In general, they're quite intrigued. If I see a new doctor, they want to know, and they say, "How did you present? What was it like the first time?" I haven't had too bad a journey with it, but mainly, a lack of info. Oh, sorry, the other person I did get to see was the ophthalmologist. I was under the care*

*of an ophthalmologist, I forgot to mention that. It was funny because he was having a lecture the next day on NMO and he asked me to look at his notes [laughs] to see how accurate they were. It's educating the medical community as well. Participant NMO\_004*

*It's been all good, all been absolutely positive, a lot of the general practitioner and my local doctor, he does it all day, any of the doctors I've seen, the GP's that they don't seem to know much about it at all. They generally have to look up the condition to find out, but the neurologist have obviously been brilliant and my physio, like I said, who knew nothing about the disease he studied for days about the disease. Participant NMO\_009*

**Participant describes an overall positive experience with health professional communication with the exception of one or two occasions**

*Very good. I've got no complaints with any times I've been in the hospitals and 99% of doctors have been really good. I've only had one doctor that just had a bad attitude. Participant NMO\_007*

*The neurologists have been helpful. A few of them have been pretty bleak about his prognosis or about the future. So I that hasn't been reassuring. Participant NMOCA\_002*

*Where we are now, definitely it's improved. We've got a good relationship with the neurologist and our GP is a lot more informed now. In the beginning, the GP had absolutely no idea of what the disease was, but she has definitely done a lot of research herself to now find out a lot more about it. Participant NMOCA\_007*

Table 6.13: Healthcare professional communication

Health professional communication	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	2	22.22	6	66.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	4	44.44	1	11.11	3	37.50	2	20.00	4	44.44	1	11.11
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	1	11.11	3	33.33
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

Health professional communication	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes an overall negative experience with health professional communication	11	61.11	7	70.00	4	50.00	5	83.33	6	50.00	5	71.43	6	54.55
Participant describes an overall positive experience with health professional communication	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Participant describes an overall positive experience with health professional communication with the exception of one or two occasions	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	0	28.57	1	9.09

Health professional communication	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes an overall negative experience with health professional communication	11	61.11	1	12.50	12	46.15	5	50.00	11	68.75	0	0.00	2	66.67	9	60.00
Participant describes an overall positive experience with health professional communication	5	27.78	3	37.50	8	30.77	0	0.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes an overall positive experience with health professional communication with the exception of one or two occasions	1	5.56	4	50.00	5	19.23	4	40.00	0	0.00	1	50.00	0	0.00	1	6.67

Table 6.14: Healthcare professional communication (Subgroup variations)

Health professional communication	More frequent	Less frequent
Participant describes an overall negative experience with health professional communication	More relapses Good to very good physical function Mid to low socioeconomic status Aged 18 to 44	Fewer relapses Moderate to very poor physical function University Higher socioeconomic status
Participant describes an overall positive experience with health professional communication	Fewer relapses Moderate to very poor physical function	More relapses Good to very good physical function Mid to low socioeconomic status

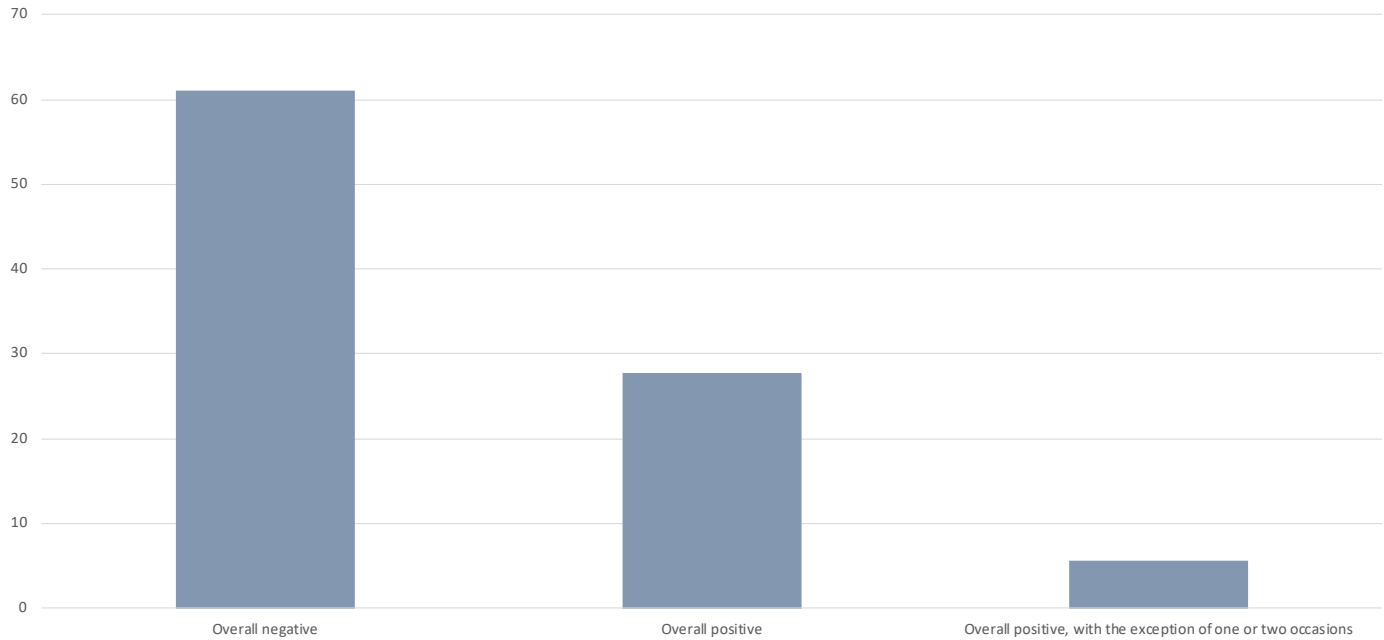


Figure 6.7: Healthcare professional communication



## Healthcare professional communication: Reasons for experience

There were eight participants (44.44%) that described health professional communication as limited in relation to their understanding of the condition. Where participants described a positive experience, this related to communication being holistic (two way, supportive and comprehensive conversations) (n=5, 27.78%).

### Participant describes health professional communication as limited in relation to their understanding of the condition

*I saw my GP six days on the trot every day when my eyesight first went because I just felt there was something really wrong. He was sending me to different people, but he hadn't clue. He'd never heard of it. He was ringing me when I was in hospital to see how I was and apologising. I said, "It's not your fault. You didn't know. It's not something that people necessarily know about, but now I know there's more people out there with it. Now, I think that more people should know about it. Participant NMO\_006*

*Really it hasn't been that great. My GP had to research it herself before she could help me out, but she has been great, don't get me wrong. It would be nice to have someone that understands, be honest, and can give some more idea of what to expect moving forward. Participant NMO\_008*

*It's not been very good. Apart from my neurologist, I've never met a health professional that knew what NMO is, and I've even seen neurologists that hadn't heard of it before. Participant NMO\_010*

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

*Being good with my immunologist. It's great to have some in-depth discussions. Participant NMO\_002*

*In general, they're quite intrigued. If I see a new doctor, they want to know, and they say, "How did you present? What was it like the first time?" I haven't had too bad a journey with it, but mainly, a lack of info. Participant NMO\_004*

*It's been all good, all been absolutely positive, a lot of the general practitioner and my local doctor, he does it all day, any of the doctors I've seen, the GP's that they don't seem to know much about it at all. They generally have to look up the condition to find out, but the neurologist have obviously been*

*brilliant and my physio, like I said, who knew nothing about the disease he studied for days about the disease. Participant NMO\_009*

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

*About my condition in itself, useless. Even the neurologist, yes it's NMO, but it affects your optic nerve and your spinal cord and that's about it and we treat you with this. When I've been back and I'm saying, "Well, I still have bladder problems or I have bowel problems." They go, "Yes, that's part of it." That's what it is. Participant NMO-006*

*Initially, I was diagnosed with MS, and I was discharged from hospital and ended up three months later in a research clinic, and I would leave the clinic with pathology tests to go and get done, and I'd take a photo of it and go home and Google what I was testing because even if I asked, my neurologist wouldn't explain what he was testing for all. Participant NMO\_010*

*To be frank, not a very good one. I understand specialist are busy people and you need to see other not just us, but we haven't been given any leaflets, no information, no referrals anywhere besides just basically being told, "Okay, this is what you have." Then we've had to search, to collect information ourselves, and I'm happy to obviously do it myself sometimes, particularly at the start, it would be helpful if there was some good example of almost like a booklet or something with for dummies kind of thing, that would answer the 30 questions, I'm obviously worried and want to know is my partner going to die? Where do I find information on what happens? The options, just something basic would be really helpful. Participant NMOCA\_003*

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

*I haven't really been through much. It's kind of just they say, we're sorry to hear that, and that's about it. Participant NMO\_003*

*Yes, pretty good, the neurologist I guess because of the day and age didn't tell me too much, he said you can go and read all about it because he knew I'd be able to and that's about it really. The ophthalmologist didn't really give me too much information and I feel like if their time is short they just give you the diagnosis and that's it. [laughs] Participant MOG\_005*

**Table 6.15: Healthcare professional communication: Reasons for experience**

Health professional communication	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	2	22.22	6	66.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	4	44.44	1	11.11	3	37.50	2	20.00	4	44.44	1	11.11
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	1	11.11	3	33.33
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

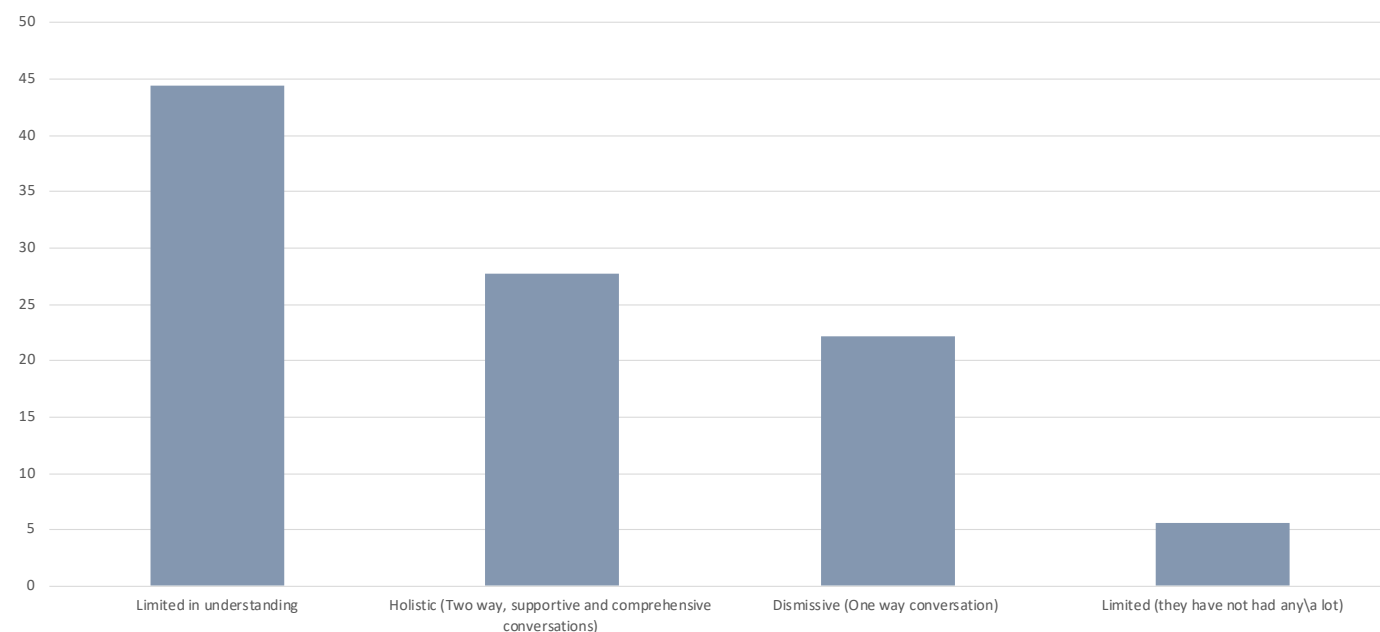
Health professional communication	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	5	50.00	3	37.50	3	50.00	5	41.67	4	57.14	4	36.36
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	1	0.00	0	0.00

Health professional communication	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	0	0.00	8	30.77	4	40.00	8	50.00	0	0.00	1	33.33	7	46.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	2	25.00	7	26.92	1	10.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	0	0.00	4	15.38	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	2	25.00	3	11.54	2	20.00	1	6.25	0	0.00	0	0.00	1	6.67

**Table 6.16: Healthcare professional communication: Reasons for experience**

Health professional communication	More frequent	Less frequent
Participant describes health professional communication as limited in relation to their understanding of the condition	More relapses Good to very good physical function Aged 18 to 44	Fewer relapses Moderate to very poor physical function
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Fewer relapses Moderate to very poor physical function	More relapses Good to very good physical function Mid to low socioeconomic status



**Figure 6.8: Healthcare professional communication: Reasons for experience**

## 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, four scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.7.

Overall, the participants in this PEEK study had an average score for **Partners in health: adherence to treatment** (mean = 12.89, SD = 2.68), in the highest quintile indicating excellent adherence to treatment.

Overall, the participants in this PEEK study had an average score for **Partners in health: knowledge** (mean = 23.00, SD = 5.39), **Partners in health: recognition and management of symptoms** (mean = 17.72, SD = 4.07), and **Partners in health: total score** (mean = 65.11, SD = 13.87) in the second highest quintile indicating good knowledge, recognition and, and overall knowledge and confidence for managing their own health.

The average score for **Partners in health: coping** (mean = 11.50, SD = 5.94), was in the middle of the scale, indicating moderate coping.

Comparisons of Partners in health have been made based on **participant type** (Tables 6.18 to 6.19, Figures 6.9 to 6.13), **relapse** (Tables 6.20 to 6.21, Figures 6.14 to 6.18), **fear of progression** (Tables 6.22 to 6.23, Figures 6.19 to 6.23), **physical function** (Tables 6.24 to 6.25, Figures 6.24 to 6.28), **education** (Table 6.26, Figures 6.29 to 6.33), **socioeconomic advantage** (Tables 6.27 to 6.28, Figures 6.34 to 6.38), **age** (Table 6.29, Figures 6.39 to 6.43), **gender**, (Table 6.30), and **location** (Table 6.31).

**Table 6.17: Partners in health summary statistics**

Partners in health scale (n=18)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge*	23.00	5.39	22.00	4.75	0 to 32	4
Partners in health: coping*	11.50	5.94	11.50	5.50	0 to 24	3
Partners in health: recognition and management of symptoms*	17.72	4.07	19.00	4.00	0 to 24	4
Partners in health: adherence to treatment*	12.89	2.68	12.50	4.50	0 to 16	5
Partners in health: total score*	65.11	13.87	62.50	17.75	0 to 96	4

\*Normal distribution use mean and SD as measure of central tendency

### Comparisons of Partners in health scales by participant type

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 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 excellent 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.

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the NMOSD group includes participants who had

a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the MOG group (n=8, 22.22%), participants in the NMOSD or MOG groups were included in the NMOSD and MOG subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the Family and carers subgroup (n=10, 27.78%).

Boxplots of each Partners in health scale by **participant type** are displayed in Figures 6.9 to 6.13, summary statistics are displayed in Tables 6.18 and 6.19.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.18).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.19).

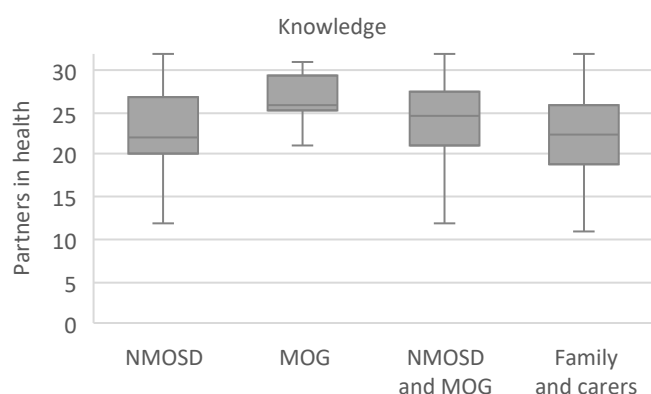
No significant differences were observed between participants by **participant type** for any of the Partners in health scales.

**Table 6.18: Partners in health by participant type ANOVA test**

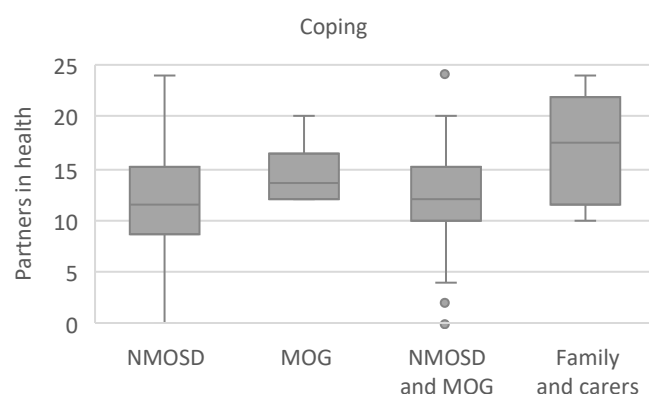
Partners in health scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Knowledge	NMOSD	18	50.00	23.00	5.39	Between groups	104.00	3.00	34.67	1.34	0.2710
	MOG	8	22.22	26.50	3.07	Within groups	1504.00	58.00	25.93		
	NMOSD and MOG	26	72.22	24.08	5.01	Total	1608.00	61.00			
	Family and carers	10	27.78	22.00	5.93						
Coping	NMOSD	18	50.00	11.50	5.94	Between groups	216.80	3.00	72.26	2.61	0.0600
	MOG	8	22.22	14.38	2.97	Within groups	1605.40	58.00	27.68		
	NMOSD and MOG	26	72.22	12.38	5.32	Total	1822.20	61.00			
	Family and carers	10	27.78	16.90	5.11						
Recognition and management of symptoms	NMOSD	18	50.00	17.72	4.07	Between groups	46.70	3.00	15.58	1.16	0.3350
	MOG	8	22.22	19.88	1.73	Within groups	782.20	58.00	13.49		
	NMOSD and MOG	26	72.22	18.38	3.62	Total	828.90	61.00			
	Family and carers	10	27.78	16.80	4.10						
Total score	NMOSD	18	50.00	65.11	13.87	Between groups	648.00	3.00	216.00	1.33	0.2730
	MOG	8	22.22	75.75	4.98	Within groups	9411.00	58.00	162.30		
	NMOSD and MOG	26	72.22	68.38	12.76	Total	10059.00	61.00			
	Family and carers	10	27.78	66.80	14.52						

**Table 6.19: Partners in health by participant type Kruskal-Wallis test**

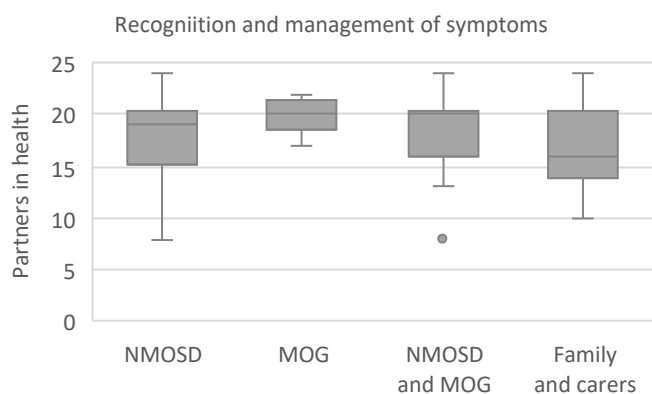
Partners in health scale	Group	Number (n=36)	Percent	Median	IQR	C <sup>2</sup>	dF	p-value
adherence to treatment	NMOSD	18	50.00	12.50	4.50	4.35	3	0.2260
	MOG	8	22.22	15.00	2.00			
	NMOSD and MOG	26	72.22	14.00	4.00			
	Family and carers	10	27.78	13.50	8.25			



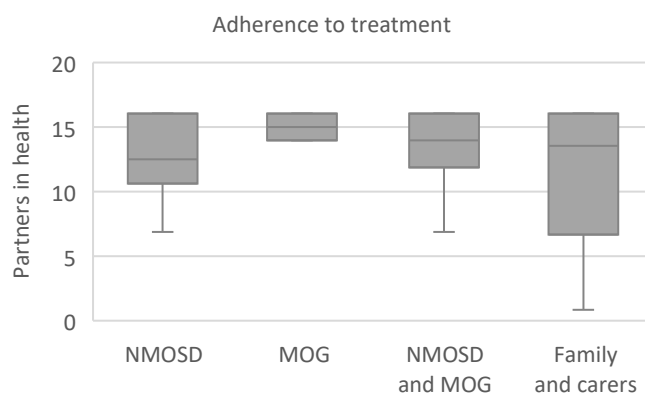
**Figure 6.9: Boxplot of Partners in health: knowledge by participant type**



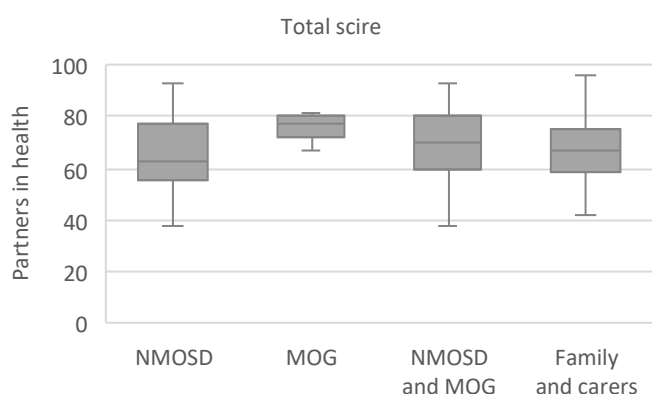
**Figure 6.10: Boxplot of Partners in health: coping by participant type**



**Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by participant type**



**Figure 6.12: Boxplot of Partners in health: adherence to treatment by participant type**



**Figure 6.13: Boxplot of Partners in health Total score by participant type**

### Comparisons of Partners in health scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **relapse** are displayed in Figures 6.14 to 6.18, summary

statistics are displayed in Tables 6.20 to 6.21. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

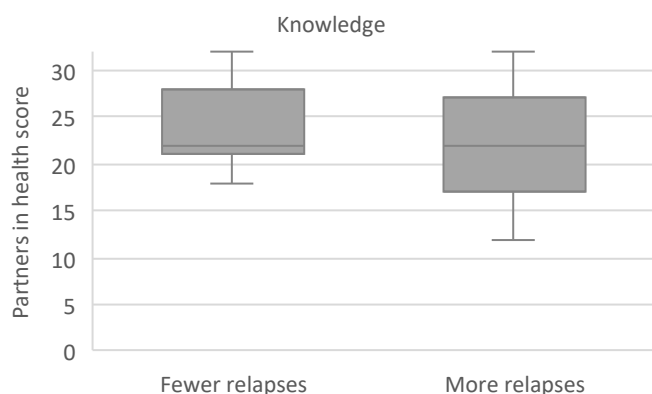
No significant differences were observed between participants in the subgroup *fewer relapses* compared to those in the subgroup lived in *more relapses* for any of the Partners in health scales.

**Table 6.20: Partners in health by relapse summary statistics and two sample t-test**

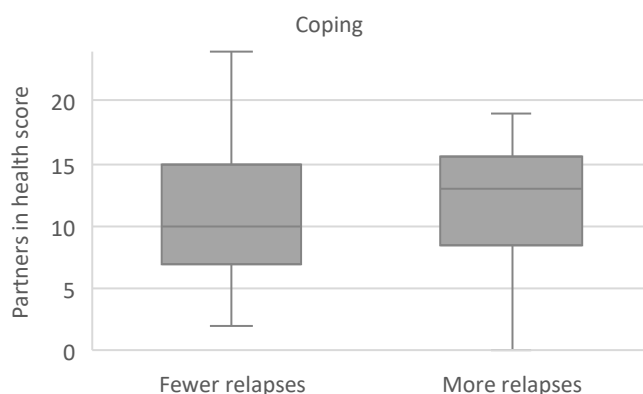
Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	<i>Fewer relapses</i>	9	50.00	23.78	4.60	0.60	16	0.5566
	<i>More relapses</i>	9	50.00	22.22	6.26			
Coping	<i>Fewer relapses</i>	9	50.00	11.22	6.63	-0.19	16	0.8497
	<i>More relapses</i>	9	50.00	11.78	5.56			
Total score	<i>Fewer relapses</i>	9	50.00	67.11	15.24	0.60	16	0.5568
	<i>More relapses</i>	9	50.00	63.11	12.94			

**Table 6.21: Partners in health by relapse summary statistics and Wilcoxon rank sum tests with continuity correction**

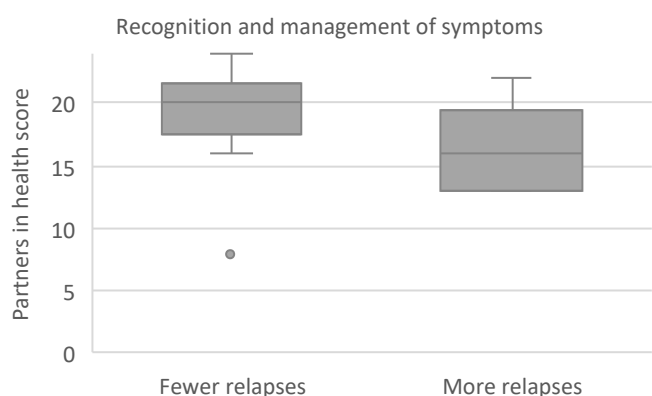
Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	<i>Fewer relapses</i>	9	50.00	20.00	2.00	58.50	0.1184
	<i>More relapses</i>	9	50.00	16.00	6.00		
Adherence to treatment	<i>Fewer relapses</i>	9	50.00	14.00	6.00	44.00	0.7873
	<i>More relapses</i>	9	50.00	12.00	2.00		



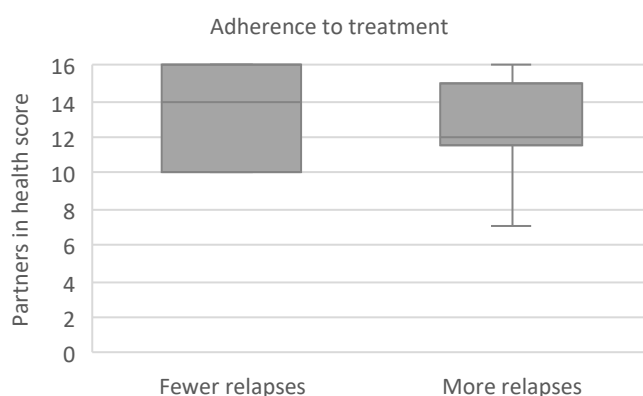
**Figure 6.14: Boxplot of Partners in health: knowledge by relapse**



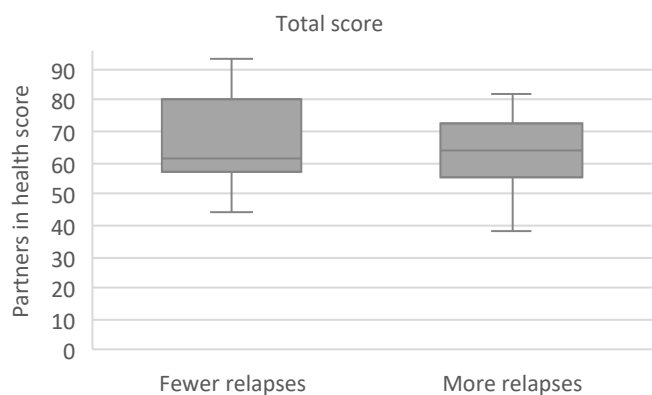
**Figure 6.15: Boxplot of Partners in health: coping by relapse**



**Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by relapse**



**Figure 6.17: Boxplot of Partners in health: adherence to treatment by relapse**



**Figure 6.18: Boxplot of Partners in health Total score by relapse**

### Comparisons of Partners in health scales by fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the Fear of progression questionnaire were included in the *High to very high fear* subgroup (n=10, 55.56%), and those that scored less than 41 were included in the *Low to*

*moderate fear* subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **fear of progression** are displayed in Figures 6.19 to 6.23, summary statistics are displayed in Tables 6.22 to 6.23. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

A two sample t-test indicated that the mean score for the **Partners in health total score** [ $t(16) = 2.20$ ,  $p=0.0428$ ] was significantly higher for participants in the *Low to moderate fear* subgroup (Mean = 72.38, SD = 11.88) compared to participants in the subgroup *High to very high fear* (Mean = 59.30, SD = 13.00).

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the *Low to moderate fear* subgroup scored lower than participants in the *High to very high fear* subgroup. However, all participants scored in the same range, this indicates that participants had very good overall knowledge, coping and confidence for managing their own health.

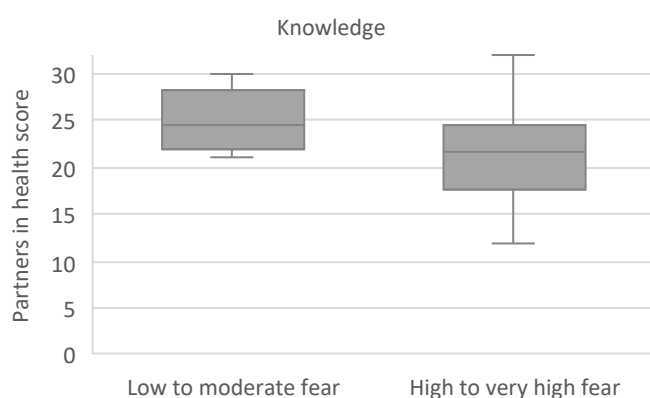
**Table 6.22: Partners in health by fear of progression summary statistics and two sample t-test**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	Low to moderate fear	8	44.44	24.88	3.31	1.35	16	0.1953
	High to very high fear	10	55.56	21.50	6.38			
Coping	Low to moderate fear	8	44.44	14.50	5.42	2.10	16	0.0521
	High to very high fear	10	55.56	9.10	5.43			
Recognition and management of symptoms	Low to moderate fear	8	44.44	19.25	3.81	1.47	16	0.1603
	High to very high fear	10	55.56	16.50	4.03			
Total score	Low to moderate fear	8	44.44	72.38	11.88	2.20	16	0.0428*
	High to very high fear	10	55.56	59.30	13.00			

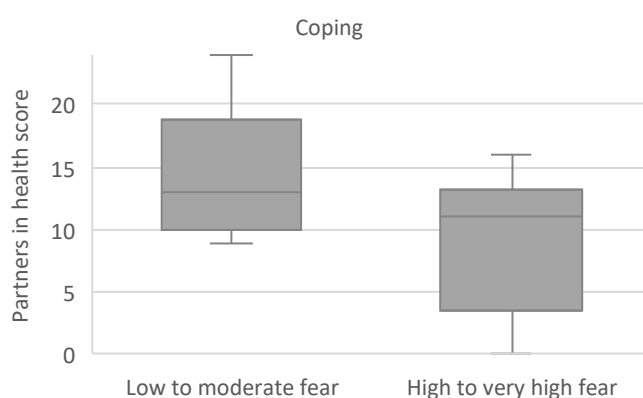
\*Significant at  $p<0.05$

**Table 6.23: Partners in health by fear of progression summary statistics and Wilcoxon rank sum tests with continuity correction**

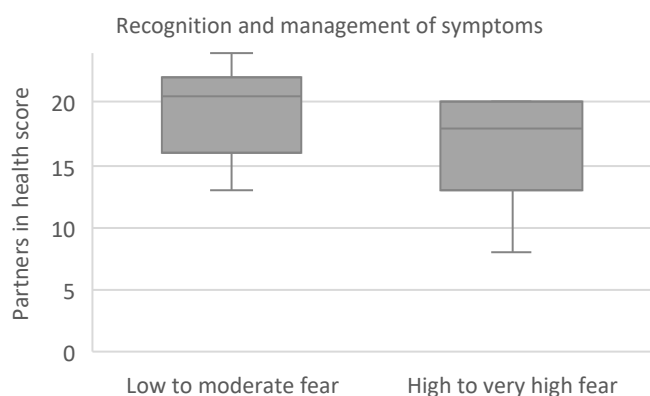
Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Adherence to treatment	Low to moderate fear	8	44.44	14.50	3.75	52.50	0.2775
	High to very high fear	10	55.56	12.00	2.25		



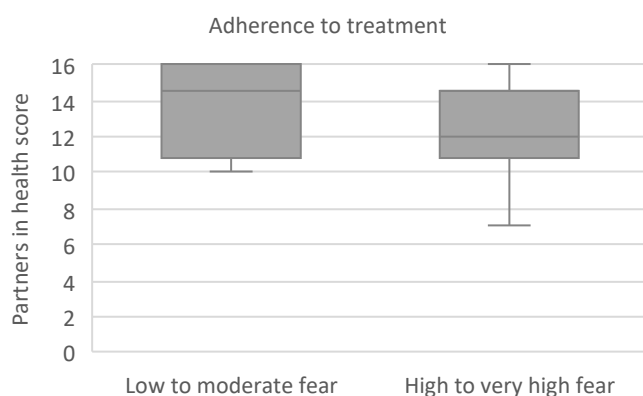
**Figure 6.19: Boxplot of Partners in health: knowledge by fear of progression**



**Figure 6.20: Boxplot of Partners in health: coping by fear of progression**

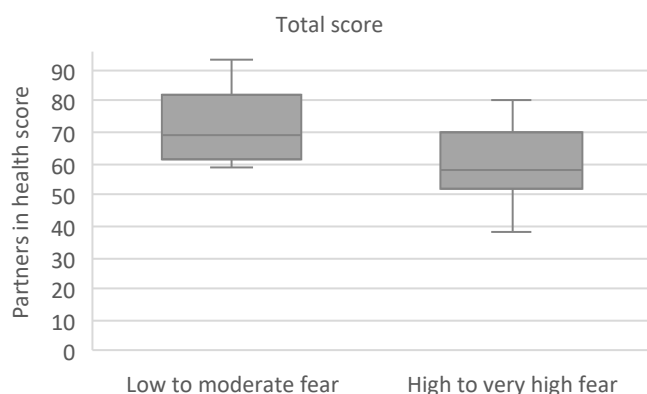


**Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by fear of progression**



**Figure 6.22: Boxplot of Partners in health: adherence to treatment by fear of progression**





**Figure 6.23: Boxplot of Partners in health Total score by fear of progression**

### Comparisons of Partners in health scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **physical** are displayed in Figures 6.24 to 6.28, summary statistics are displayed in Tables 6.24 to 6.25. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for any of the Partners in health scales.

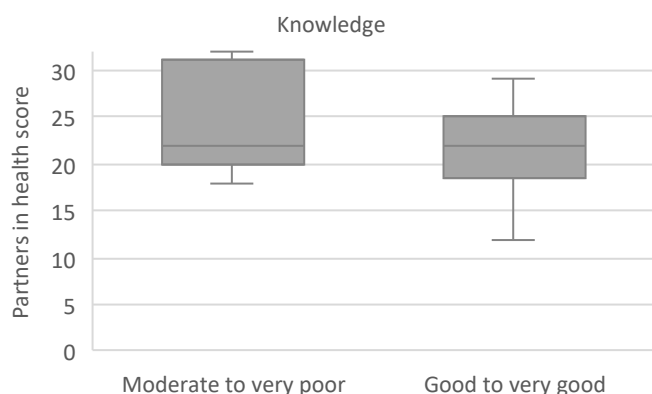
**Table 6.24: Partners in health by physical function summary statistics and two sample t-test**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	<i>Moderate to very poor physical function</i>	9	50.00	24.56	5.55	1.24	16	0.2315
	<i>Good to very good physical function</i>	9	50.00	21.44	5.05			
Recognition and management of symptoms	<i>Moderate to very poor physical function</i>	9	50.00	17.89	4.88	0.17	16	0.8681
	<i>Good to very good physical function</i>	9	50.00	17.56	3.36			
Adherence to treatment	<i>Moderate to very poor physical function</i>	9	50.00	13.44	3.00	0.88	16	0.3948
	<i>Good to very good physical function</i>	9	50.00	12.33	2.35			

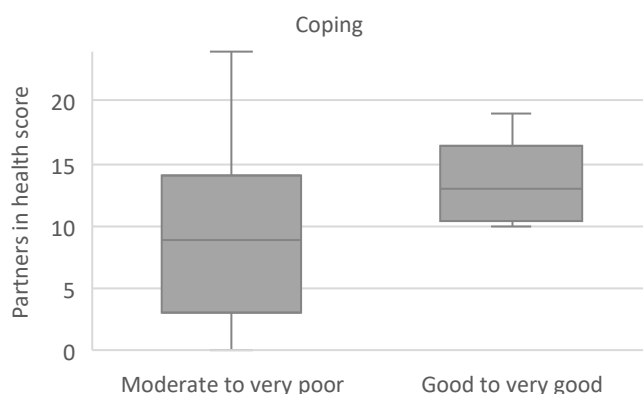
**Table 6.25: Partners in health by physical function summary statistics and Wilcoxon rank sum tests with continuity correction**

Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Coping	<i>Moderate to very poor physical function</i>	9	50.00	9.00	8.00	20.5	0.08428
	<i>Good to very good physical function</i>	9	50.00	13.00	4.00		
Total score	<i>Moderate to very poor physical function</i>	9	50.00	68.00	21.00	42.5	0.8945
	<i>Good to very good physical function</i>	9	50.00	61.00	10.00		

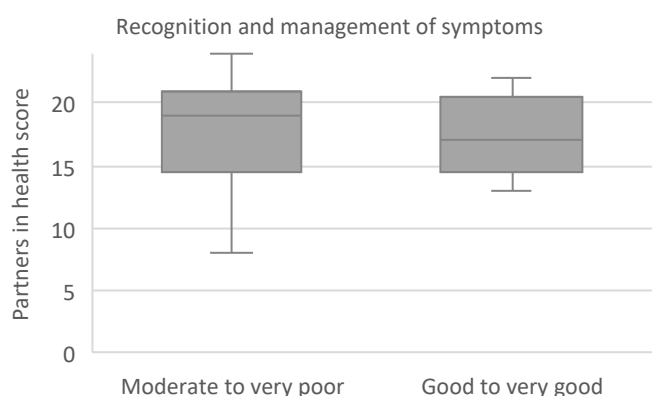




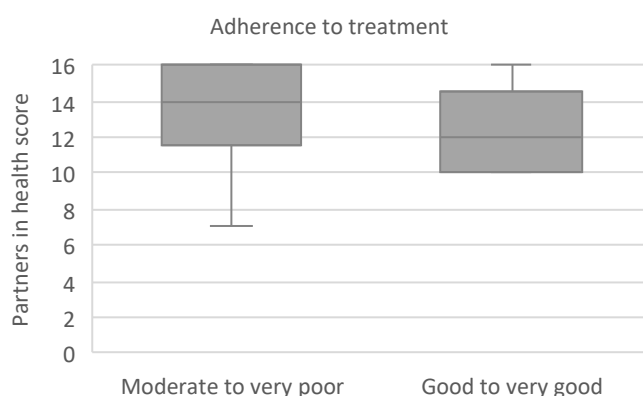
**Figure 6.24: Boxplot of Partners in health: knowledge by physical function**



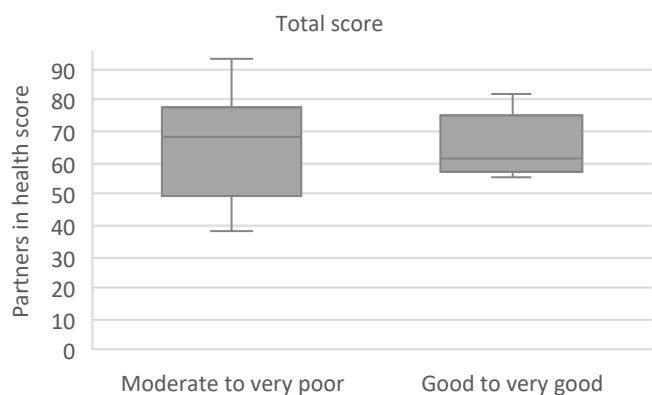
**Figure 6.25: Boxplot of Partners in health: coping by physical function**



**Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by physical function**



**Figure 6.27: Boxplot of Partners in health: adherence to treatment by physical function**



**Figure 6.28: Boxplot of Partners in health Total score by physical function**

### Comparisons of Partners in health scales by education

Comparisons were made by Education status, between those with trade or high school qualifications, trade or high school (n=10, 55.56%), and those with a university qualification, University (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by education are displayed in Figures 6.29 to 6.33,

summary statistics are displayed in Table 6.26. Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.26).

A two sample t-test indicated that the mean score for the **Partners in health: recognition and management of symptoms** [ $t(16) = -2.59, p = 0.0198$ ] was significantly higher for participants in the *University* subgroup (mean = 20.13, SD = 3.27) compared to participants in the *Trade or high school* subgroup (mean = 15.80, SD = 3.71).

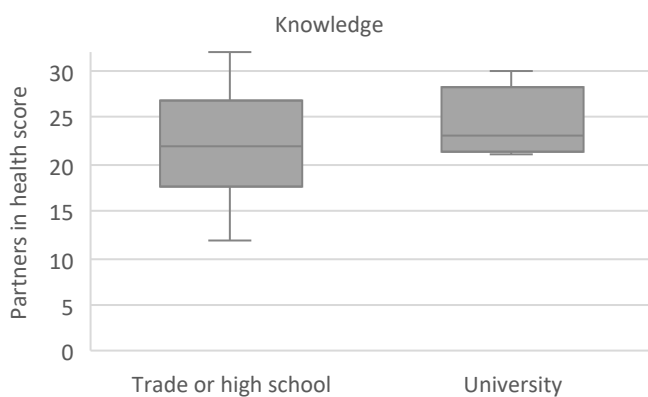
The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the *University* subgroup scored higher than

participants in the *Trade or high school* subgroup. This indicates that participants in the *University* subgroup, had excellent recognition and management of symptoms, compared to very good recognition and management of symptoms for participants in the *Trade or high school* subgroup.

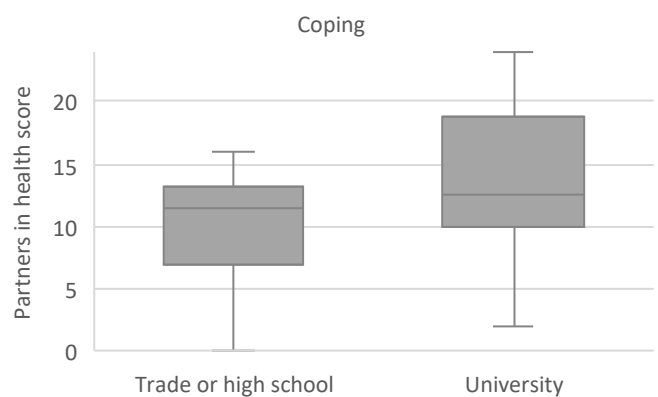
**Table 6.26: Partners in health by education summary statistics and two sample t-test**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	Trade or high school	10	55.56	21.90	6.47	-0.97	16	0.3484
	University	8	44.44	24.38	3.58			
Coping	Trade or high school	10	55.56	9.90	4.84	-1.30	16	0.2110
	University	8	44.44	13.50	6.89			
Recognition and management of symptoms	Trade or high school	10	55.56	15.80	3.71	-2.59	16	0.0198*
	University	8	44.44	20.13	3.27			
Adherence to treatment	Trade or high school	10	55.56	12.40	2.76	-0.86	16	0.4026
	University	8	44.44	13.50	2.62			
Total score	Trade or high school	10	55.56	60.00	12.99	-1.87	16	0.0795
	University	8	44.44	71.50	12.90			

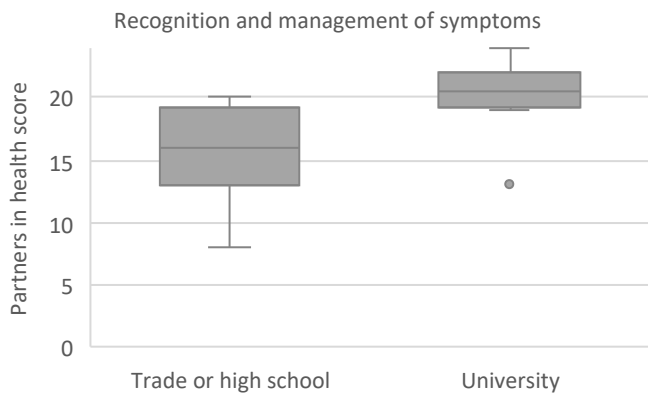
\*Significant at  $p < 0.05$



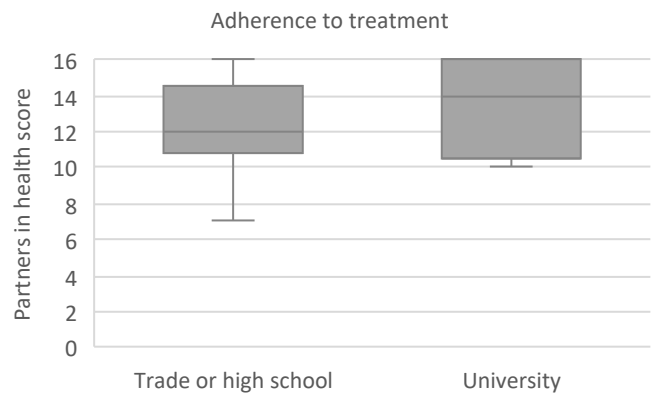
**Figure 6.29: Boxplot of Partners in health: knowledge by education**



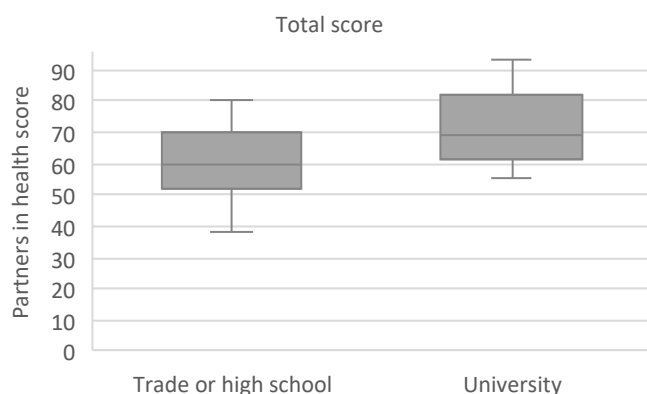
**Figure 6.30: Boxplot of Partners in health: coping by education**



**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**

### Comparisons of Partners in health scales by socioeconomic advantage

Comparisons were made by socioeconomic advantage, using the Socio-economic Indexes for Areas (SEIFA) ([www.abs.gov.au](http://www.abs.gov.au)), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=12, 66.67%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **socioeconomic advantage** are displayed in Figures 6.34 to 6.38, summary statistics are displayed in Tables 6.27 to 6.28. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.27), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.28).

A two sample t-test indicated that the mean score for the **Partners in health: coping** [ $t(16) = -2.13$ ,  $p=0.0494$ ] was significantly higher for participants in the *Higher status* subgroup (Mean = 13.42, SD = 5.71) compared to participants in the *Mid to low status* subgroup (Mean = 7.67, SD = 4.68)

A two sample t-test indicated that the mean score for the **Partners in health: recognition and management of symptoms** [ $t(16) = -2.41$ ,  $p=0.0282$ ] was significantly higher for participants in the *Higher status* subgroup (Mean = 19.17, SD = 3.38) compared to participants in the *Mid to low status* subgroup (Mean = 14.83, SD = 4.02).

A two sample t-test indicated that the mean score for the **Partners in health: total score** [ $t(16) = -3.00$ ,  $p=0.0084$ ] was significantly higher for participants in the *Higher status* subgroup (Mean = 70.83, SD =

11.90) compared to participants in the *Mid to low status* subgroup (Mean = 53.67, SD = 10.33)

### Recognition and management of symptoms

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 *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *Higher status* subgroup, had a moderate ability to manage the effects of their health condition, compared to a poor ability to manage for participants in the *Mid to low status* subgroup.

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. However, all participants scored in the same range, this indicates that participants 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 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 overall knowledge, coping and confidence for managing their own health, compared to moderate overall knowledge, coping and confidence for participants in the *Mid to low status* subgroup.

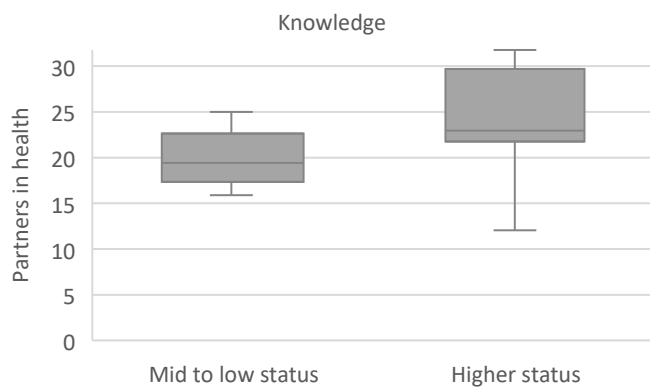
**Table 6.27: Partners in health by socioeconomic advantage summary statistics and two sample t-test**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	Mid to low status	6	33.33	20.00	3.29	-1.77	16	0.0955
	Higher status	12	66.67	24.50	5.71			
Coping	Mid to low status	6	33.33	7.67	4.68	-2.13	16	0.0494*
	Higher status	12	66.67	13.42	5.71			
Recognition and management of symptoms	Mid to low status	6	33.33	14.83	4.02	-2.41	16	0.0282*
	Higher status	12	66.67	19.17	3.38			
Total score	Mid to low status	6	33.33	53.67	10.33	-3.00	16	0.0084*
	Higher status	12	66.67	70.83	11.90			

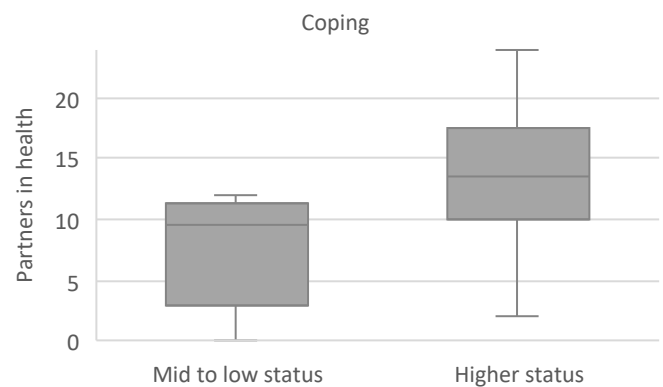
\*Significant at  $p < 0.05$

**Table 6.28: Partners in health by socioeconomic advantage summary statistics and Wilcoxon rank sum tests with continuity correction**

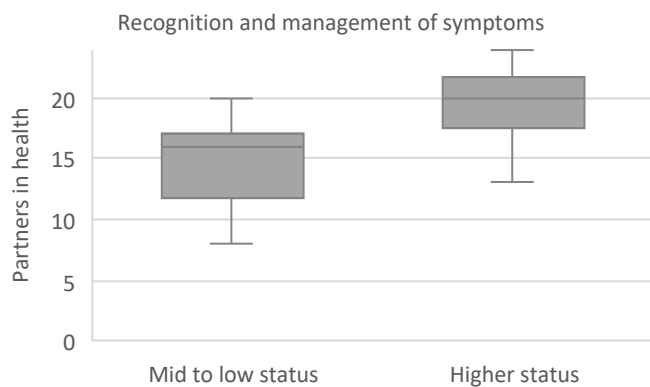
Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Adherence to treatment	Mid to low status	6	33.33	11.00	3.50	16.50	0.0699
	Higher status	12	66.67	14.00	4.00		



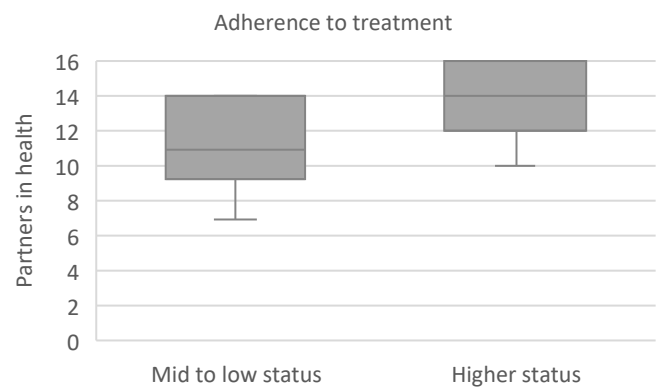
**Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic advantage**



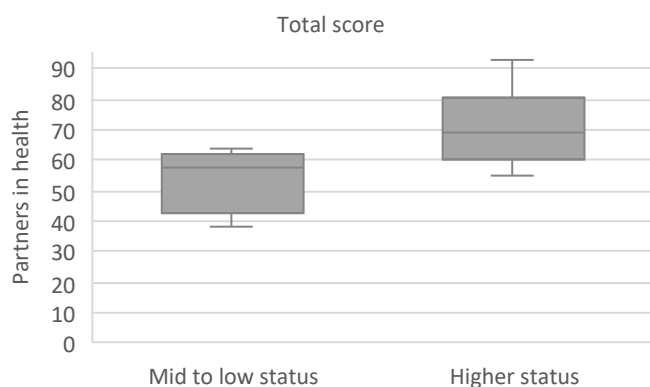
**Figure 6.35: Boxplot of Partners in health: coping by socioeconomic advantage**



**Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic advantage**



**Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic advantage**



**Figure 6.38: Boxplot of Partners in health Total score by socioeconomic advantage**

### Comparisons of Partners in health scales by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

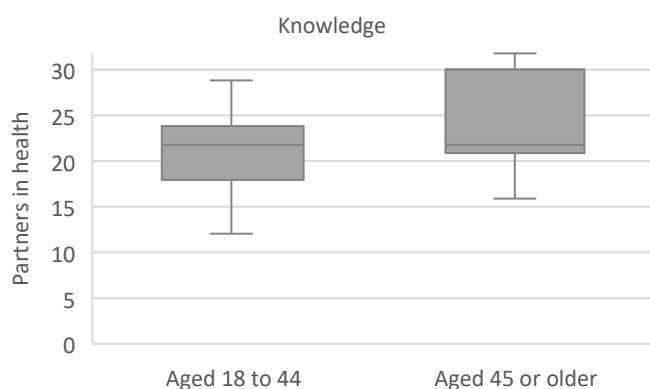
Boxplots of each Partners in health scale by **age** are displayed in Figures 6.39 to 6.43, summary statistics

are displayed in Table 6.29. Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.29).

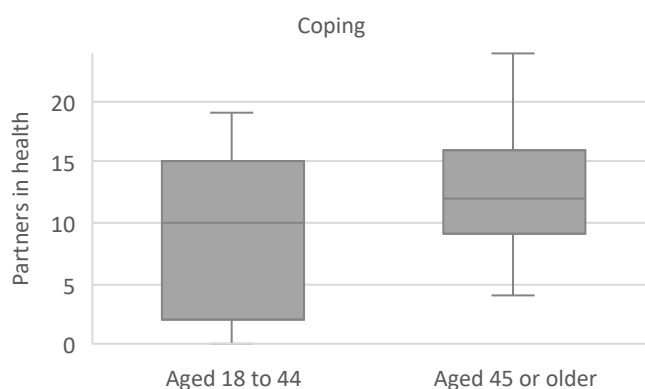
No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* for any of the partners in health scales.

**Table 6.29: Partners in health by age summary statistics and two sample t-test**

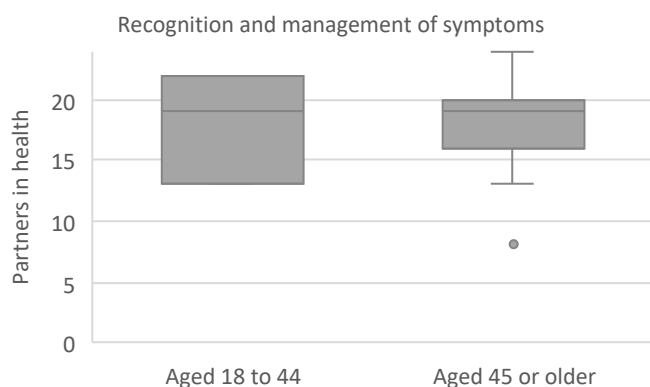
Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	<i>Aged 18 to 44</i>	7	38.89	21.14	5.24	-1.18	16	0.2555
	<i>Aged 45 or older</i>	11	61.11	24.18	5.38			
Coping	<i>Aged 18 to 44</i>	7	38.89	10.00	6.90	-0.85	16	0.4095
	<i>Aged 45 or older</i>	11	61.11	12.45	5.37			
Recognition and management of symptoms	<i>Aged 18 to 44</i>	7	38.89	18.00	3.83	0.22	16	0.8253
	<i>Aged 45 or older</i>	11	61.11	17.55	4.39			
Adherence to treatment	<i>Aged 18 to 44</i>	7	38.89	12.29	3.20	-0.75	16	0.4624
	<i>Aged 45 or older</i>	11	61.11	13.27	2.37			
Total score	<i>Aged 18 to 44</i>	7	38.89	61.43	14.06	-0.89	16	0.3849
	<i>Aged 45 or older</i>	11	61.11	67.45	13.89			



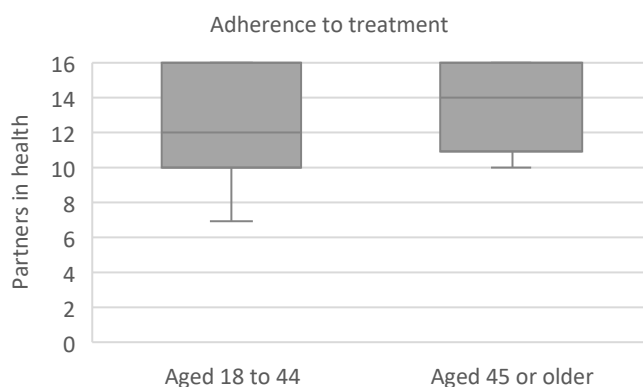
**Figure 6.39: Boxplot of Partners in health: knowledge by age**



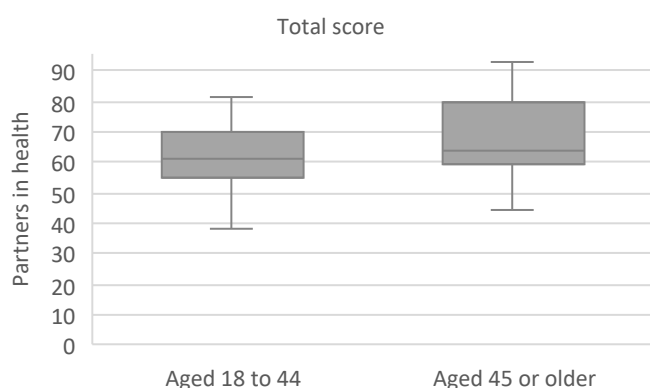
**Figure 6.40: Boxplot of Partners in health: coping by age**



**Figure 6.41: Boxplot of Partners in health: recognition and management of symptoms by age**



**Figure 6.42: Boxplot of Partners in health: adherence to treatment by age**



**Figure 6.43: Boxplot of Partners in health Total score by age**

#### Comparisons of Partners in health scales by gender

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%)

for comparisons to be made. Data by **gender** is displayed for NMOSD participants in Table 6.30, but no analysis conducted.

**Table 6.30: Partners in health by gender summary statistics**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Knowledge	Female	16	88.89	22.75	5.08	22.00	4.25
	Male	2	11.11	25.00	9.90	25.00	7.00
Coping	Female	16	88.89	12.19	5.91	12.00	5.25
	Male	2	11.11	6.00	2.83	6.00	2.00
Recognition and management of symptoms	Female	16	88.89	18.19	3.45	19.00	4.25
	Male	2	11.11	14.00	8.49	14.00	6.00
Adherence to treatment	Female	16	88.89	12.63	2.70	12.00	4.50
	Male	2	11.11	15.00	1.41	15.00	1.00
Total score	Female	16	88.89	65.75	13.41	62.50	14.25
	Male	2	11.11	60.00	22.63	60.00	16.00

#### Comparisons of Partners in health scales 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. There were 15

participants with NMOSD (83.33%) that lived in Metropolitan areas, however, too few participants with NMOSD lived in Regional or remote areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants in Table 6.31, but no analysis conducted.

**Table 6.31: Partners in health by location summary statistics**

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Knowledge	Regional and remote	3	16.67	19.67	4.73	18.00	4.50
	Metropolitan	15	83.33	23.67	5.41	22.00	6.00
Coping	Regional and remote	3	16.67	8.33	4.04	9.00	4.00
	Metropolitan	15	83.33	12.13	6.16	12.00	5.50
Recognition and management of symptoms	Regional and remote	3	16.67	13.33	4.62	16.00	4.00
	Metropolitan	15	83.33	18.60	3.48	20.00	4.00
Adherence to treatment	Regional and remote	3	16.67	13.33	1.15	14.00	1.00
	Metropolitan	15	83.33	12.80	2.91	12.00	5.50
Total score	Regional and remote	3	16.67	54.67	10.07	56.00	10.00
	Metropolitan	15	83.33	67.20	13.82	68.00	18.50

### Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals (Table 6.32, Figure 6.44).

#### NMOSD

Participants with NMOSD were most commonly given information about treatment options (n=10, 55.56%), and disease management (n=6, 33.33%). There were five participants (27.78%) that received very little information from healthcare professionals.

#### MOG

All participants with MOG were given information about treatment options (n=8, 100.00%), and half of

the participants were given information about disease management (n=4, 50.00%).

#### NMOSD or MOG

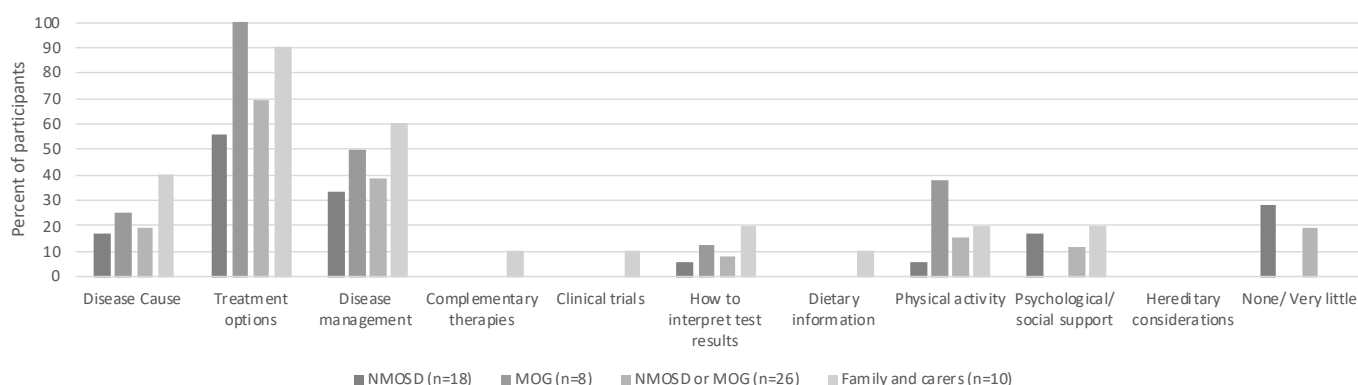
Overall, participants with NMOSD or MOG were most commonly given information about treatment options (n=18, 69.23%), disease management (n=10, 38.46%), and disease cause (n=5, 19.23%). There were five participants (19.23%) that received very little information from healthcare professionals.

#### Family and carers

Carers and family were most commonly given information about treatment options (n=9, 90.00%), disease management (n=6, 60.00%), and disease cause (n=4, 40.00%).

**Table 6.32: Information given by health professionals**

Information given by health professionals	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Disease Cause	3	16.67	2	25.00	5	19.23	4	40.00
Treatment options	10	55.56	8	100.00	18	69.23	9	90.00
Disease management	6	33.33	4	50.00	10	38.46	6	60.00
Complementary therapies	0	0.00	0	0.00	0	0.00	1	10.00
Clinical trials	0	0.00	0	0.00	0	0.00	1	10.00
How to interpret test results	1	5.56	1	12.50	2	7.69	2	20.00
Dietary information	0	0.00	0	0.00	0	0.00	1	10.00
Physical activity	1	5.56	3	37.50	4	15.38	2	20.00
Psychological/social support	3	16.67	0	0.00	3	11.54	2	20.00
Hereditary considerations	0	0.00	0	0.00	0	0.00	0	0.00
None/Very little	5	27.78	0	0.00	5	19.23	0	0.00



**Figure 6.44: 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 (Table 6.33, Figure 6.45).

### NMOSD

Participants with NMOSD most commonly searched for information about disease management (n=16, 88.89%), disease cause (n=15, 83.33%), treatment options (n=12, 66.67%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants looked for information about how to interpret test results, dietary information, and psychological/social support (n=9, 50.00%).

### MOG

Participants with MOG most commonly searched for information about complementary therapies (n=6, 75.00%), disease management (n=5, 62.50%), and disease Cause (n=5, 62.50%). Half of the

participants looked for information about treatment options, and dietary information (n=4, 50.00%)

### NMOSD or MOG

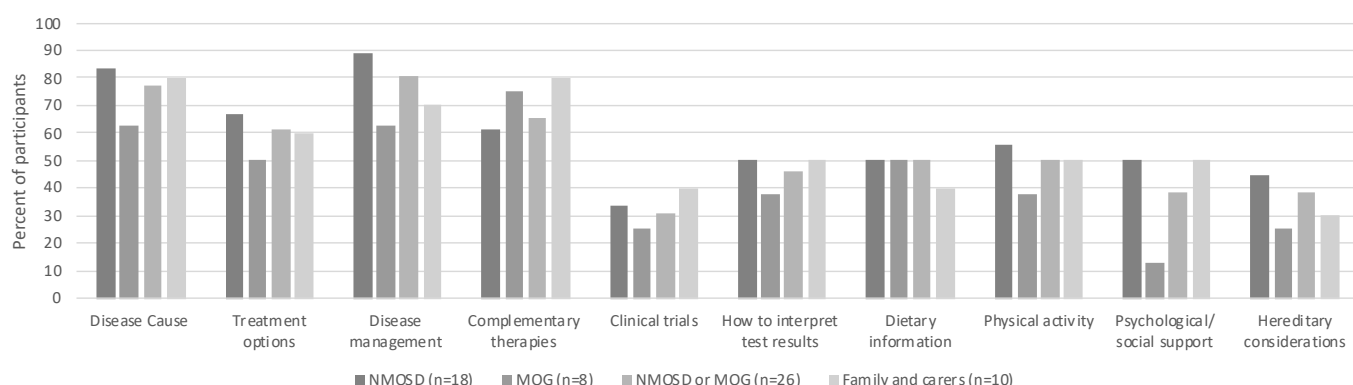
Overall, Participants with NMOSD or MOG most commonly searched for information about disease management (n=21, 80.77%), disease cause (n=20, 76.92%), complementary therapies (n=17, 65.38), and treatment options (61.54%). Half of the participants looked for information about dietary information, and physical activity (n=13, 50.00%).

### Family and carers

Carers and family most commonly searched for information about disease cause (n=8, 80.00%), complementary therapies (n=8, 80.00%), disease management (n=7, 70.00%), and treatment options (n=6, 60.00%). Half of the family and carers searched for information about physical activity, how to interpret test results, and psychological/social support (n=5, 50.00%).

**Table 6.33: Information searched for independently**

Information searched for independently	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Disease Cause	15	83.33	5	62.50	20	76.92	8	80.00
Treatment options	12	66.67	4	50.00	16	61.54	6	60.00
Disease management	16	88.89	5	62.50	21	80.77	7	70.00
Complementary therapies	11	61.11	6	75.00	17	65.38	8	80.00
Clinical trials	6	33.33	2	25.00	8	30.77	4	40.00
How to interpret test results	9	50.00	3	37.50	12	46.15	5	50.00
Dietary information	9	50.00	4	50.00	13	50.00	4	40.00
Physical activity	10	55.56	3	37.50	13	50.00	5	50.00
Psychological/social support	9	50.00	1	12.50	10	38.46	5	50.00
Hereditary considerations	8	44.44	2	25.00	10	38.46	3	30.00



**Figure 6.45: Information searched for independently**



Information gaps: participants with NMOSD

The topic most often given to participants by healthcare professionals and not searched for independently was about treatment options (n = 5, 27.78%).

The topics most commonly given to participants by healthcare professionals and searched for independently were disease management (n=5, 27.78%), and treatment options (n=5, 27.78%).

Topics most often not given by health professional and not searched for independently were clinical

trials (n=12, 66.67%), hereditary considerations (n=10, 55.56%), and dietary information (n=9, 50.00%).

The most common topics that were searched for and not given by a healthcare professional were disease cause (n=13, 72.22%), disease management (n=11, 61.11%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants searched for how to interpret test results, and dietary information without receiving information from healthcare professionals (n=9, 50.00%) (Table 6.34, Figure 6.46).

Table 6.34: Information gaps: participants with NMOSD

NMOSD	Given by health professional only		Given by health professional, searched for independently		Not given by health professional, not searched for independently		Searched for independently only	
	n=18	Percent	n=18	Percent	n=18	Percent	n=18	Percent
Disease Cause	1	5.56	2	11.11	2	11.11	13	72.22
Treatment options	5	27.78	5	27.78	1	5.56	7	38.89
Disease management	1	5.56	5	27.78	1	5.56	11	61.11
Complementary therapies	0	0.00	0	0.00	7	38.89	11	61.11
Clinical trials	0	0.00	0	0.00	12	66.67	6	33.33
How to interpret test results	1	5.56	0	0.00	8	44.44	9	50.00
Dietary information	0	0.00	0	0.00	9	50.00	9	50.00
Physical activity	1	5.56	0	0.00	7	38.89	10	55.56
Psychological/social support	2	11.11	1	5.56	7	38.89	8	44.44
Hereditary considerations	0	0.00	0	0.00	10	55.56	8	44.44

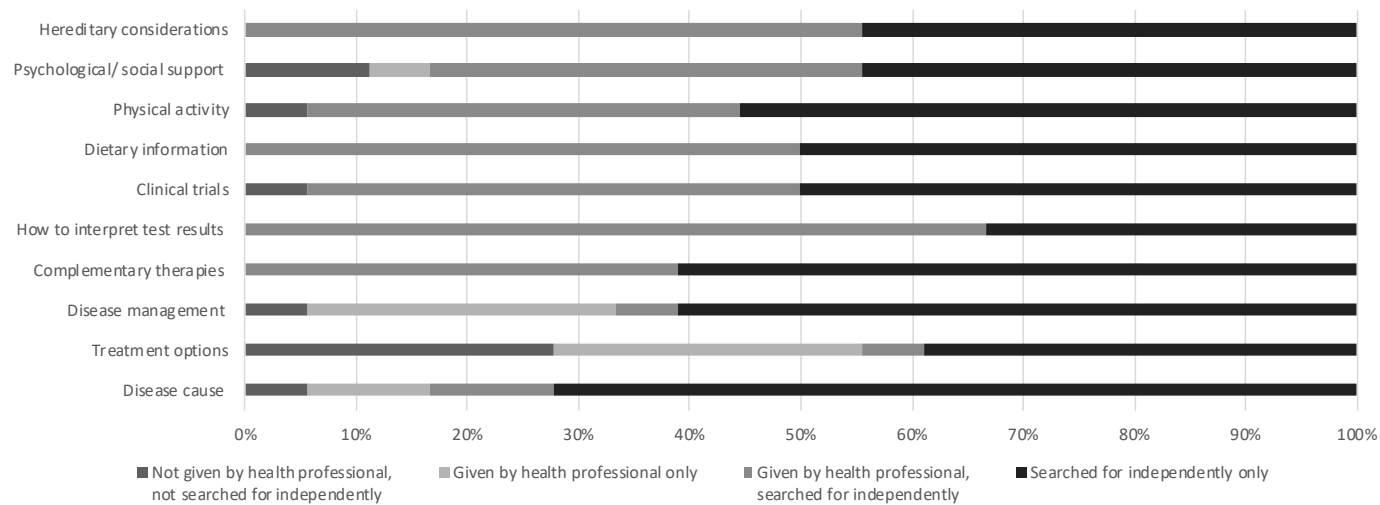


Figure 6.46: Information gaps: participants with NMOSD

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.35 and Figure 6.47. With a weighted ranking, the higher the score, the more accessed the source of information.

NMOSD

Participants with NMOSD accessed information from non-profits organisations, charities, or patient

organisations most often, followed by medical journals, and from the government least often

MOG

Participants with MOG accessed information from medical journals, most often, followed by non-profits organisations, charities, or patient organisations and from the government least often

NMOSD or MOG

Participants with NMOSD or MOG accessed information from medical journals, most often, followed by non-profits organisations, charities, or patient organisations and from the government least often

Family and carers

Family and carers accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often.

Table 6.35: Most accessed information

Information source	NMOSD	MOG	NMOSD or MOG	Family or carers
Non-profit organisations, charity or patient organisations	3.83	3.00	3.58	4.00
Government	2.33	2.63	2.42	1.80
Pharmaceutical companies	2.44	2.88	2.58	2.50
Hospital or clinic I am being treated in	2.67	2.75	2.69	3.30
Medical journals	3.72	3.75	3.73	3.40

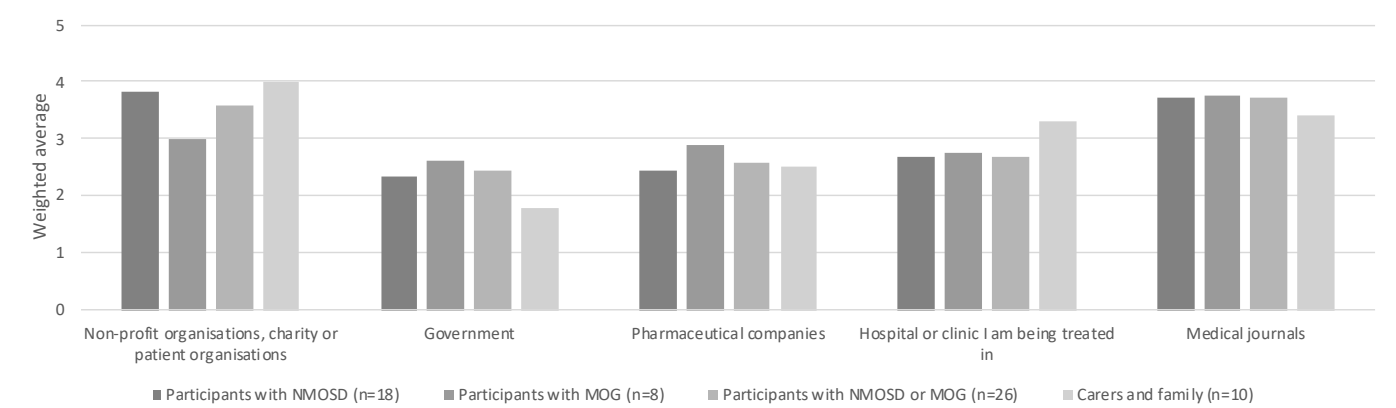


Figure 6.47: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. Participants were asked if they had accessed it (Table 6.36, Figure 6.48), and if they had accessed it, how useful it was (Table 6.37, Figure 6.49).

NMOSD

There were nine participants with NMOSD (50.00%) that had accessed My Health Record, seven participants (38.89%) that had not. There was one participant (5.56%) that wasn't sure, and one participant (5.56%) that's did not know what it is.

Of those that had accessed My Health Record, there were three participants (33.33%) that thought the usefulness was very poor, two participants (22.22%) that thought it was poor, and four participants (44.44%) found it acceptable)

MOG

There were two participants with MOG (25.00%) that had accessed My Health Record, five participants (62.50%) that had not. There was one participant (12.50%) that's did not know what it is.

NMOSD or MOG

There were 11 participants with NMOSD or MOG (42.31%) that had accessed My Health Record, 12 participants (46.15%) that had not. There was one participant (3.85%) that wasn't sure, and two participants (7.69%) that's did not know what it is.

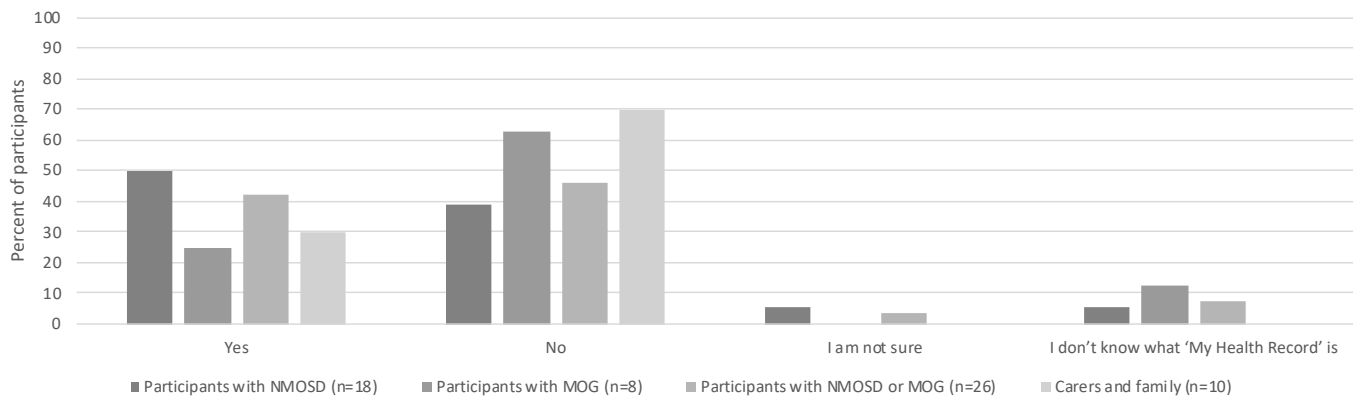
Of those that had accessed My Health Record, there were four participants (36.36%) that thought the usefulness was very poor, two participants (18.18%) that thought it was poor, and five participants (45.45%) found it acceptable)

Family and carers

There were three family and carers (30.00%) that had accessed My Health Record, seven participants (70.00%) that had not.

**Table 6.36: Accessed My Health Record**

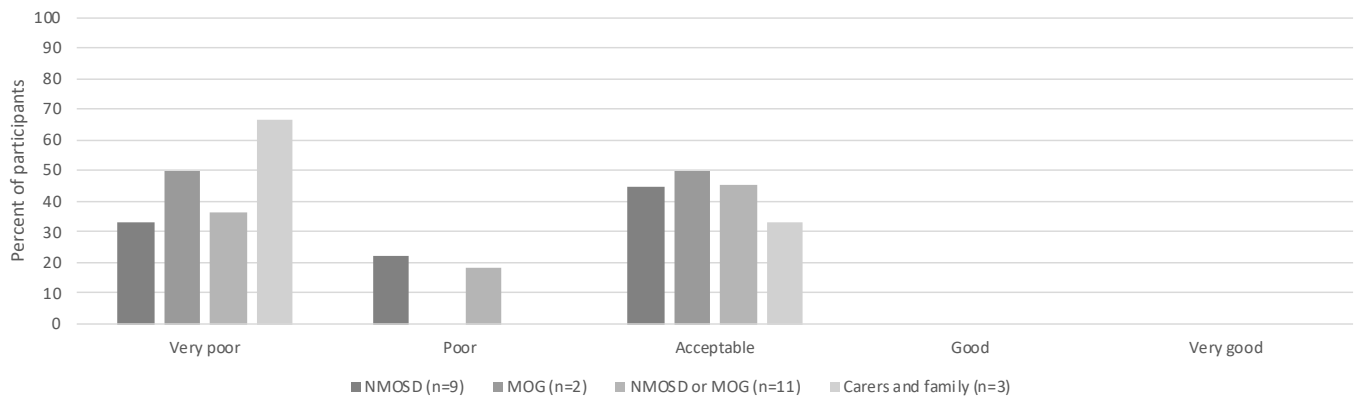
Accessed My Health Record	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Yes	9	50.00	2	25.00	11	42.31	3	30.00
No	7	38.89	5	62.50	12	46.15	7	70.00
I am not sure	1	5.56	0	0.00	1	3.85	0	0.00
I don't know what 'My Health Record' is	1	5.56	1	12.50	2	7.69	0	0.00



**Figure 6.48: Accessed My Health Record**

**Table 6.37: How useful was My Health Record**

How useful was My Health Record	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Very poor	3	33.33	1	50.00	4	36.36	2	66.67
Poor	2	22.22	0	0.00	2	18.18	0	0.00
Acceptable	4	44.44	1	50.00	5	45.45	1	33.33
Good	0	0.00	0	0.00	0	0.00	0	0.00
Very good	0	0.00	0	0.00	0	0.00	0	0.00



**Figure 6.49: How useful was My Health Record**