

Section 9

Expectations and messages to decision-makers

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will have fewer or less intense side effects (n=6, 33.33%), and this was followed by the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) (n=5, 27.78%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was the expectation that future information will be more specific to their condition/disease (n=5, 27.78%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will be more transparent and information more forthcoming (n=7, 38.89%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) (n=5, 27.78%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was low cost/free medical care (n=6, 33.33%). This was followed by being grateful for hospitals (n=6, 33.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported by participants with NMOSD were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects to participants with NMOSD were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important was "My ability to follow and stick to a treatment regime".

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values for participants with NMOSD were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants with NMOSD (n=11, 64.11%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were two participants (11.11%) that would take medication for five to 10 years, four participants (22.22%) that would take it for one to four years.

Most effective form of medicine

Participants were asked in the online questionnaire, In what form did they think medicine was most effective in. Participants with NMOSD most commonly responded that they were not sure (n=7, 38.89%), followed by IV form (n=6, 33.33%), and four participants (n=4, 22.22%) thought IV and pill forms were equally effective.

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to invest in new treatments and make them more accessible (n=7, 38.89%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will have fewer or less intense side effects (n=6, 33.33%), and this was followed by the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) (n=5, 27.78%).

Participant describes the expectation that future treatments will have fewer or less intense side effects

Well, it's probably a dream, but I'd like to see- the treatments at the moment are all like steroids with reduced inflammation and the immunosuppression stops further relapses in the future, what would be super cool is if something could be developed that actually remodel and fixes the nerves that can fix the damage that's already done because at the moment, that's the dream, we can't do that. Other than that, I mean, the steroids treatment is the first line and it's got such horrendous side effects. It's the worst. I'll avoid steroids as much as I can. I think they're awful.. Participant NMO_010

Well, less side effects would be fantastic. Participant NMO_016

I'm not sure if I am able to answer that because we have literally only used one or two treatments and I'm not sure whether I'm qualified, but just in overall, I think just the side effects, managing the side effects that would be perhaps the one that I would mention. Participant NMOCA_003

Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)

My neurologist there are new treatments for NMO in the US, but PBS doesn't have them or something. We just can't get it here, otherwise it would cost hundreds of thousands of dollars for an infusion. I guess more access to international drugs that are used and are effective and safe. Participant NMO_002

Like the doctors in LOCATION OVERSEAS-- To give you an example, doctors in LOCATION OVERSEAS, I'm constantly in contact with them. They told me, "Oh, maybe try tocilizumab," because I was relapsing in all the previous treatments. It's just not available. I had to write my neurologist a letter, she had to write to pharmaceutical companies, to medical boards, to everywhere, for it to get approved. Participant NMO_005

An injection would be great, or transfusion is fine, and a lot more affordable on the PBS would be amazing and more options because I feel like I don't have any options. Participant NMO_003

Participant describes expecting future treatments to be more affordable

The cost in regards to taking part in things that-- The NDIS doesn't cover pool access and all those kinds of things, which is hugely beneficial for me to be able to do. Participant NMO_006

It's just definitely the cost is a huge part of it. Participant NMO_014

Support with cost of ongoing treatment, better access to rehab facilities, and more priority around rehab. Participant NMOCA_002

Table 9.1: Expectations of future treatment

| Expectations of future treatment | 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 the expectation that future treatments will have fewer or less intense side effects | 6 | 33.33 | 4 | 44.44 | 2 | 22.22 | 3 | 37.50 | 3 | 30.00 | 2 | 22.22 | 4 | 44.44 |
| Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) | 5 | 27.78 | 1 | 11.11 | 4 | 44.44 | 3 | 37.50 | 2 | 20.00 | 2 | 22.22 | 3 | 33.33 |
| Participant describes expecting future treatments to be more affordable | 3 | 16.67 | 1 | 11.11 | 2 | 22.22 | 1 | 12.50 | 2 | 20.00 | 1 | 11.11 | 2 | 22.22 |

| Expectations of future treatment | 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 the expectation that future treatments will have fewer or less intense side effects | 6 | 33.33 | 3 | 30.00 | 3 | 37.50 | 3 | 50.00 | 3 | 25.00 | 3 | 42.86 | 3 | 27.27 |
| Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) | 5 | 27.78 | 3 | 30.00 | 2 | 25.00 | 2 | 33.33 | 3 | 25.00 | 3 | 42.86 | 2 | 18.18 |
| Participant describes expecting future treatments to be more affordable | 3 | 16.67 | 3 | 30.00 | 0 | 0.00 | 1 | 16.67 | 2 | 16.67 | 2 | 14.29 | 1 | 9.09 |

| Expectations of future treatment | 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 the expectation that future treatments will have fewer or less intense side effects | 6 | 33.33 | 5 | 62.50 | 11 | 42.31 | 4 | 40.00 | 6 | 37.50 | 0 | 0.00 | 0 | 0.00 | 6 | 40.00 |
| Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) | 5 | 27.78 | 0 | 0.00 | 5 | 19.23 | 1 | 10.00 | 4 | 25.00 | 1 | 50.00 | 2 | 66.67 | 3 | 20.00 |
| Participant describes expecting future treatments to be more affordable | 3 | 16.67 | 1 | 12.50 | 4 | 15.38 | 1 | 10.00 | 3 | 18.75 | 0 | 0.00 | 0 | 0.00 | 3 | 20.00 |

Table 9.2: Expectations of future treatment (Subgroup variations)

| Expectations of future treatment | More frequent | | | | Less frequent | | | |
|---|--|--|--|--|--|--|--|--|
| Participant describes the expectation that future treatments will have fewer or less intense side effects | Fewer relapses Good to very good physical function Mid to low socioeconomic status | | | | More relapses Moderate to very poor physical function | | | |
| Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) | More relapses Aged 18 to 44 | | | | Fewer relapses | | | |

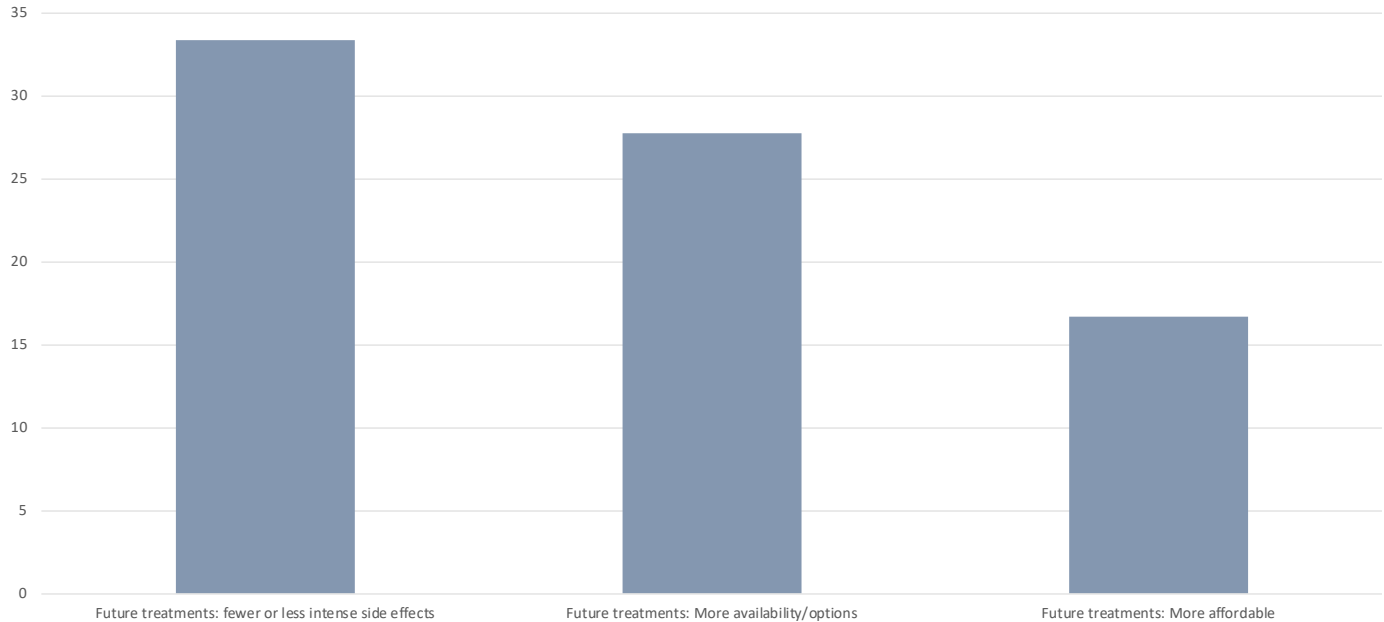


Figure 9.1: Expectations of future treatment

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The

most common theme was the expectation that future information will be more specific to their condition/disease (n=5, 27.78%).

Participant describes the expectation that future information will be more specific to their condition/disease

I just think maybe more information on it. I just feel like it's under the branch of MS, and that's kind of all there really is. They used to think it was a type of MS but now it's not, and it's worse. I just wish there was more accurate information out there that wasn't under the umbrella of MS because I feel like MS is gets all the funding. MS gets all the like the Readathon, the walkathons. They get all the funding, and it's kind of like what about NMO?... I just feel like NMO gets forgotten about. Participant NMO_003

I think the information is getting better. I think it's one of those things where it's a rare disease and it affects so few people, but also there just isn't a lot of information about. Even the medications we use, they're not really NMO medications. They're medications for other diseases that we know kind of work. I don't know, I would like-it's probably a dream too, but I would like the neurologists and the research clinics that I've been to be a little bit more accommodating, where you can ask questions. Participant NMO_010

Just that it is presented. The only thing that they could refer me to was a place called Sparks and everything that was related to NMO was through MS. Yet MS and NMO are treated so differently. I would like to see it have a home of its own. Do you know what I mean. Participant NMO_011

Participant describes the expectation that future information will provide more details about where to find available services

What services that they can have, because like some people, it might be in their spine, or hip first, so it'd be more the transverse. It might be physiotherapy for being able to walk again. Just certain specialists maybe be a helpline like in Australia, or whatever, anyway. It might be like the NDIS or whatever, because of some disabilities. Participant NMO_012

I think there just needs to be information about support thing, like where people can get support but that's about it. Participant NMOCA_005

I think when you're initially diagnosed with the condition, it would be really, really beneficial to have some leaflet or information on the condition itself, the treatment options that are used to treat the condition, and maybe some literature on where to find help and support. Participant NMOCA_007

Table 9.3: Expectations of future information

| Expectations of future 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 the expectation that future information will be more specific to their condition/disease | 5 | 27.78 | 2 | 22.22 | 3 | 33.33 | 3 | 37.50 | 2 | 20.00 | 2 | 22.22 | 3 | 33.33 |
| Participant describes the expectation that future information will provide more details about where to find available services | 2 | 11.11 | 0 | 0.00 | 2 | 22.22 | 0 | 0.00 | 2 | 20.00 | 1 | 11.11 | 1 | 11.11 |

| Expectations of future 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 the expectation that future information will be more specific to their condition/disease | 5 | 27.78 | 3 | 30.00 | 2 | 25.00 | 1 | 16.67 | 4 | 33.33 | 3 | 42.86 | 2 | 18.18 |
| Participant describes the expectation that future information will provide more details about where to find available services | 2 | 11.11 | 2 | 20.00 | 0 | 0.00 | 1 | 16.67 | 1 | 8.33 | 0 | 28.57 | 2 | 18.18 |

| Expectations of future 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 the expectation that future information will be more specific to their condition/disease | 5 | 27.78 | 2 | 25.00 | 7 | 26.92 | 2 | 20.00 | 5 | 31.25 | 0 | 0.00 | 1 | 33.33 | 4 | 26.67 |
| Participant describes the expectation that future information will provide more details about where to find available services | 2 | 11.11 | 1 | 12.50 | 3 | 11.54 | 3 | 30.00 | 1 | 6.25 | 1 | 50.00 | 1 | 33.33 | 1 | 6.67 |

Table 9.4: Expectations of future information (Subgroup variations)

| Expectations of future information | More frequent | Less frequent |
|--|---------------|---------------------------------|
| Participant describes the expectation that future information will be more specific to their condition/disease | Aged 18 to 44 | Mid to low socioeconomic status |

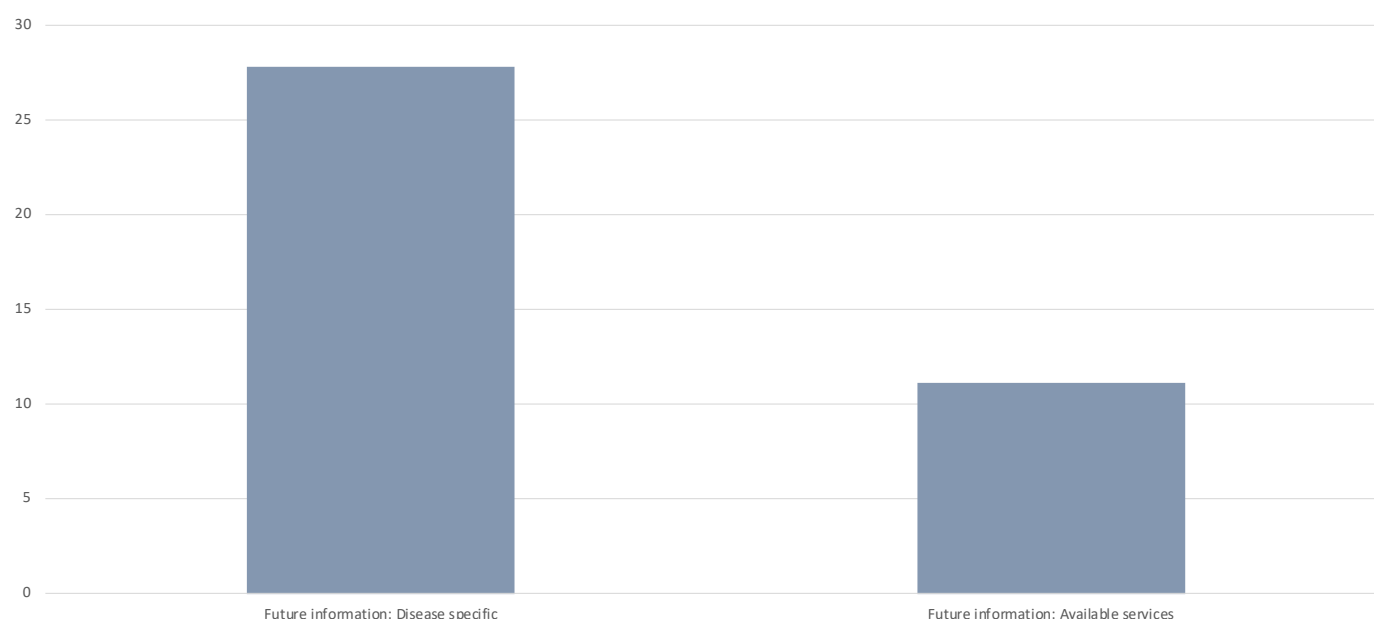


Figure 9.2: Expectations of future information

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will be more transparent and information more forthcoming (n=7, 38.89%).

Participant describes the expectation that future communication will be more transparent and information more forthcoming

I think yes. I think if we could communicate, it's sometimes really difficult to get any answers, especially early on, when things are changing so rapidly. I found the process of contacting the MS nurse and then waiting for a reply until she contacted the neurologist, it could take several days, and sometimes you do need to find out if there was an answer. You feel like you've been forgotten. I think prompt delivery of information when a patient's looking for it would be really good. Participant NMO_004

Yes, discuss in the room not out of the room. That's the first thing. Not when you're walking down the hallway with me. Explain, don't just do tests and then say, "Yes, it's all good," and then not tell you what's happened in there. I've got all these lesions that I didn't even know about. I had the disease for a couple of years and didn't even know about it. I

had to find out from another doctor, things like that. Tell me what I may expect. Just be a little bit more informative. Participant NMO_011

Some dialogue would be very nice, even if they just say like, actually tells you, "This is how we've come about the diagnosis and this is what it means. These are the testing that we've done." Just the information about your health that should be available to you. Participant NMO_014

Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about

I wish they had a bit more time rather than rushing to see the next patient particularly in the first couple of weeks really give us the time that we need, I feel like even 45 minutes to an hour, whatever it might be because if it's new just go through everything even if it needs to be repeated a couple of times and then really just make you understand what it is about that we are dealing with now and what the treatments are. Participant NMOCA_003

Like I say, just what I said is probably a bit more contact. We've got a lady, MS nurse, that we've got those details of. I think they should have more of those ladies and they could ring the patients up and see how they're going every three months, would be really awesome. I think for the patient, I think you need that. I think NAME PERSON CARED

FOR feels like she just has the treatment and then off she goes. "See you next year." I just think-- Like I say, I know time's important to them. That's the only thing really. Participant NMOCA_005

What I found with mine because, obviously, the neurologist is very busy, so he has an MS nurse who books you in or if you have any questions or concerns, you can message them or contact them. I've found that over three years, and I know they're busy too, it might be a week, sometimes they're off a week or they're on holiday, you never get your messages returned. Participant NMO_013

Participant describes the expectation that future communication will include listening to the patient, as they know their body best

Certainly having that empathy maybe that they just listen, listen to what she's saying because she's giving you all the clues that you need to see that she needs some assistance. It can be very frustrating. Participant NMO_016

I think listening to what a patient wants and needs, and I have to sort of try and work in with what's in that person's life. Like you can't just take time off because they want to start you on this new drug and just little things like that to me-- I'm a pretty stubborn personality and I can articulate how I feel because I've got a medical background. I think that's made a big difference where when I went to the NMO patient day, people don't speak to their neurologist. They don't articulate exactly what they want. They just go along with doctor knows best, but I don't think that's always the case. I think the patient actually has a voice and they should be given that opportunity to actually voice it, what it is, whatever it may be they want. Participant NMO_017

Participant describes the expectation that future communication will be more empathetic

I think if they just could communicate instead of they're looking at all the numbers of blood tests and all that stuff. They do a fantastic job. They need to have more of a sympathetic thing. It's like, "Okay. Well, what are they going to be feeling after this diagnosis?" Just to have a bit of a heart. Instead of just thinking, "Okay. This is another person. This is number 50. This is their diagnosis, let them go. This is the treatment." It's just seems like they're just concerned about just the

treatment and not the person. Participant NMO_012

Probably a little bit more empathy or compassion. Participant NMOCA_007

Yes. I think mostly like the allied health that I've seen has been really awesome. The physios and OTs and even a dietitian has been- that part's been really good, but the specialists I found just quite difficult to ask questions or to have them communicate it at the right level. I feel like- I was sent to this research centre, which is great, it's where I wanted to be, but every time I went there, I felt like the little subject that's come in for their tests and they're sent away, but not like a person. Participant NMO_010

Participant describes the expectation that in the future health professionals have a better understanding of the condition they are treating

Yes. I find sometimes say you go and it maybe you see something that you're trying to explain to them and you get hit on the head. I've gone through it. I know if I go in "Oh, you've got arthritis." Oh, my neurologist some 15 years ago told me I was lazy. "Go and do an exercise," and things like that. What I'm trying to say is these things are happening, but they don't know themselves sometimes. I was sent from one doctor who was very good in LOCATION METROPOLITAN. He couldn't find out what was wrong with me. There was another doctor, I don't know what they call him. If there's something that's wrong with you and the doctor can't find it, he will send you to NAME DOCTOR. He was the one that done all the tests. Yes, so what I'm trying to say is so he was thorough, but then he had diagnosed me with MS because he'd never heard of NMO anyway. Participant NMO_013

I think they should be more informed about diseases such as NMO and MOG, because every single time I've been to the emergency, they just don't understand. Participant NMO_005

I guess more awareness. I think the issue is a lot of medical professionals are a little bit out of their depth when it comes to the disease, so a little bit more awareness or knowledge about it. Participant NMOCA_007

Participant has no recommendations/experienced good communication

No, that part is all good. Like I said, the neurologist, he's very good. Participant NMO_007

No, I find they've been fantastic both the neurologist and the physio, so the communication's been fine. Participant NMO_009

Not really. I think no. I think I've got a pretty good team. I think I'm lucky in that sense. Participant NMOCA_005

Table 9.5: Expectations of future healthcare professional communication

| Expectations of future 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 the expectation that future communication will be more transparent and information more forthcoming | 7 | 38.89 | 3 | 33.33 | 4 | 44.44 | 5 | 62.50 | 2 | 20.00 | 4 | 44.44 | 3 | 33.33 |
| Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about | 3 | 16.67 | 1 | 11.11 | 2 | 22.22 | 0 | 0.00 | 3 | 30.00 | 1 | 11.11 | 2 | 22.22 |
| Participant describes the expectation that future communication will include listening to the patient, as they know their body best | 3 | 16.67 | 1 | 11.11 | 2 | 22.22 | 2 | 25.00 | 1 | 10.00 | 1 | 11.11 | 2 | 22.22 |
| Participant describes the expectation that future communication will be more empathetic | 2 | 11.11 | 1 | 11.11 | 1 | 11.11 | 1 | 12.50 | 1 | 10.00 | 0 | 0.00 | 2 | 22.22 |
| Participant describes the expectation that in the future health professionals have a better understanding of the condition they are treating | 2 | 11.11 | 1 | 11.11 | 1 | 11.11 | 1 | 12.50 | 1 | 10.00 | 1 | 11.11 | 1 | 11.11 |
| Participant has no recommendations/experienced good communication | 2 | 11.11 | 1 | 11.11 | 1 | 11.11 | 0 | 0.00 | 2 | 20.00 | 2 | 22.22 | 0 | 0.00 |

| Expectations of future 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 the expectation that future communication will be more transparent and information more forthcoming | 7 | 38.89 | 4 | 40.00 | 3 | 37.50 | 2 | 33.33 | 5 | 41.67 | 3 | 42.86 | 4 | 36.36 |
| Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about | 3 | 16.67 | 2 | 20.00 | 1 | 12.50 | 2 | 33.33 | 1 | 8.33 | 2 | 42.86 | 1 | 9.09 |
| Participant describes the expectation that future communication will include listening to the patient, as they know their body best | 3 | 16.67 | 1 | 10.00 | 2 | 25.00 | 1 | 16.67 | 2 | 16.67 | 2 | 28.57 | 1 | 9.09 |
| Participant describes the expectation that future communication will be more empathetic | 2 | 11.11 | 1 | 10.00 | 1 | 12.50 | 1 | 16.67 | 1 | 8.33 | 1 | 14.29 | 1 | 9.09 |
| Participant describes the expectation that in the future health professionals have a better understanding of the condition they are treating | 2 | 11.11 | 1 | 10.00 | 1 | 12.50 | 0 | 0.00 | 2 | 16.67 | 1 | 14.29 | 1 | 9.09 |
| Participant has no recommendations/experienced good communication | 2 | 11.11 | 2 | 20.00 | 0 | 0.00 | 1 | 16.67 | 1 | 8.33 | 0 | 0.00 | 2 | 18.18 |

| Expectations of future 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 the expectation that future communication will be more transparent and information more forthcoming | 7 | 38.89 | 1 | 12.50 | 8 | 30.77 | 3 | 30.00 | 7 | 43.75 | 0 | 0.00 | 1 | 33.33 | 6 | 40.00 |
| Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about | 3 | 16.67 | 1 | 12.50 | 4 | 15.38 | 3 | 30.00 | 3 | 18.75 | 0 | 0.00 | 0 | 0.00 | 3 | 20.00 |
| Participant describes the expectation that future communication will include listening to the patient, as they know their body best | 3 | 16.67 | 1 | 12.50 | 4 | 15.38 | 1 | 10.00 | 3 | 18.75 | 0 | 0.00 | 0 | 0.00 | 3 | 20.00 |
| Participant describes the expectation that future communication will be more empathetic | 2 | 11.11 | 1 | 12.50 | 3 | 11.54 | 3 | 30.00 | 2 | 12.50 | 0 | 0.00 | 1 | 33.33 | 1 | 6.67 |
| Participant describes the expectation that in the future health professionals have a better understanding of the condition they are treating | 2 | 11.11 | 2 | 25.00 | 4 | 15.38 | 1 | 10.00 | 2 | 12.50 | 0 | 0.00 | 0 | 0.00 | 2 | 13.33 |
| Participant has no recommendations/experienced good communication | 2 | 11.11 | 3 | 37.50 | 5 | 19.23 | 0 | 0.00 | 0 | 0.00 | 2 | 100.00 | 1 | 33.33 | 1 | 6.67 |

Table 9.6: Expectations of future healthcare professional communication (Subgroup variations)

| Expectations of future communication | More frequent | Less frequent |
|---|----------------------|------------------------|
| Participant describes the expectation that future communication will be more transparent and information more forthcoming | Low to moderate fear | High to very high fear |

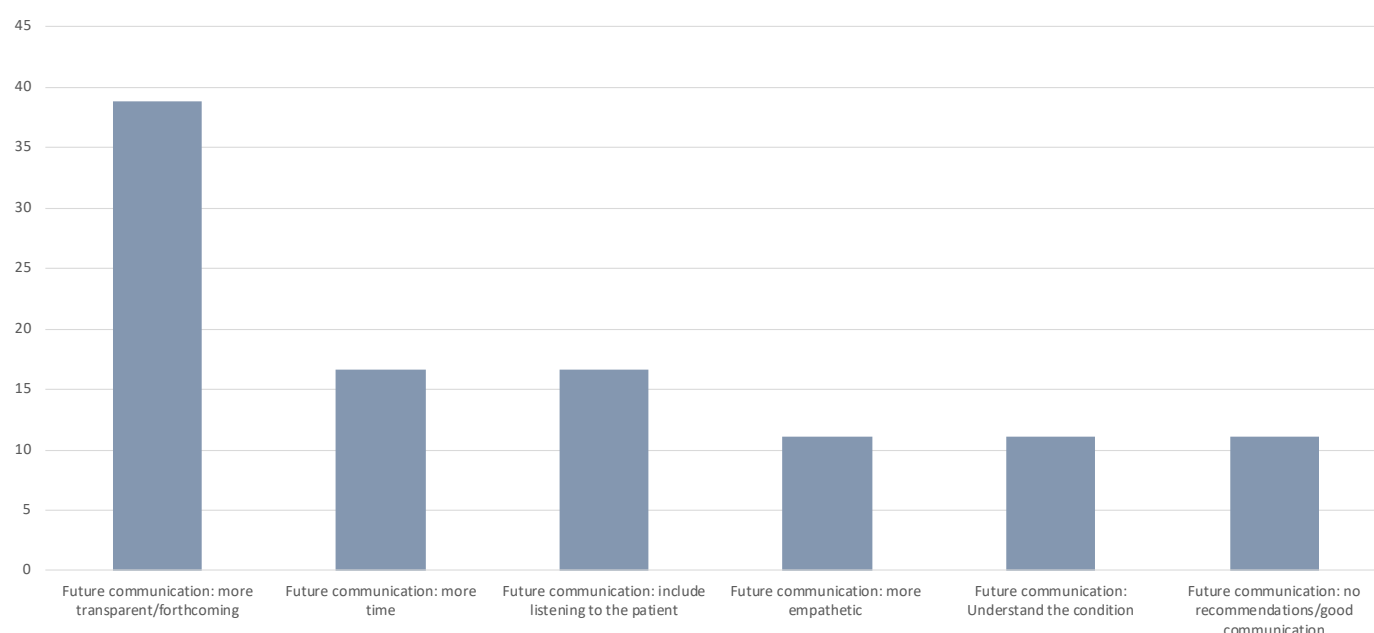


Figure 9.3: Expectations of future healthcare professional communication

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) (n=5, 27.78%).

Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

It would be nice to have a specialist that does even just research or something that you can talk to or whatever. They can say yay or nay. Participant NMO_013

Like some sort of a club is one. When something is happening to be able to reach out and talk to someone and say, "Look, XYZ is going on, what should I do?" Do I take her to hospital, do I-- I don't know, go to the GP? Where do we go from here? Someone that actually knows about the condition because the symptoms that she displays are so different to anything else. She doesn't get a fever like normal people get a fever because of the damage in her spinal cord. Participant NMO_016

I think maybe having someone there that you could talk to maybe about it and obviously that person knowing the condition being able to give you answers. Participant NMOCA_006

Participant describes the expectation that future care and support will be more specific to their condition and have more specific information

I don't know if this relates, but I feel like it would be great if we would have an organisation here that would help with, for example, audiobooks, or those kinds of things, because I've seen in America, they have quite a few organisations, and I feel like we don't. Participant NMO_005

I guess like a booklet or a pamphlet like something about NMO in Australia where there are support groups or doctors or rehab facilities that that are there for the therapy with NMO. Participant NMO_002

Research into the disease and information. Get the word out there what it's about. Participant NMO_011

Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I think I've touched on that before. I think just continuing to have our own support groups with NMO People. Participant NMO_004

Some kind of support network or some kind, just so that if somebody's newly diagnosed, that may be like, we now on part of the NMOSD Australia page, and since now, I'd be happy to give my details through them. I know there's a mentoring type thing that a few of us are taking part in. If somebody gets an early diagnosis, telling them that there's this page, there's these people contact them, and they'll see if there's somebody who could just keep checking in with the people. Participant NMO_006

I guess maybe more support groups. Participant NMO_008

Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services, NDIS etc.)

I think more support to the families, a contact for the family to actually contact with. They may need support caring for somebody. I'd like to see, either it'd be a social worker. I know that there's people trying to navigate around NDIS around what they're entitled to and that can be really difficult for people who aren't into the medical profession. Participant NMO_017

I suppose looking after NAME PERSON CARED FOR myself, no one has reached out and said, "This is what is available to you as the carer." Not so much NAME PERSON CARED FOR, because they've got a whole team looking after her, or just being aware of what's around there. Participant NMOCA_004

My greatest problem is really transportation, because I don't drive, I've had to depend on others. Participant NMO_007

Table 9.7: Expectations of future care and support

| Expectations of future care and support | 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 the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) | 5 | 27.78 | 3 | 33.33 | 2 | 22.22 | 2 | 25.00 | 3 | 30.00 | 3 | 33.33 | 2 | 22.22 |
| Participant describes the expectation that future care and support will be more specific to their condition and have more specific information | 4 | 22.22 | 2 | 22.22 | 2 | 22.22 | 4 | 50.00 | 0 | 0.00 | 2 | 22.22 | 2 | 22.22 |
| Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums) | 4 | 22.22 | 1 | 11.11 | 3 | 33.33 | 2 | 25.00 | 2 | 20.00 | 2 | 22.22 | 2 | 22.22 |
| Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.) | 2 | 11.11 | 1 | 11.11 | 1 | 11.11 | 1 | 12.50 | 1 | 10.00 | 1 | 11.11 | 1 | 11.11 |

| Expectations of future care and support | 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 the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) | 5 | 27.78 | 4 | 40.00 | 1 | 12.50 | 2 | 33.33 | 3 | 25.00 | 1 | 14.29 | 4 | 36.36 |
| Participant describes the expectation that future care and support will be more specific to their condition and have more specific information | 4 | 22.22 | 2 | 20.00 | 2 | 25.00 | 2 | 33.33 | 2 | 16.67 | 1 | 28.57 | 3 | 27.27 |
| Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums) | 4 | 22.22 | 1 | 11.11 | 3 | 33.33 | 2 | 25.00 | 2 | 20.00 | 2 | 28.57 | 2 | 18.18 |
| Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.) | 2 | 11.11 | 1 | 10.00 | 1 | 12.50 | 0 | 0.00 | 2 | 16.67 | 0 | 0.00 | 2 | 18.18 |

| Expectations of future care and support | 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 the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) | 5 | 27.78 | 0 | 0.00 | 5 | 19.23 | 1 | 10.00 | 5 | 31.25 | 0 | 0.00 | 0 | 0.00 | 5 | 33.33 |
| Participant describes the expectation that future care and support will be more specific to their condition and have more specific information | 4 | 22.22 | 3 | 37.50 | 7 | 26.92 | 3 | 30.00 | 4 | 25.00 | 0 | 0.00 | 1 | 33.33 | 3 | 20.00 |
| Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums) | 4 | 22.22 | 1 | 12.50 | 5 | 19.23 | 2 | 28.57 | 4 | 25.00 | 0 | 0.00 | 0 | 0.00 | 4 | 26.67 |
| Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.) | 2 | 11.11 | 1 | 12.50 | 3 | 11.54 | 3 | 30.00 | 1 | 6.25 | 1 | 50.00 | 0 | 0.00 | 2 | 13.33 |

Table 9.8: Expectations of future care and support

| Expectations of future care and support | More frequent | Less frequent |
|--|----------------------|-----------------------------|
| Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) | Trade or high school | University Aged 18 to 44 |

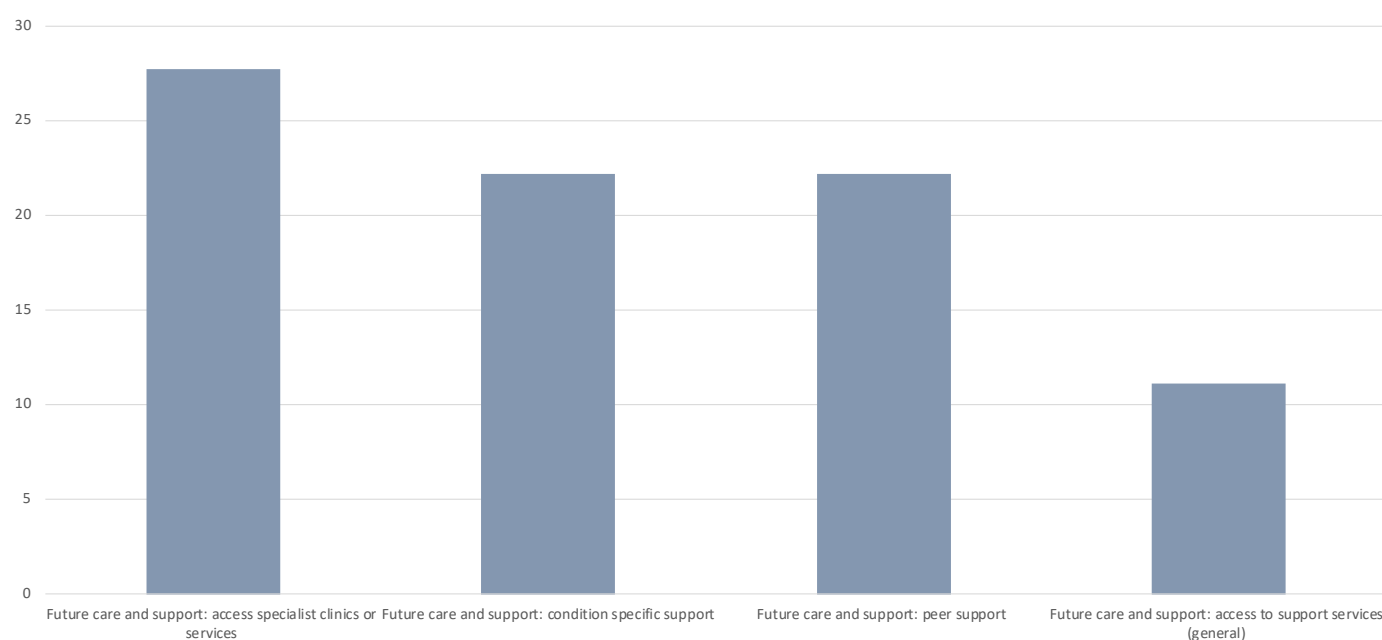


Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was low cost/free medical care (n=6, 33.33%). This was followed by being grateful for hospitals (n=6, 33.33%).

Participant is grateful for low cost/free medical care through the government

Totally. Everything that I've had has been amazing. As in, within the hospital system and the infusions, they've been able to pay for the whole. I really can't complain with that. Participant NMO_008

Yes, I see on our Facebook group that people in America in particular, when they have a relapse, they're relying on their insurance companies to cover the cost of their meds, which are incredibly expensive, like \$30,000 at a time. In Australia, I remember when we were talking immunosuppression, my neurologist said that he's assigned a piece of paper and he gets another neurologist to sign and then you get your meds. [chuckles]. That's all that it is, but which is pretty cool. I'm very, very grateful for that. Participant NMO_010

The public system just paid for it all. I'm so grateful for that. Participant NMOCA_005

Participant describes being grateful for hospitals

I've got to say that my hospital stay has been very, very good. Because I've been in hospital in LOCATION OVERSEAS, which is also very great, but I also been in LOCATION OVERSEAS, which is not so great, so I've been able to compare, and I think the whole hospital system in Australia is amazing. Participant NMO_005

Like I said, the hospitals have been really good. Participant NMO_007

Our public hospital systems are pretty damn good. Okay, some of the -- a lot of the doctors have never heard of the rare disease, but the fact that we can access the hospitals and access this care that doesn't cost us anything is a huge gift. Participant NMO_016

Participant is grateful for healthcare staff

Like I said, the hospitals have been really good. The doctors so far I've had, like NAME DOCTOR and my own GP, they've been fantastic as well. Participant NMO_007

I think the nurses need to get a bit more recognition on what they do have, because I'm saying, they're more than, obviously, the specialist and stuff, but just a caring nature, I think, is with the nurses. I think that out of all of it, it has made it more pleasant, going through what I've gone through, because they're knowledgeable. I reckon some of them are more knowledgeable than the doctors. Just saying. Participant NMO_012

The staff of that hospital are fantastic, they are dedicated health workers and I'm grateful every day I walk in there. It's not like walking into a hospital, it's like walking into a caring institution for us. Participant NMOCA_004

Participant is grateful for the entire health system

No, no, it's been perfect. We're very, very lucky here. Especially when you speak to people in the United States. Participant NMO_009

I think every single day you look at the health system in Australia, you have to be grateful for that. That is well thought out, it's a great system. Participant NMOCA_004

I think the whole hospital system in Australia is amazing. Participant NMO_005

Participant is grateful for low cost/free medical treatments through the government

The PBS. Participant NMO_014

Oh, I'm very grateful that we have Medicare, we've got the public system, I'm getting Rituximab because on the Facebook there's people in America with their insurances, and some of the treatments are refused or it's just horror stories. Participant NMO_015

I'm really, really grateful that on this health system by the way all the costs are covered. Finding out that you have something that's so rare, you don't know how it's going to affect your life, the quality of your life and then to have to worry about the cost of all the treatments, I think that would be a lot for any parent or any person that has this. Participant NMOCA_006

Table 9.9: What participants are grateful for in the health system

| Aspects of the health service they are grateful for | 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 is grateful for low cost/free medical care through the government | 6 | 33.33 | 3 | 33.33 | 3 | 33.33 | 3 | 37.50 | 3 | 30.00 | 3 | 33.33 | 3 | 33.33 |
| Participant describes being grateful for hospitals | 6 | 33.33 | 1 | 11.11 | 5 | 55.56 | 3 | 37.50 | 3 | 30.00 | 5 | 55.56 | 1 | 11.11 |
| Participant is grateful for healthcare staff | 4 | 22.22 | 0 | 0.00 | 4 | 44.44 | 0 | 0.00 | 4 | 40.00 | 3 | 33.33 | 1 | 11.11 |
| Participant is grateful for the entire health system | 3 | 16.67 | 2 | 22.22 | 1 | 11.11 | 2 | 25.00 | 1 | 10.00 | 2 | 22.22 | 1 | 11.11 |
| Participant is grateful for low cost/free medical treatments through the government | 3 | 16.67 | 3 | 33.33 | 0 | 0.00 | 2 | 25.00 | 1 | 10.00 | 0 | 0.00 | 3 | 33.33 |

| Aspects of the health service they are grateful for | 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 is grateful for low cost/free medical care through the government | 6 | 33.33 | 3 | 30.00 | 3 | 37.50 | 1 | 16.67 | 5 | 41.67 | 4 | 57.14 | 2 | 18.18 |
| Participant describes being grateful for hospitals | 6 | 33.33 | 4 | 40.00 | 2 | 25.00 | 2 | 33.33 | 4 | 33.33 | 3 | 14.29 | 3 | 27.27 |
| Participant is grateful for healthcare staff | 4 | 22.22 | 4 | 40.00 | 0 | 0.00 | 2 | 33.33 | 2 | 16.67 | 2 | 57.14 | 2 | 18.18 |
| Participant is grateful for the entire health system | 3 | 16.67 | 1 | 10.00 | 2 | 25.00 | 1 | 16.67 | 2 | 16.67 | 1 | 14.29 | 2 | 18.18 |
| Participant is grateful for low cost/free medical treatments through the government | 3 | 16.67 | 1 | 10.00 | 2 | 25.00 | 2 | 33.33 | 1 | 8.33 | 0 | 0.00 | 3 | 27.27 |

| Aspects of the health service they are grateful for | 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 is grateful for low cost/free medical care through the government | 6 | 33.33 | 3 | 37.50 | 9 | 34.62 | 5 | 50.00 | 6 | 37.50 | 0 | 0.00 | 0 | 0.00 | 6 | 40.00 |
| Participant describes being grateful for hospitals | 6 | 33.33 | 0 | 0.00 | 6 | 23.08 | 0 | 0.00 | 5 | 31.25 | 1 | 50.00 | 1 | 33.33 | 5 | 33.33 |
| Participant is grateful for healthcare staff | 4 | 22.22 | 3 | 37.50 | 7 | 26.92 | 1 | 10.00 | 3 | 18.75 | 1 | 50.00 | 1 | 33.33 | 3 | 20.00 |
| Participant is grateful for the entire health system | 3 | 16.67 | 2 | 25.00 | 5 | 19.23 | 1 | 10.00 | 2 | 12.50 | 1 | 50.00 | 1 | 33.33 | 2 | 13.33 |
| Participant is grateful for low cost/free medical treatments through the government | 3 | 16.67 | 1 | 12.50 | 4 | 15.38 | 2 | 20.00 | 3 | 18.75 | 0 | 0.00 | 0 | 0.00 | 3 | 20.00 |

Table 9.10: What participants are grateful for in the health system

| Aspects of the health service they are grateful for | More frequent | Less frequent |
|---|--|--|
| Participant is grateful for low cost/free medical care through the government | Aged 18 to 44 | Mid to low socioeconomic status Aged 45 or older |
| Participant describes being grateful for hospitals | More relapses Moderate to very poor physical function | Fewer relapses Good to very good physical function Aged 18 to 44 |

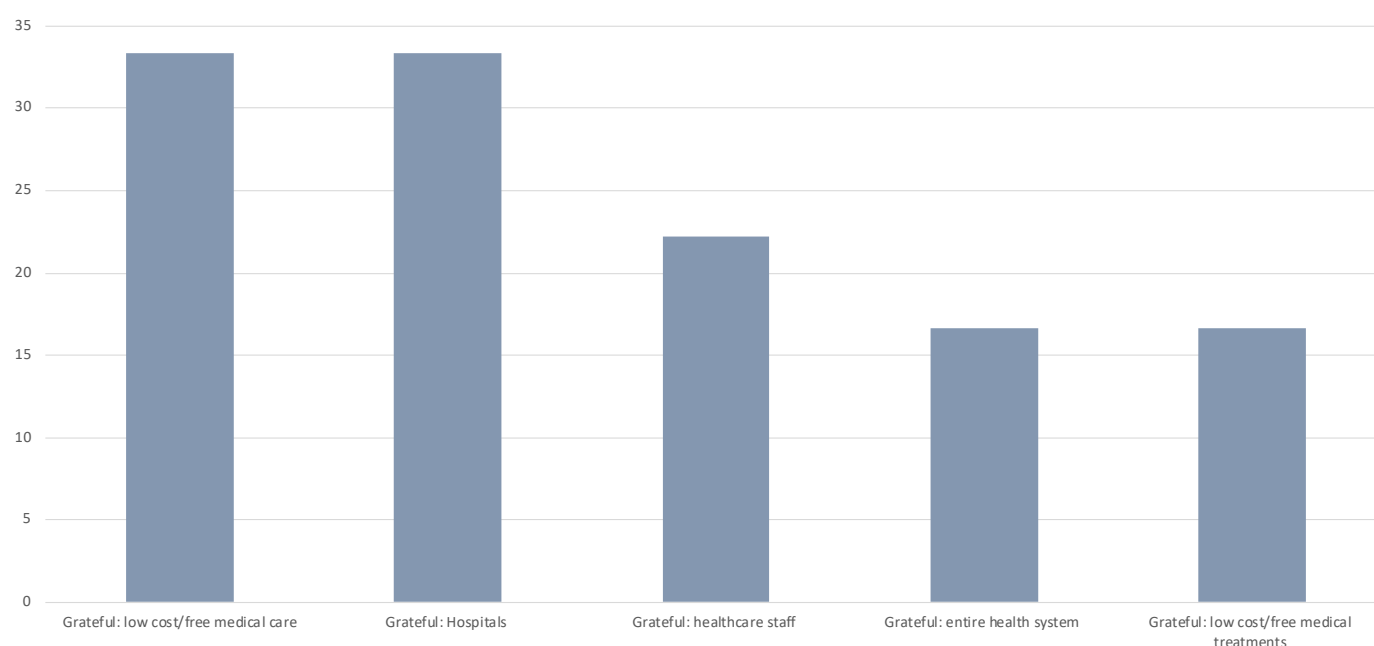


Figure 9.5: What participants are grateful for in the health system

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 13 is the least important. A weighted average is presented in Table 9.11, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The most important aspects reported by participants with NMOSD were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

MOG

The most important aspects reported by participants with MOG were: loss of clear vision, weakness or paralysis of arms and legs, and loss of bowel or bladder control.

NMOSD or MOG

Overall, the most important aspects reported by participants with NMOSD or MOG were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

Family or carers

The most important aspects reported by participants with MOG were: loss of clear vision, weakness or paralysis of arms and legs, and eye pain.

Table 9.11: Symptoms and aspects of quality of life

| Symptoms and aspects of quality of life | Participants with NMOSD (n=18) | Participants with MOG (n=8) | Participants with NMOSD or MOG (n=26) | Family or carers (n=10) |
|---|--------------------------------|-----------------------------|---------------------------------------|-------------------------|
| Eye pain | 4.35 | 5.13 | 4.67 | 7.10 |
| Loss of clear vision | 6.83 | 7.25 | 6.88 | 8.60 |
| Pain in spine and/or limbs | 5.44 | 5.50 | 5.52 | 6.20 |
| Weakness or paralysis of arms and legs | 7.28 | 6.50 | 7.00 | 7.50 |
| Loss of bowel or bladder control | 6.83 | 6.00 | 6.56 | 5.30 |
| Painful muscle spasms | 4.94 | 3.63 | 4.64 | 4.10 |
| Sensory loss | 3.72 | 4.25 | 3.80 | 2.30 |
| Prolonged hiccups | 2.50 | 2.50 | 2.56 | 2.90 |
| Prolonged nausea and vomiting | 3.28 | 4.25 | 3.52 | 1.00 |

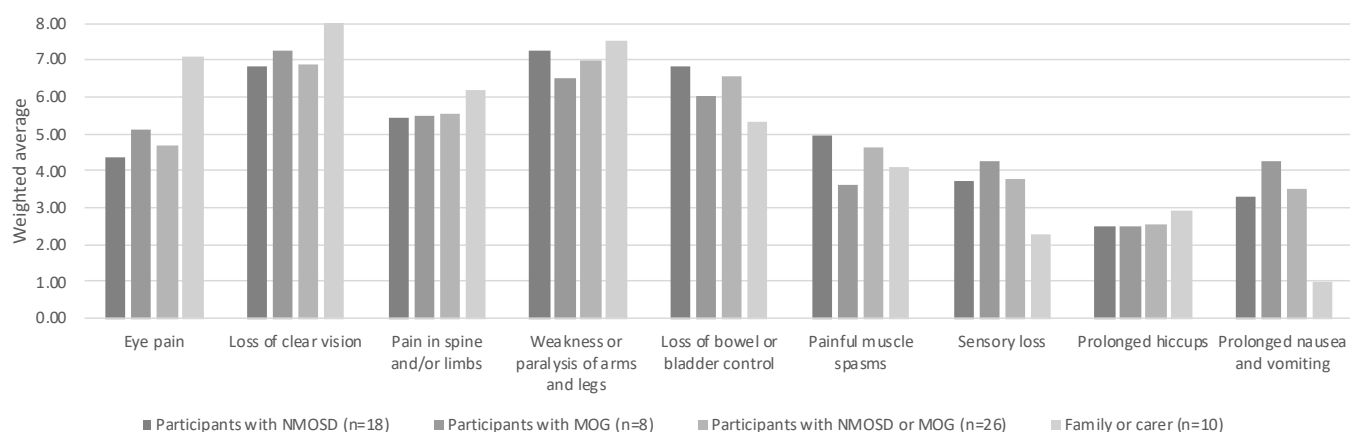


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Table 9.12 and Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The most important aspects to participants with NMOSD were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “My ability to follow and stick to a treatment regime”.

MOG

The most important aspects to participants with MOG were “How safe the medication is and

weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “The financial costs to me and my family”.

NMOSD or MOG

Overall, the most important aspects to participants with NMOSD or MOG were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “The financial costs to me and my family”.

Family or carers

The most important aspects to family and carers were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “The ability to include my family in making treatment decisions”.

Table 9.12: Values in making decisions

| Values in making decisions | Participants with NMOSD (n=18) | Participants with MOG (n=8) | Participants with NMOSD or MOG (n=26) | Family or carer (n=10) |
|---|--------------------------------|-----------------------------|---------------------------------------|------------------------|
| How safe the medication is and weighing up the risks and benefits | 7.61 | 7.38 | 7.52 | 7.70 |
| The severity of the side effects | 6.56 | 6.50 | 6.52 | 6.70 |
| Time impact of the treatment on my quality of life | 5.33 | 6.00 | 5.52 | 5.70 |
| How the treatment is administered | 3.89 | 3.63 | 3.92 | 3.30 |
| How personalised the treatment is for me | 4.33 | 4.50 | 4.36 | 4.40 |
| The ability to include my family in making treatment decisions | 2.72 | 2.88 | 2.76 | 2.50 |
| My ability to follow and stick to a treatment regime | 2.44 | 3.25 | 2.72 | 2.70 |
| The financial costs to me and my family | 3.11 | 1.88 | 2.68 | 3.00 |

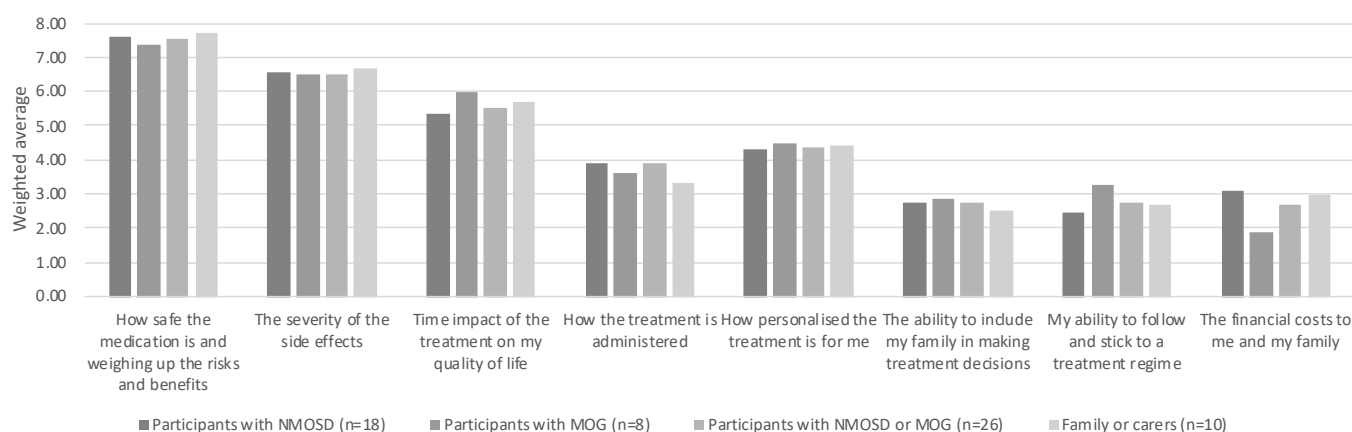


Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Table 9.13 and Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The two most important values for participants with NMOSD were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

MOG

The two most important values for participants with MOG were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

NMOSD or MOG

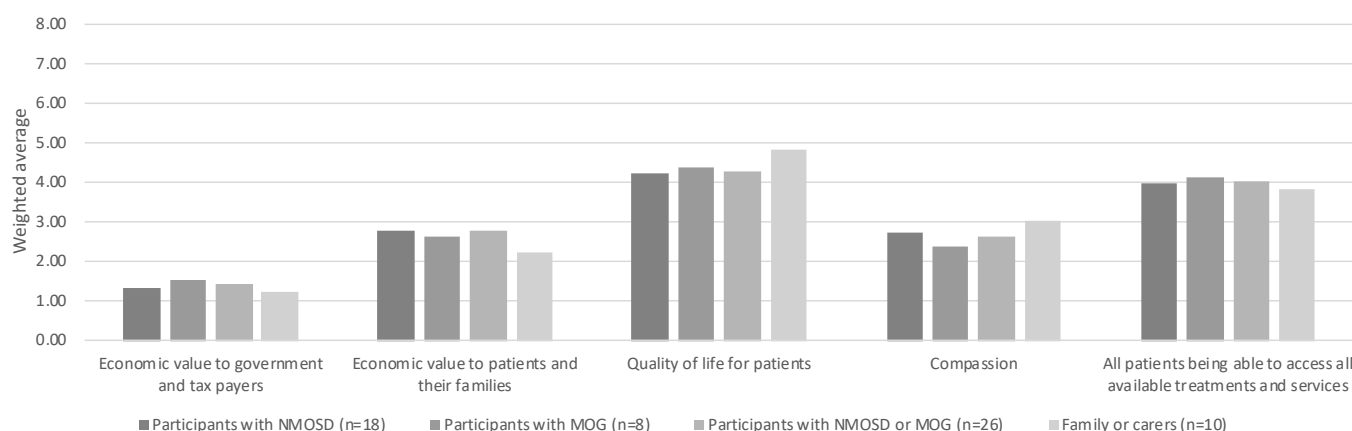
The two most important values for participants with NMOSD or MOG were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Family and carers

The two most important values for family and carers were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Table 9.13: Values for decision makers

| Values for decision makers | Participants with NMOSD (n=18) | Participants with MOG (n=8) | Participants with NMOSD or MOG (n=26) | Family or carer (n=10) |
|---|--------------------------------|-----------------------------|---------------------------------------|------------------------|
| Economic value to government and tax payers | 1.33 | 1.50 | 1.40 | 1.20 |
| Economic value to patients and their families | 2.78 | 2.63 | 2.76 | 2.20 |
| Quality of life for patients | 4.22 | 4.38 | 4.24 | 4.80 |
| Compassion | 2.72 | 2.38 | 2.60 | 3.00 |
| All patients being able to access all available treatments and services | 3.94 | 4.13 | 4.00 | 3.80 |

**Figure 9.8: Values for decision makers**

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure (Table 9.14, Figure 9.9).

NMOSD

The majority of participants with NMOSD (n=11, 64.11%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were two participants (11.11%) that would take medication for five to 10 years, four participants (22.22%) that would take it for one to four years.

MOG

The majority participants with MOG would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n=5, 62.50%).

NMOSD or MOG

Overall, for participants with NMOSD or MOG, the majority of participants (n=16, 61.54%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were three participants (11.54%) that would take medication for five to 10 years, five participants (19.23%) that would take it for one to four years, and two participants (7.69%) that would take it for less than one year.

Family and carers

Family and carers most commonly would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n=4, 40.00%). There were two participants (20.00%) that would take medication for five to 10 years, two participants (20.00%) that would take it for one to four years, and two participants (20.00%) that would take it for less than one year.

Table 9.14: Time taking treatment to improve quality of life

| Time taking medication to improve quality of life | Participants with NMOSD | | Participants with MOG | | Participants with NMOSD or MOG | | Family or carer | |
|---|-------------------------|---------|-----------------------|---------|--------------------------------|---------|-----------------|---------|
| | Number (n=18) | Percent | Number (n=8) | Percent | Number (n=26) | Percent | Number (n=10) | Percent |
| Less than 1 year | 1 | 5.56 | 1 | 12.50 | 2 | 7.69 | 2 | 20.00 |
| 1 to 4 years | 4 | 22.22 | 1 | 12.50 | 5 | 19.23 | 2 | 20.00 |
| 5 to 10 years | 2 | 11.11 | 1 | 12.50 | 3 | 11.54 | 2 | 20.00 |
| More than 10 years | 11 | 61.11 | 5 | 62.50 | 16 | 61.54 | 4 | 40.00 |

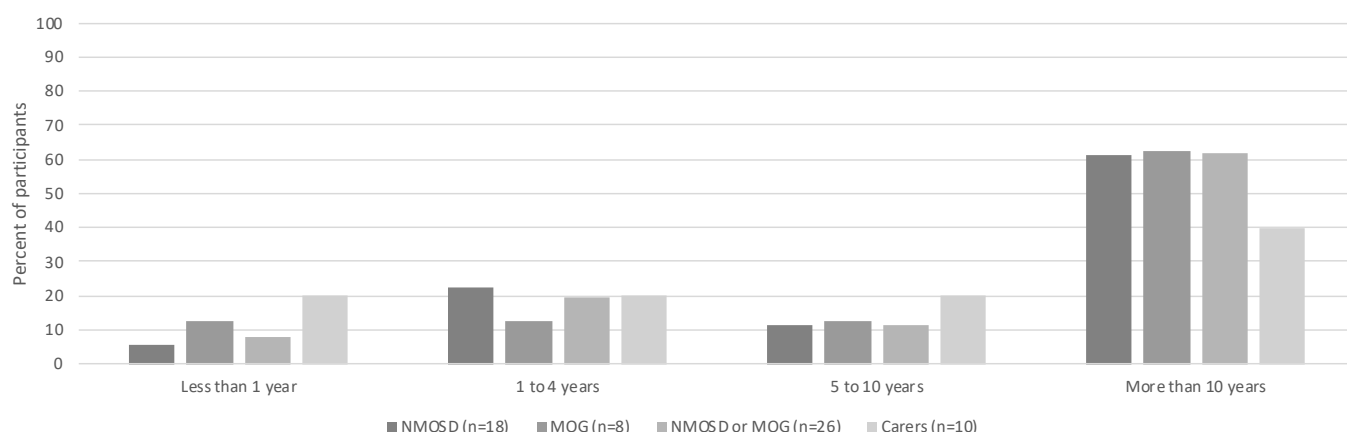


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. (Table 9.15, Figure 9.10).

NMOSD

Participants with NMOSD most commonly responded that they were not sure (n=7, 38.89%), followed by IV form (n=6, 33.33%), and four participants (n=4, 22.22%) thought IV and pill forms were equally effective.

MOG

Half of the participants with MOG thought that treatment was most effective in IV form (n=4, 50.00%).

There were three participants (37.50%) that thought IV and pill forms were equally effective.

NMOSD or MOG

Overall, participants with NMOSD or MOG most commonly thought that treatment was most effective in IV form (n=10, 38.46%), followed by not being sure (n=8, 30.77%). There were seven participants (26.92%) thought IV and pill forms were equally effective.

Family and carers

Half of the family and carers thought IV and pill forms were equally effective (n=5, 50.00%). There were three participants (30.00%) that thought IV form was more effective, and two participants (20.00%) that were not sure.

Table 9.15: Most effective form of medicine

| Treatment most effective in what form | Participants with NMOSD | | Participants with MOG | | Participants with NMOSD or MOG | | Family or carer | |
|---|-------------------------|---------|-----------------------|---------|--------------------------------|---------|-----------------|---------|
| | Number (n=18) | Percent | Number (n=8) | Percent | Number (n=26) | Percent | Number (n=10) | Percent |
| IV form (through a drip in hospital) | 6 | 33.33 | 4 | 50.00 | 10 | 38.46 | 3 | 30.00 |
| In a pill form that I can take at home effective I'm not sure | 1 | 5.56 | 0 | 0.00 | 1 | 3.85 | 0 | 0.00 |
| I think they are equally | 4 | 22.22 | 3 | 37.50 | 7 | 26.92 | 5 | 50.00 |
| I'm not sure | 7 | 38.89 | 1 | 12.50 | 8 | 30.77 | 2 | 20.00 |

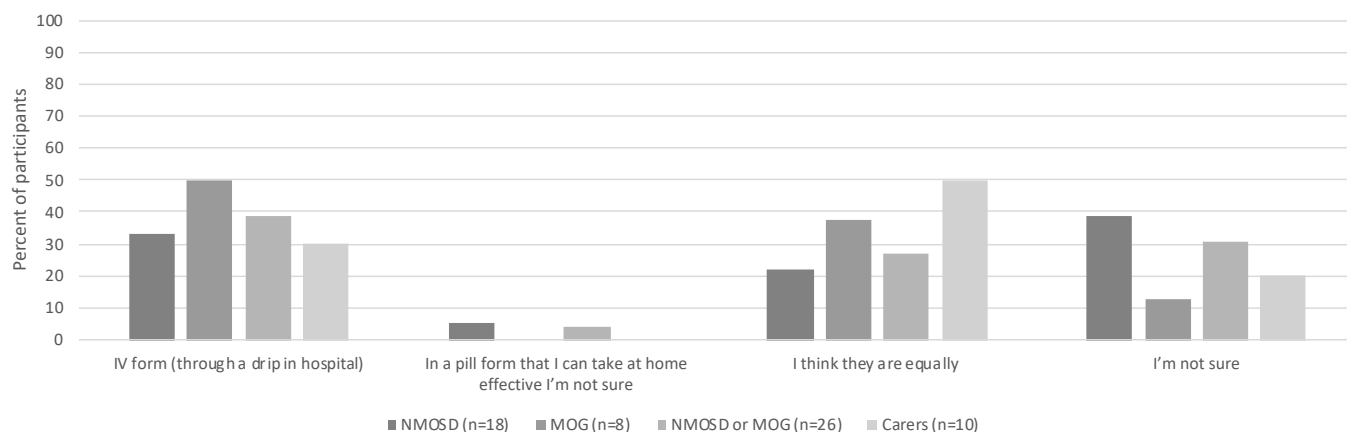


Figure 9.10: Most effective form of medicine

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to invest in new treatments and make them more accessible (n=7, 38.89%).

Participant's message to decision-makers is to invest in new treatments and make them more accessible

Everything that we pretty much are prescribed is off-label, so I would tell him that he needs to definitely make some things more available for us. Put some medications under the PBS, make things available. It's not always about what's cheapest, you can't always think about that. You have to think about what's best. Participant NMO_005

That there's not enough in Australia for NMO specific conditions. There needs to be more treatment options, better funding and more support, I think. Participant NMO_001

I think we need to get some of the newer drugs on the PBS and easier access for people with NMO. Participant NMO_016

Participant's message is to invest in research

I would say there needs to be more research conducted in Australia because Australia seems to be quite up there with research and development, well, except for NMO because it might actually unlock things that might lead to discoveries in other rare diseases or even MS. The fact that we've got a blood test for NMO is pretty unique when it comes to these sorts of neurological conditions. I think maybe more funding for research. Participant NMO_002

I'm sure that between all of us, we could start something to try and raise some money for research. I think that it was supposed to be a rare disease, but you can see that it's starting to increase. It's more and more people getting it, and I'd like to just get some more information about how to stop it. Participant NMO_011

My message to the Health Minister would be, just because there's not a lot of people with the disease in the country, it still warrants research money. Participant NMO_017

Participant's message is to improve access to support and care

That there's not enough in Australia for NMO specific conditions. There needs to be more treatment options, better funding and more support, I think. Participant NMO_001

It's not the same everywhere I now know. Not everybody has that 12-weeks rehab in the community. That was essential because that gave me and my family time to settle and to know that they're putting some voluntary groups in for us, putting some free hours. That is essential to anybody who is initially affected by the likes of a TM attack or NMO, that kind of thing. Participant NMO_006

People who are reeling from a life-changing situation might feel a bit better if they know that there's support out there, there is a treatment. It will change your life, there's no doubt about that, but it's the best thing that you can do at the moment and give them some hope. Participant NMOCA_004

Participant's message is to invest in professional development so that clinicians understand the condition

As a doctor in training, for example, to make this disease aware, more aware to the ones that are-- put a slot in there of what they have to learn of the NMO. What kind of GP, the specialist, all those kinds of people out there, just to know- because there's so many things of our conditions that looks like MS. That could be you just thinking that. A lot of the time, they make you feel like is this real or not with the disease. I honestly think in the doctor's training, definitely to have a slot in there for NMO in their study. Participant NMO_012

That while our public health system is good, there is not enough knowledge on NMO amongst health professionals. Participant NMOCA_002

Table 9.16: Messages to decision-makers

| Message to decision-makers | 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's message to decision-makers is to invest in new treatments and make them more accessible | 7 | 38.89 | 4 | 44.44 | 3 | 33.33 | 3 | 37.50 | 4 | 40.00 | 3 | 33.33 | 4 | 44.44 |
| Participant's message is to invest in research (including to find new treatments) | 4 | 22.22 | 2 | 22.22 | 2 | 22.22 | 3 | 37.50 | 1 | 10.00 | 2 | 22.22 | 2 | 22.22 |
| Participant's message is to improve access to support and care | 4 | 22.22 | 1 | 11.11 | 3 | 33.33 | 2 | 25.00 | 2 | 20.00 | 2 | 22.22 | 2 | 22.22 |
| Participant's message is to invest in professional development so that clinicians understand the condition | 1 | 5.56 | 0 | 0.00 | 1 | 11.11 | 0 | 0.00 | 1 | 10.00 | 0 | 0.00 | 1 | 11.11 |

| Message to decision-makers | 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's message to decision-makers is to invest in new treatments and make them more accessible | 7 | 38.89 | 4 | 40.00 | 3 | 37.50 | 3 | 50.00 | 4 | 33.33 | 4 | 57.14 | 3 | 27.27 |
| Participant's message is to invest in research (including to find new treatments) | 4 | 22.22 | 2 | 20.00 | 2 | 25.00 | 2 | 33.33 | 2 | 16.67 | 1 | 14.29 | 3 | 27.27 |
| Participant's message is to improve access to support and care | 4 | 22.22 | 2 | 20.00 | 2 | 25.00 | 0 | 0.00 | 4 | 33.33 | 3 | 42.86 | 1 | 9.09 |
| Participant's message is to invest in professional development so that clinicians understand the condition | 1 | 5.56 | 1 | 10.00 | 0 | 0.00 | 1 | 16.67 | 0 | 0.00 | 0 | 0.00 | 1 | 9.09 |

| Message to decision-makers | 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's message to decision-makers is to invest in new treatments and make them more accessible | 7 | 38.89 | 2 | 25.00 | 9 | 34.62 | 2 | 20.00 | 7 | 43.75 | 0 | 0.00 | 0 | 0.00 | 7 | 46.67 |
| Participant's message is to invest in research (including to find new treatments) | 4 | 22.22 | 1 | 12.50 | 5 | 19.23 | 2 | 20.00 | 3 | 18.75 | 1 | 50.00 | 2 | 66.67 | 2 | 13.33 |
| Participant's message is to improve access to support and care | 4 | 22.22 | 1 | 12.50 | 5 | 19.23 | 2 | 20.00 | 4 | 25.00 | 0 | 0.00 | 0 | 0.00 | 4 | 26.67 |
| Participant's message is to invest in professional development so that clinicians understand the condition | 1 | 5.56 | 2 | 25.00 | 3 | 11.54 | 2 | 20.00 | 1 | 6.25 | 0 | 0.00 | 1 | 33.33 | 0 | 0.00 |

Table 9.17: Messages to decision-makers (Subgroup variations)

| Message to decision-makers | More frequent | Less frequent |
|---|--|------------------|
| Participant's message to decision-makers is to invest in new treatments and make them more accessible | Mid to low socioeconomic status Aged 18 to 44 | Aged 45 or older |

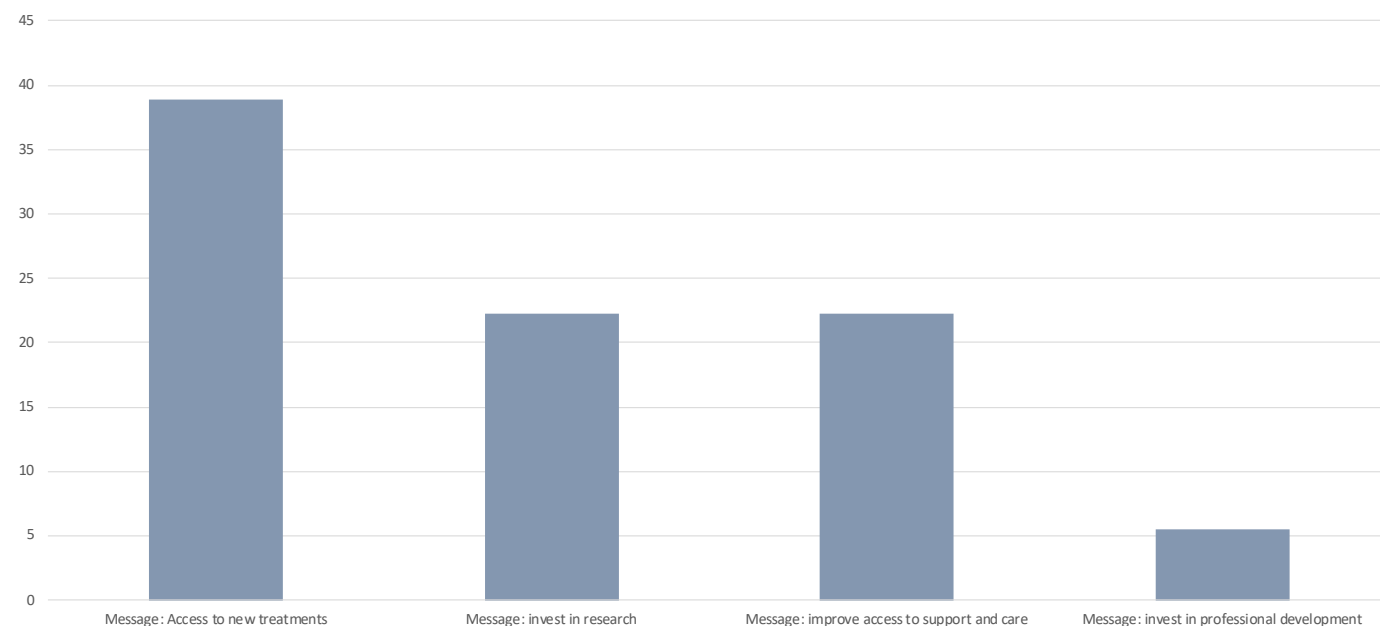


Figure 9.11: Messages to decision-makers