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NEUROMYELITIS OPTICA AUSTRALIAN STUDY 2020



Section 1



















Introduction
&
Methodology

This is where you can read about the PEEK methodology, information about the recruitment period and approach.

There is also a review of other mixed methodology studies in the field to identify the position of the PEEK study in the context of other literature. PEEK studies are often the largest of their kind in depth and participant numbers.



 Full Report	 Summary of Results	 Infographic	 Slide Set
 Introduction & Methodology	 Demographics	 Symptoms & Diagnosis	 Decision-making
 Treatment	 Communication & Information	 Care & Support	 Quality of Life
 Expectations & Messages to Decision-Makers	 Advice from current patients to patients in the future	 Discussion	 Where to from here?

This study was generously sponsored by Alexion.

Alexion provided arm's length sponsorship for the Centre for Community-Driven Research to implement the PEEK protocol with people who have experienced NMOSD. The sponsor had no input into the methodology, data collection, data analysis or reporting

Thank you to each and every person that participated in this PEEK study, and to MS Australia and NMO & NMOSD Australia Support Group.



In this PEEK study, 18 people diagnosed with NMOSD throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in NMOSD is therefore the only mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

A comparison of studies is available in Section 1.

A search was conducted in Pubmed (August 18, 2020) to identify NMOSD quality of life or patient experience studies of adults that had been conducted in the past ten years worldwide (Table 1.1). Meta-analysis studies, studies conducted in developing countries, and studies of less than five participants were excluded.

There were 14 studies identified that collected patient self-reported data. There was a single qualitative study of 15 NMOSD participants, where 15 interviews were focused on quality of life. There were 13 quantitative studies of between five and 522 participants with NMOSD. There were seven studies focused on symptoms, two studies on COVID-19, two Quality of life studies, one focused on co-morbidities, and one on Reproductive history. There were no studies that were conducted in an Australian population.



Section 2



Demographics

The demographic section is where you can find information about the study cohort. This is also where the sub-groups used throughout the study are described and where the baseline health of the cohort is described, using the SF36 questionnaire.



18 NMOSD Participants



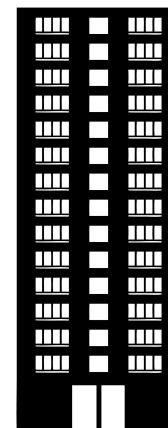
High status
12



Mid to low status
6



8 University
10 Trade/High school



11 Metropolitan



10 Carers
18 NMOSD



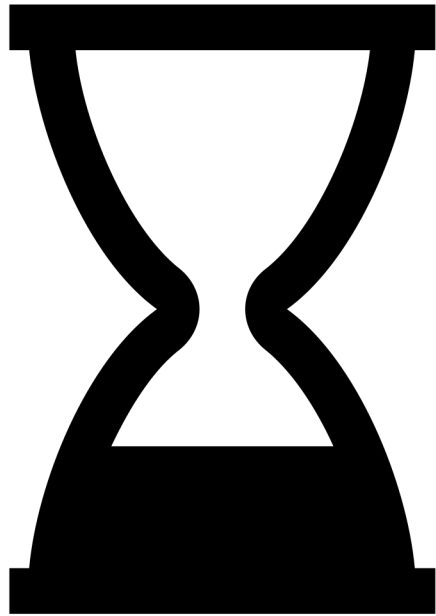
3 Regional/Remote



16



2



Average interview time of 56 minutes 45 seconds



Subgroup	Characteristic	Number (n=18)	Percent
Participant type (n=36)	NMOSD	18	50.00
	MOG	8	22.22
	NMOSD and MOG	26	72.22
	Family and carers	10	27.78
Relapses	Fewer relapses	9	50.00
	More relapses	9	50.00
Fear of progression	Low to moderate fear	8	44.44
	High to very high fear	10	55.56
Gender	Female	16	88.89
	Male	2	11.11
Education	Trade or high school	10	55.56
	University	8	44.44
Age	Aged 18 to 44	7	38.89
	Aged 45 or older	11	61.11
Location	Regional or remote	3	16.67
	Metropolitan	15	83.33
Socioeconomic advantage	Mid to low status	6	33.33
	Higher status	12	66.67

Calculations are presented for each of the sub-groups throughout the full report.

Qualitative: Where there is a variation between a sub-group and the general cohort this has been highlighted in red for less than 10% variation, and green for more than 10% variation. These variation tables can be viewed in the full report.

Quantitative: Where there is a statistically significant p-value variation, where $p < 0.05$, these have been included.

In this study, participant numbers are assigned by their extent of disability. For example, a participant diagnosed with NMOSD would appear as NMO_001, a participant diagnosed with MOG appears as MOG_001, family and carers to NMO would appear as NMOCA_001, and family and carers to MOG as MOGCA_001.



Sub-groups with most variations		Themes with most variations	
1	Aged 18 to 44	1	Burden on family
2	Mid to low socioeconomic status	2	Experience of quality of life
3	Low to moderate fear	3	Considerations when making decisions about treatment
4	More relapses	4	Information preferences: Rationale + Personal goals of treatment or care



SF36 scale (n=18)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning*	53.61	31.98	62.50	53.75	0 to 100	3
Role functioning/physical	30.56	45.82	0.00	87.50	0 to 100	1
Role functioning/emotional	31.48	43.49	0.00	66.67	0 to 100	1
Energy/Fatigue*	28.33	20.72	27.50	25.00	0 to 100	2
Emotional well-being*	57.56	24.85	62.00	34.00	0 to 100	3
Social functioning*	47.92	22.79	50.00	37.50	0 to 100	3
Pain*	43.06	30.07	45.00	42.50	0 to 100	3
General health*	32.78	23.65	32.50	32.50	0 to 100	2
Health change	43.06	35.15	37.50	43.75	0 to 100	2

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. **On average, physical health interfered quite a lot with work or other activities.**

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. **On average, emotional problems interfered quite a lot with work or other activities.**

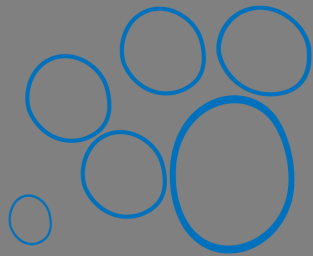
SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. **On average, participants had poor energy and a lot of fatigue .**

The **SF36 General health** scale measures perception of health. **On average, participants reported poor health.**

The **SF36 Health change** scale measures health compared to a year ago. **On average, participants have health that is somewhat worse now compared to one year ago.**



Section 3



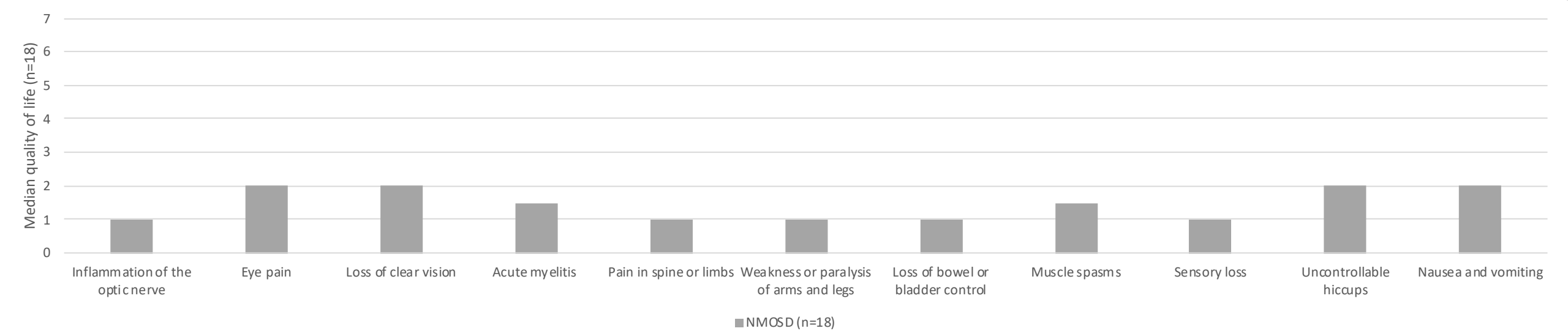
Symptoms &
Diagnosis

The symptoms and diagnosis section is where you can find information about experience of symptoms before diagnosis, as well as the symptoms that led to the diagnosis. There is information about the diagnostic tests that were performed, where the tests were conducted and the time from tests to diagnosis. In this section, there is also information about the participant's understanding of their condition and their understanding of their prognosis.



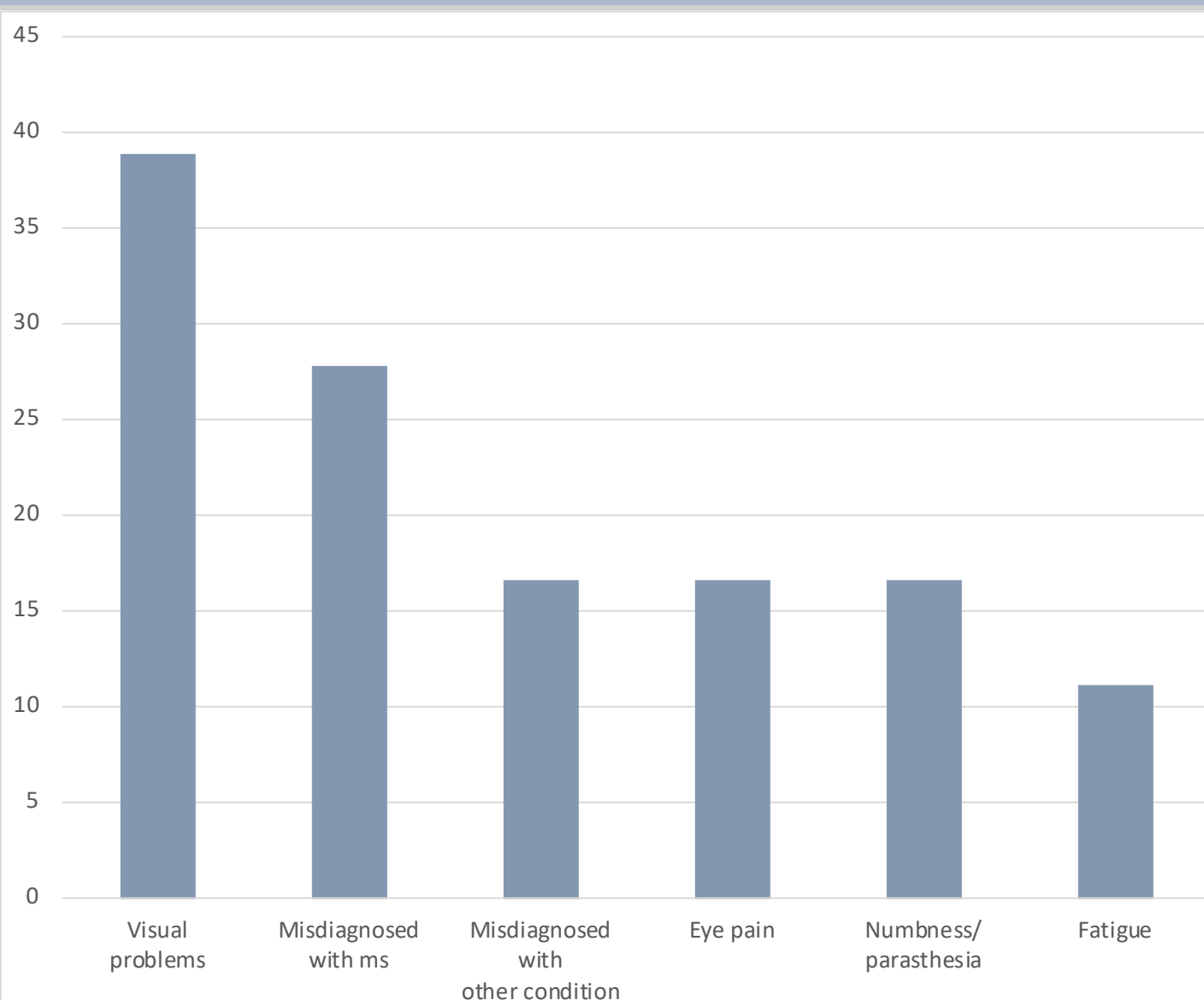
Symptoms before diagnosis	Participants with NMOSD		Number of symptoms before diagnosis	Participants with NMOSD	
	Number (n=18)	Percent		Number (n=18)	Percent
Inflammation of the optic nerve	11	61.11	No symptoms	0	0.00
Eye pain	13	72.22	1 to 2	2	11.11
Loss of clear vision	13	72.22	3 to 4	2	11.11
Acute myelitis	10	55.56	5 to 6	3	16.67
Pain in spine or limbs	9	50.00	7 to 8	5	27.78
Weakness or paralysis of arms and legs	11	61.11	9 or more	6	33.33
Loss of bowel or bladder control	11	61.11			
Muscle spasms	12	66.67			
Sensory loss	12	66.67			
Uncontrollable hiccups	3	16.67			
Nausea and vomiting	4	22.22			
Participants with other symptoms	12	66.67			

Quality of life from symptoms before diagnosis	Participants with NMOSD		Participants with NMOSD	
	Number (n=18)	Percent	Median	IQR
Inflammation of the optic nerve	11	61.11	1.00	0.50
Eye pain	13	72.22	2.00	1.00
Loss of clear vision	13	72.22	2.00	1.00
Acute myelitis	10	55.56	1.50	1.75
Pain in spine or limbs	9	50.00	1.00	1.00
Weakness or paralysis of arms and legs	11	61.11	1.00	1.00
Loss of bowel or bladder control	11	61.11	1.00	1.00
Muscle spasms	12	66.67	1.50	2.25
Sensory loss	12	66.67	1.00	1.25



Quality of life was rated on a Likert scale from 1 to 7, where 1 is “Life was very distressing” and 7 is “Life was great” (Table 3.2, Figure 3.2). The median quality of life was between 1.00 and 2.00, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was distressing” range.

Section 3



I woke up and had lost my eyesight and before that I didn't even have a headache or anything, so even the night before, I didn't have-- I was working, it was over Easter. I didn't have any symptoms at all and woke up and lost half my vision, the upper field of my- at that time it was my right eye. Participant NMO_017

I went and had an MRI and it showed some lesions in my brainstem and my spinal cord and I was referred to a neurologist. I was first admitted to a hospital and diagnosed with MS. It was about six months later when I was diagnosed with NMO. Participant NMO_010

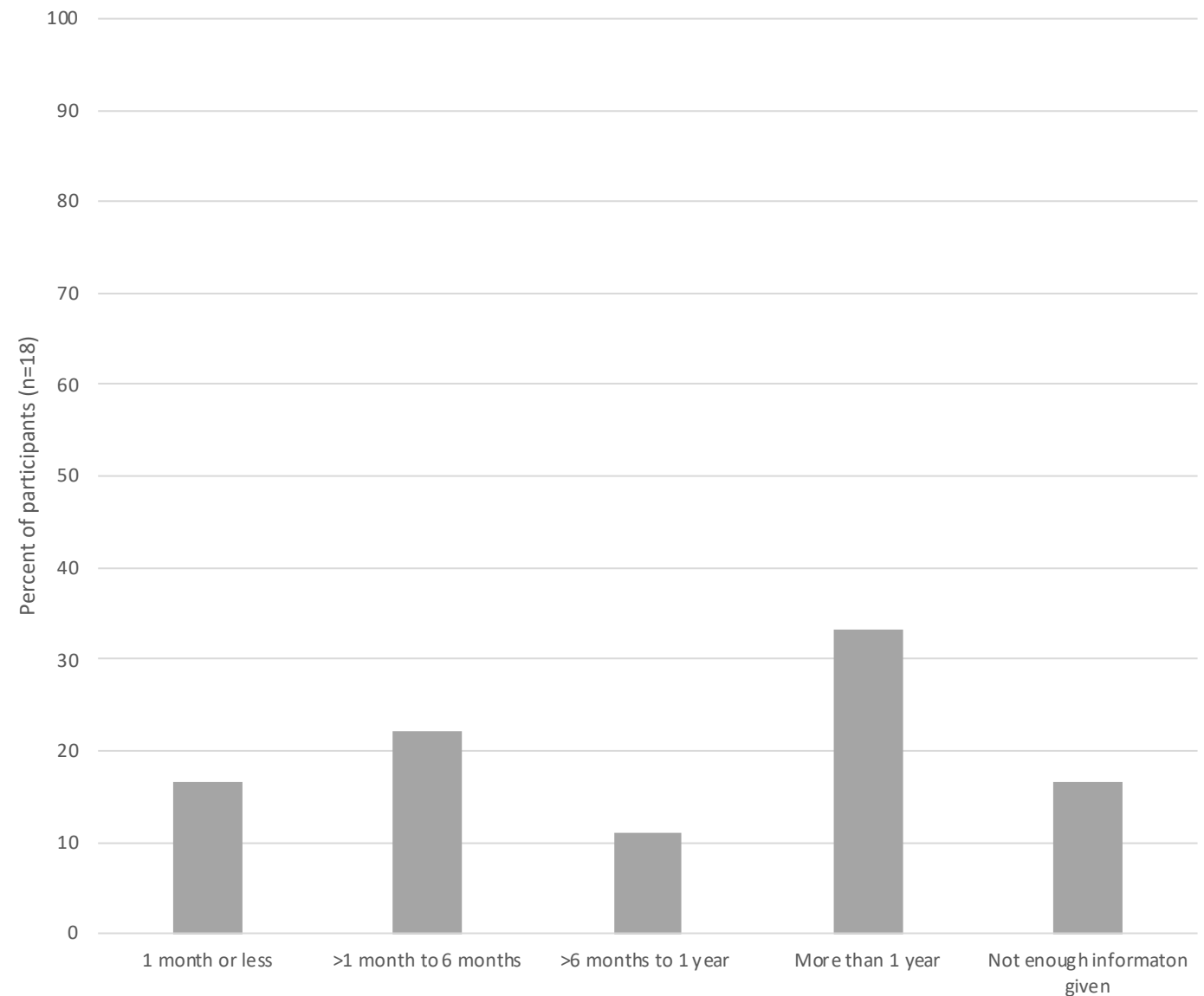
I started to get sore eyes and I thought it must have been windy or something the day before and then it just got worse so I went off to see the eye doctor and they referred me on to a specialist. Participant NMO_007



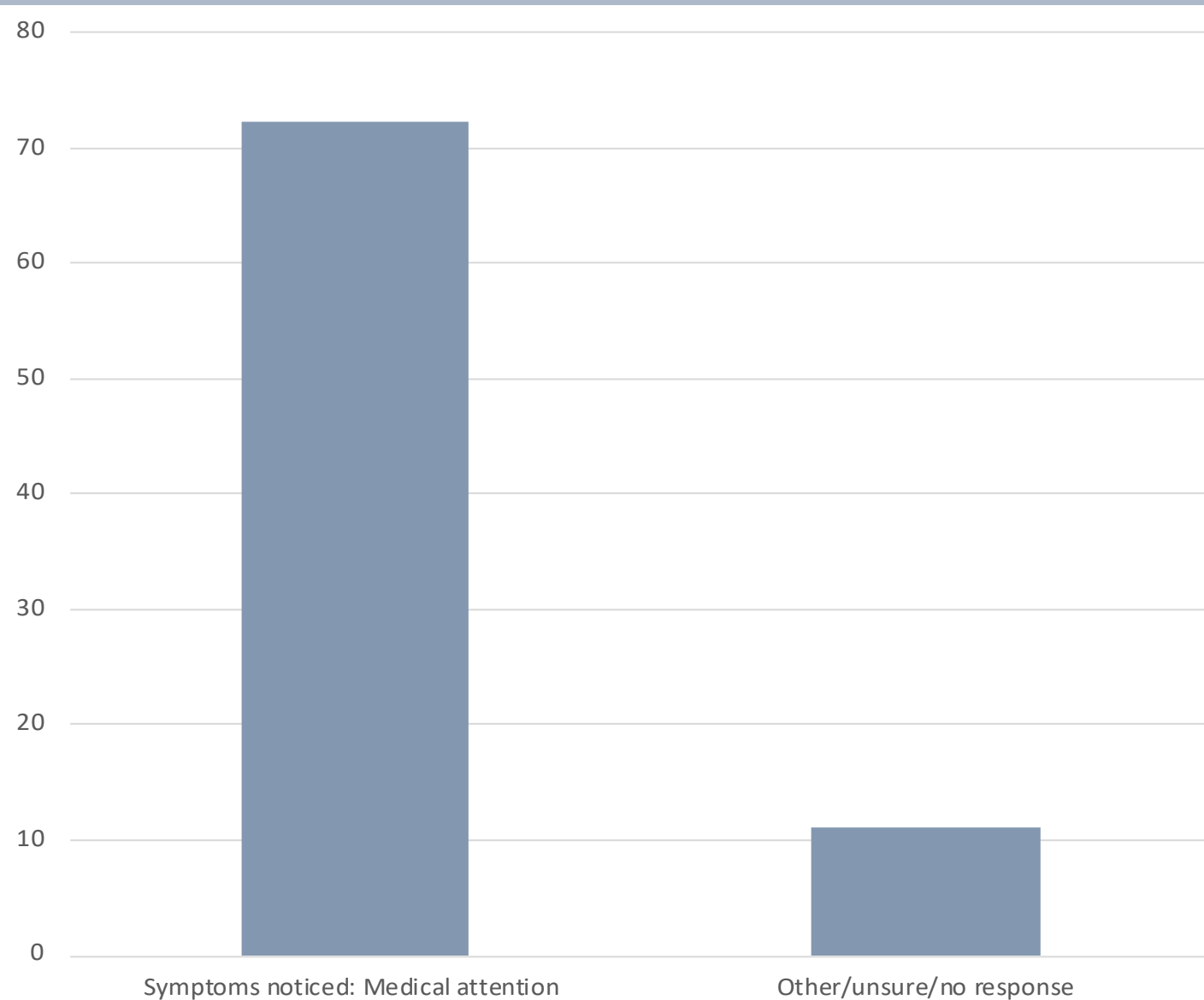
Time from diagnosis test to diagnosis	Participants with NMOSD	
	Number (n=18)	Percent
Diagnosed immediately at the consultation	2	11.11
Less than 1 week	5	27.78
Between 1 and 2 weeks	3	16.67
Between 2 and 3 weeks	0	0.00
Between 3 and 4 weeks	0	0.00
4 weeks or more	5	27.78
More than a year	3	16.67

Out of pocket expenses for diagnostic tests	Participants with NMOSD	
	Number (n=18)	Percent
\$0	5	27.78
More than \$1000	3	16.67
Not sure	10	55.56

Burden of diagnostic costs	Participants with NMOSD	
	Number (n=8)	Percent
Not at all significant	1	12.50
Slightly significant	1	12.50
Somewhat significant	2	25.00
Moderately significant	3	37.50
Extremely significant	1	12.50



Section 3

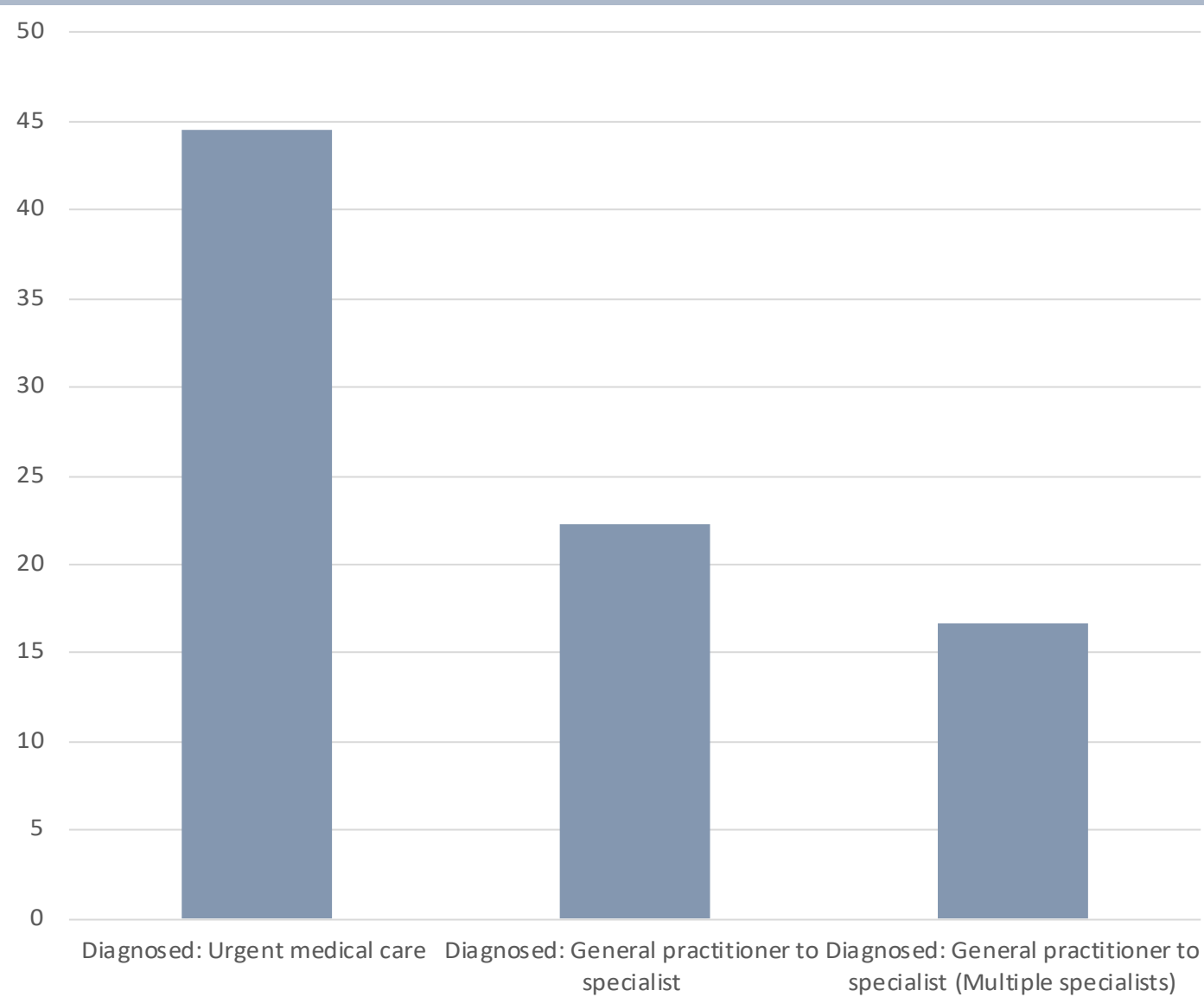


Yes. Back in November last year, I was actually trying to recover from whooping cough. I was resting at home, I had a nap in the afternoon and then after I woke up from the nap, the TV was on and when I looked at the TV, it was blurry. Then I tried to get up from my couch and then I started to lose balance. I didn't know what it was. I went to hospital. I just assumed that my whooping cough got worse and that's how it all started. Participant NMO_001

The most dramatic thing was on the 4th of December 2018. We were out the back putting a net over a fruit tree to stop the birds eating our fruit. My wife complained about, she said a dark smudge in her eyesight. That was about ten o'clock in the morning. That progressively got worse and by three o'clock she went to see her GP, who referred her to an ophthalmologist, who she'd seen about four days before for a regular check-up. On that occasion her eyesight was good but this time when she got to the ophthalmologist, she could hardly see, and she was nearly totally blind. Participant NMOCA_004



Section 3



I was getting really sick, said to my daughter, nine years ago, "There is something wrong with me, take me to the hospital." I couldn't move the whole thing of-- Just know there was something going on and they opened me up. On the Monday, I could not move from my neck down, I was in hospital for 12 months. Participant NMO_013

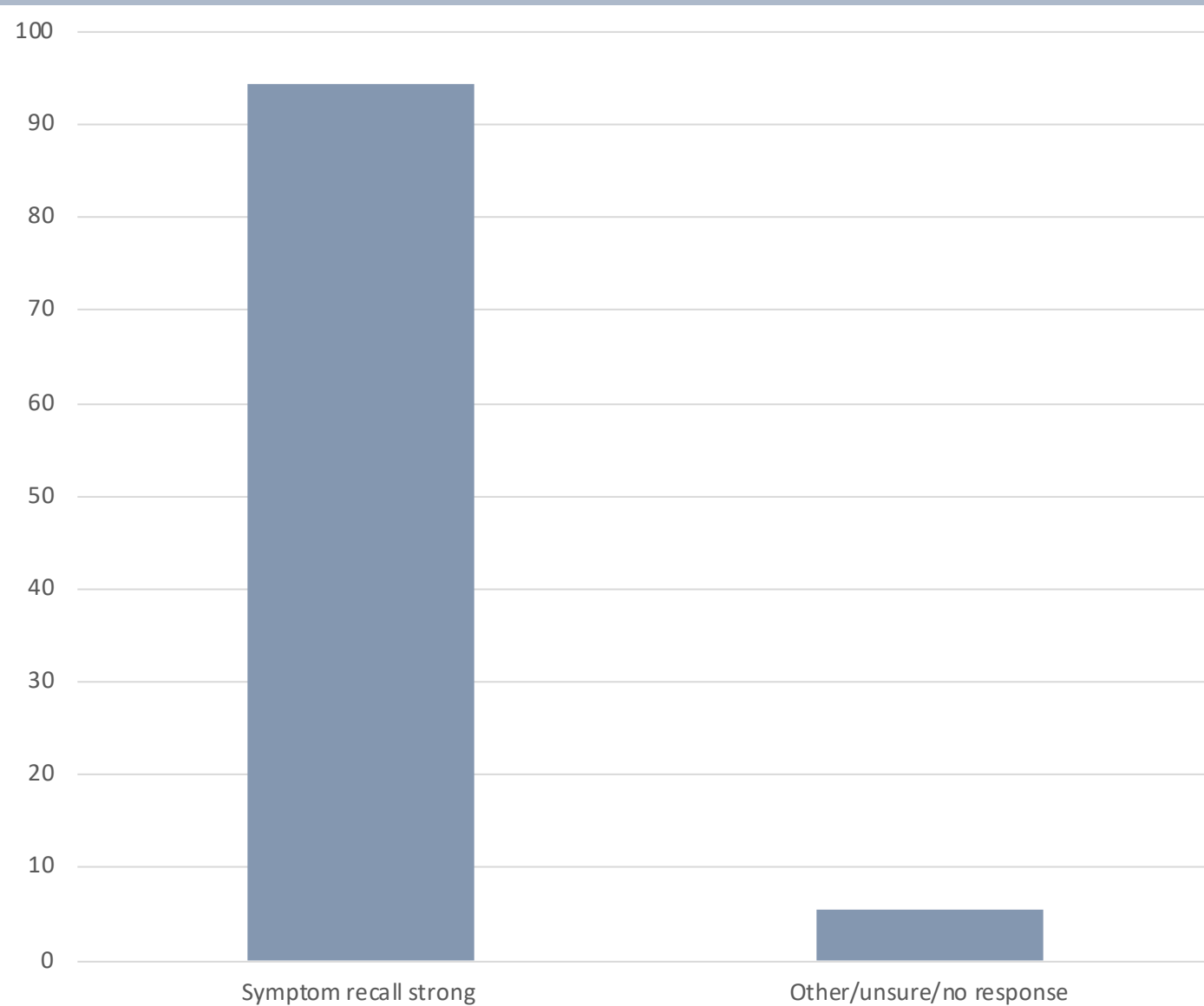
So that was a long winded prognosis. In 2010, I got a test for the blood test for NMO spectrum disorder and that was ordered by a neurologist. Participant NMO_002



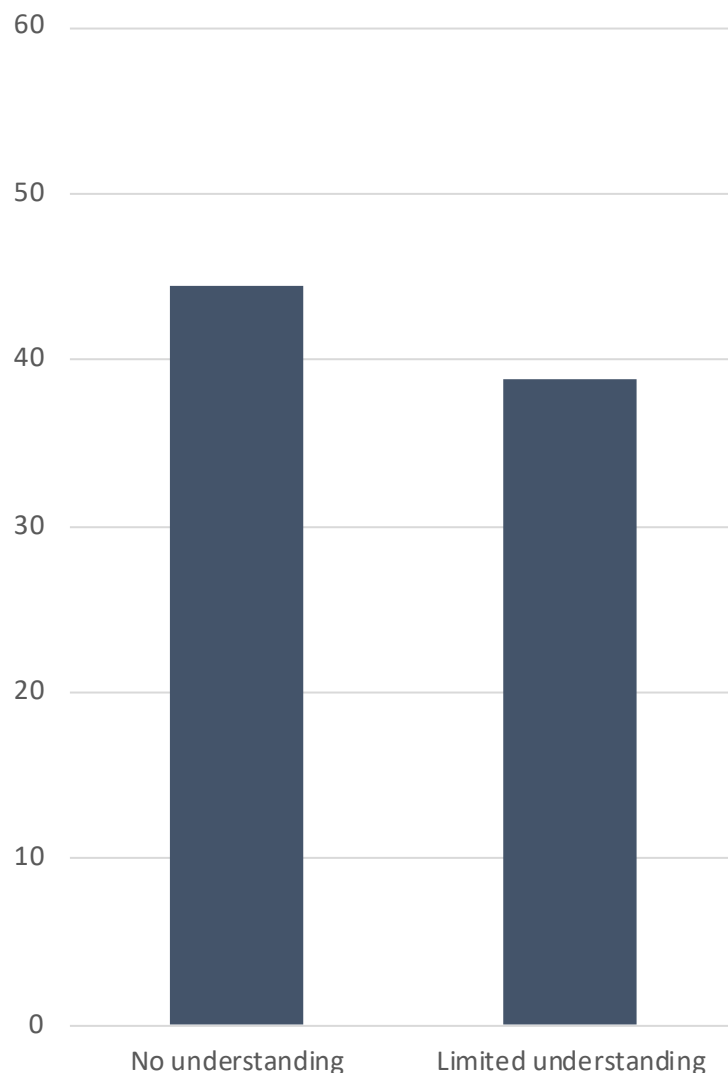
Section 3

I woke up about three in the morning and I couldn't feel my right-hand side. It was just all of the sudden. I had no pre-symptoms at all. Participant NMO_009

Yes. My first issues were with my eyes, where I had pain when I moved my eyeballs. I had this for about a week or two, like on and off, and I would always joke that maybe I rolled my eyes too much, because it was hurting so much and I just thought I strained a muscle or something. Then it just started to get more and more painful, and then on one eye, I started to get very blurred vision. I went to bed, I woke up, and I didn't see anything. Participant NMO_005



Section 3



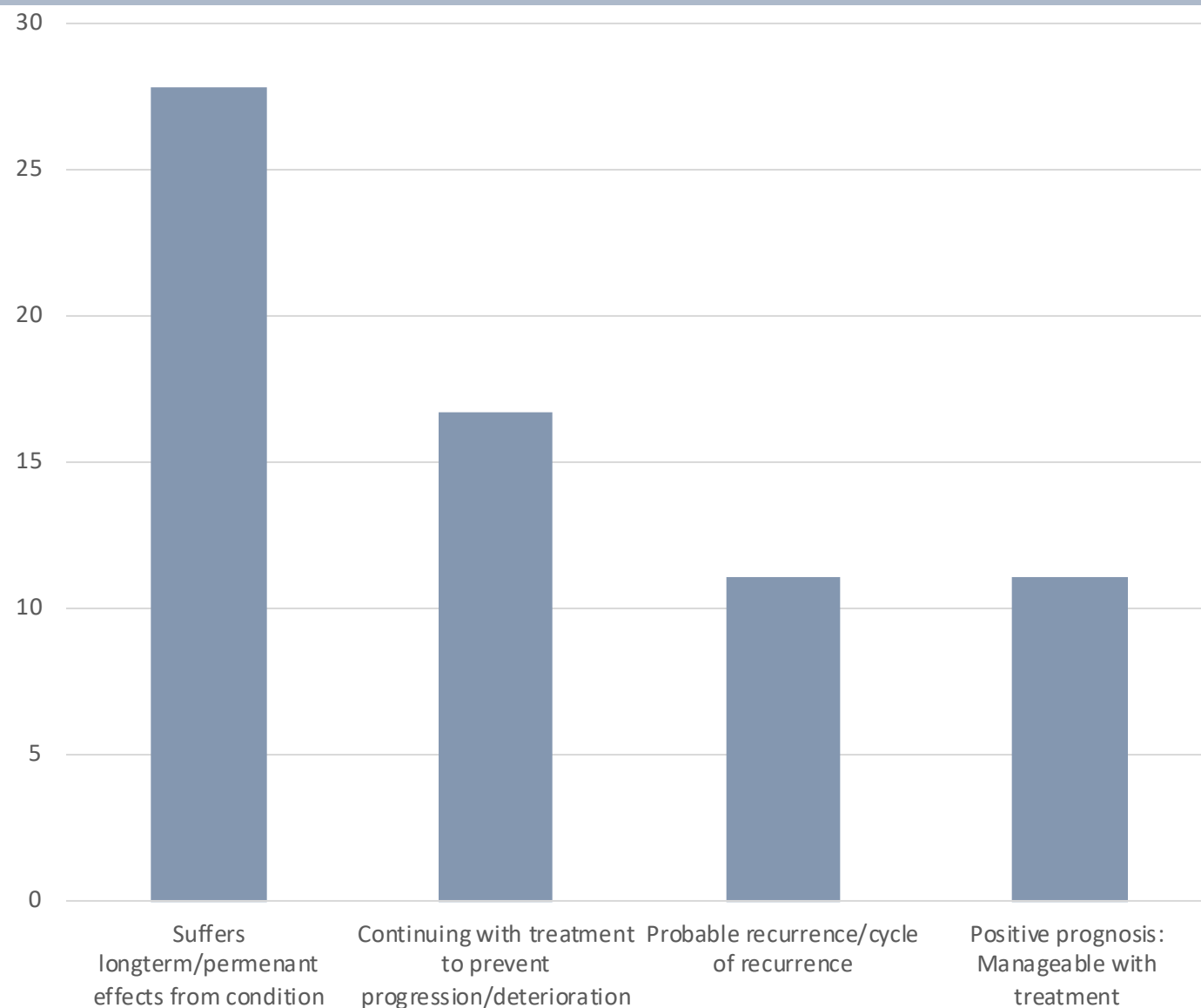
Nothing. When I was diagnosed, no. Nothing. Participant NMO_001

Not a lot. It was painted as a very, very scary condition back in 2010 because it was all likely way worse than MS. It took a long time to be okay with it and I suppose with the medication and after time, not having a relapse that made me feel better but I didn't know much. Participant NMO_010

Not really a lot. When I was first diagnosed I was told very, very little. All I was told was that there was no definitive cure for the disease and no definitive cause, that was all I was told. It was more from groups on Facebook that's where I found help, which was absolutely perfect. Participant NMO_009



Section 3



At this very moment in time I have still poor vision in my right eye and I also during the space of two days of being diagnosed with the blood test, I had a TM episode so I now have a lesion from T5 to T10 on my spine, so I walk with a walker or a stick if I've got my husband or somebody with me and it's only short. I have hand controls in my car now but fatigue and mobility and vision impairs me doing my old life, put it that way. I have a new life, which is okay. Participant NMO_006

Well, if the medication keeps working, I can finish 10 days of running 10km a day which I've never done before in my life but that was a challenge I set myself. Things are pretty good at the moment. Participant NMO_002



Section 4

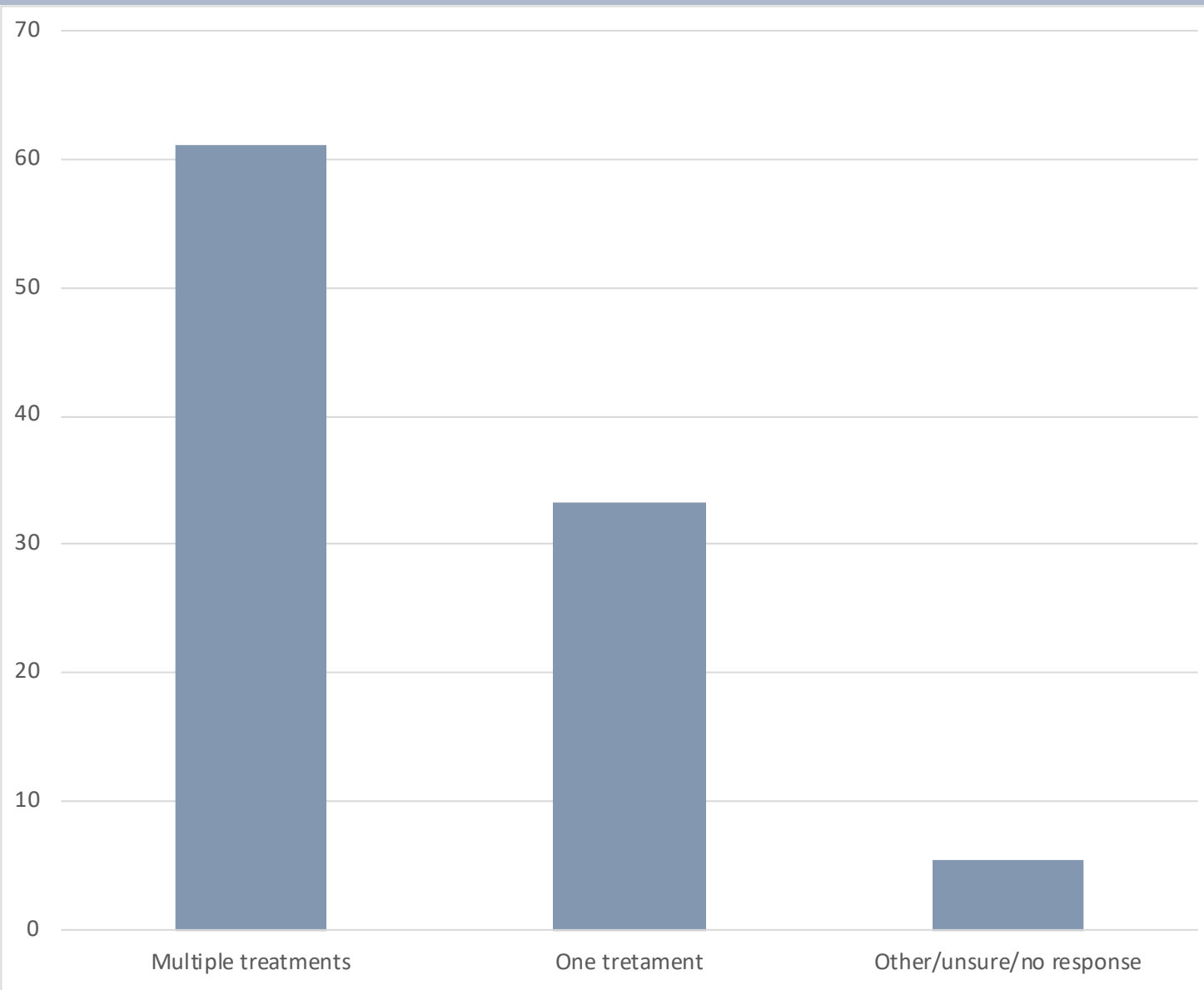


Decision Making

In the decision making section, you can find information about the conversations that were had about treatment options at diagnosis, what is important to people when they make decisions about treatment, and whether decision-making changes over time.



Section 4



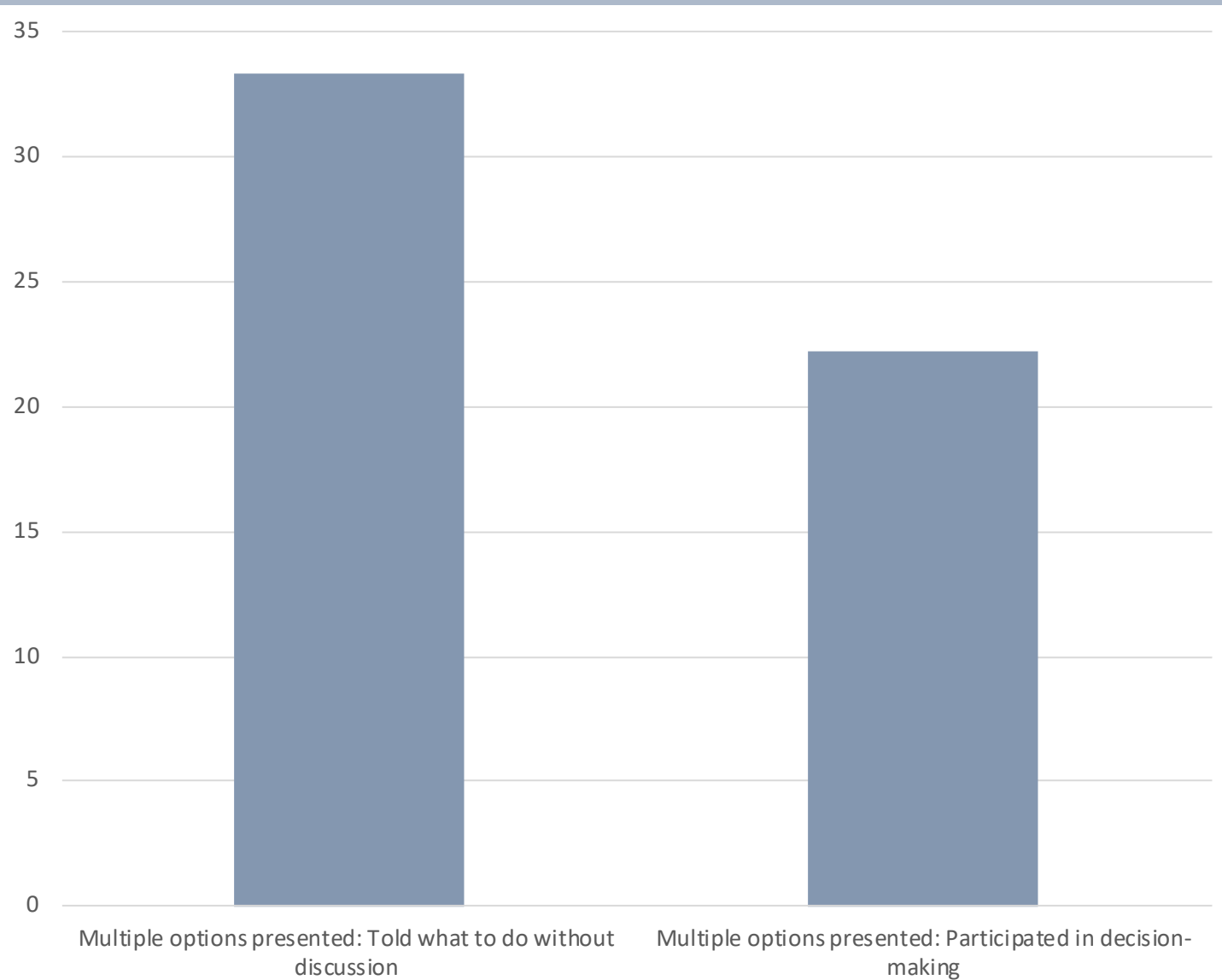
They said to me that they would-- The steroids and then the IVIg and then the plasmapheresis. That's what they've given her. Participant NMOCA_006

They put me on a high dose of steroids again. Then they put me on CellCept which I had a reaction to and I actually got, I think they call it pseudogout. My knee puffed up and it was full of fluid and I couldn't walk. I went back to the hospital and they drained that, twice I had to do it and then that settled down, but it was making me very ill as well, so he took me off that. I've been on plasma exchanges and Rituximab and Methotrexate. Participant NMO_007

Pretty much that I was told I just needed one treatment which was an infusion, and I had to wait for approval from the board of the hospital before I could have it. Once they got the approval, then they could put me in for it, and that's rituximab. Participant NMO_008



Section 4



In the hospital, because I still don't know what was going on, I knew I was on a heavy steroid infusion. IV methyl pred. The neurologist saying that once I'm discharged from hospital, I will probably need infusions and could also need to take oral prednisolone. That was all that was given to me. I wouldn't call an option as such because I know nothing about it and she basically told me, "Yes, this is what you'll do. This is what you'll do. Participant NMO_001

There was a lot of discussion about safety and efficacy of the various medications that were available, and the three of us made an informed decision about which ones to trial. The neurologist, the professor was basically saying, "Look, it might take a few goes to find the right one for you so, I think you should start with this one and then move on to that one and we'll just see how you go." We had lots of discussion about which ones. Participant NMO_016

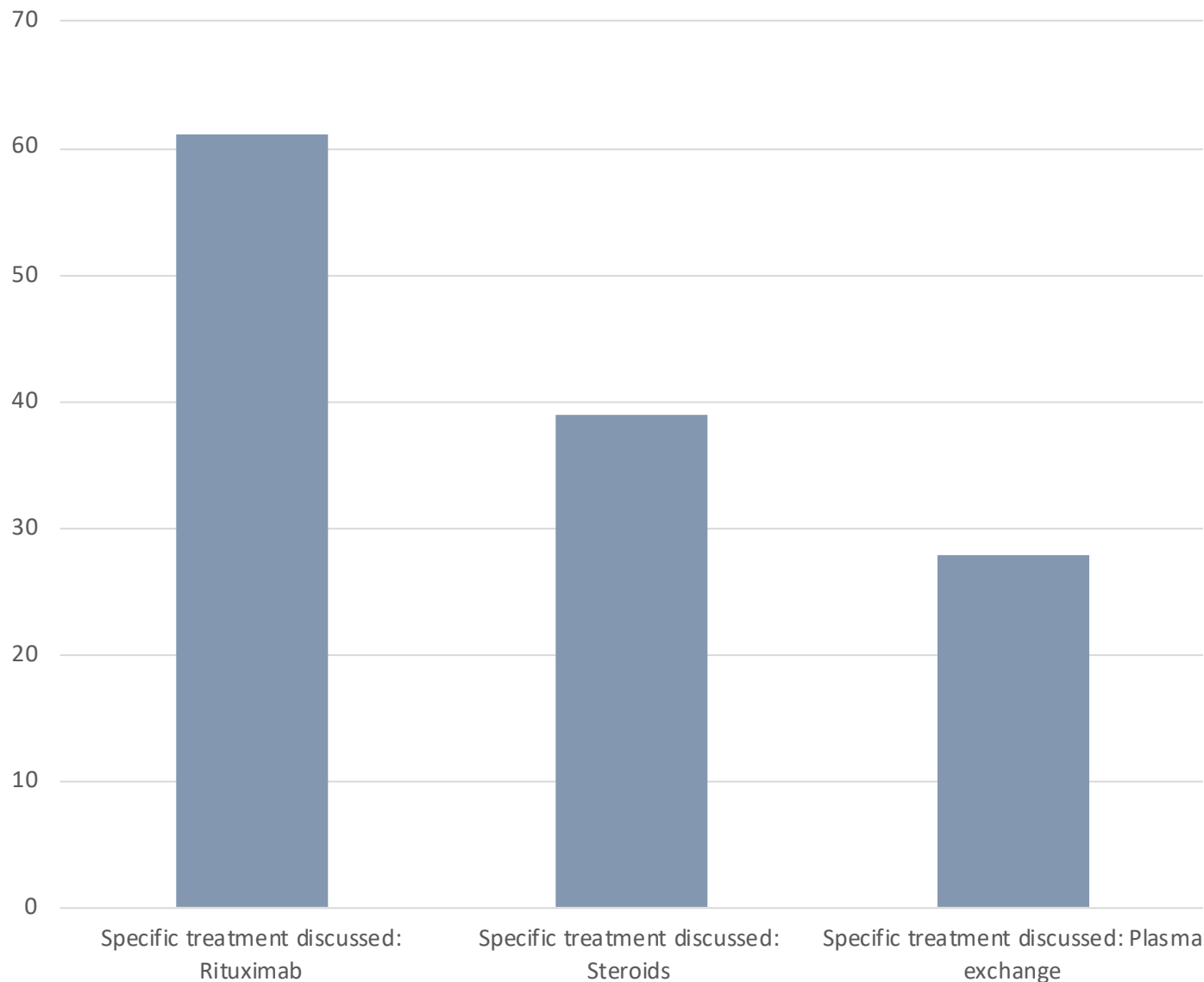


Section 4

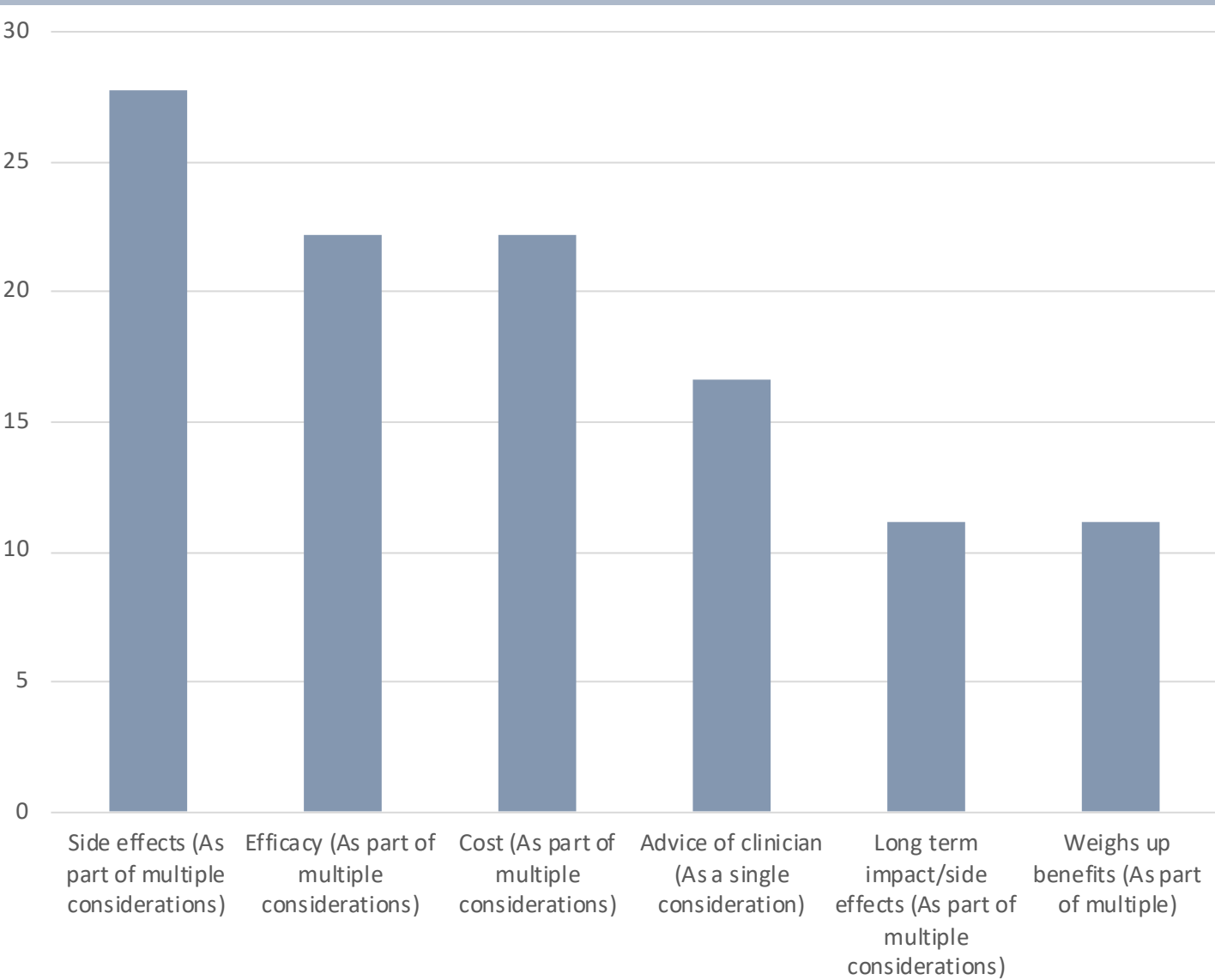
After the second I went, that's when they put me on Rituximab and really, that's the only thing apart from my vitamin D3/B12 that I have. Participant NMO_012

Well, they basically told us that he needed to be admitted into hospital and he needed to be on high dose steroids. Participant NMOCA_007

Yes. They, obviously, had started the steroids and the plasma exchange before diagnosing him with NMO. They believed it was an autoimmune disease they were just looking into, or they weren't certain on which one it was yet. They explained their treatment for most autoimmune diseases would be the plasma exchange and the steroids. Once they diagnosed him with the NMO they explained that Rituximab would deplete his B cells, so they started it that day. Participant NMOCA_002



Section 4



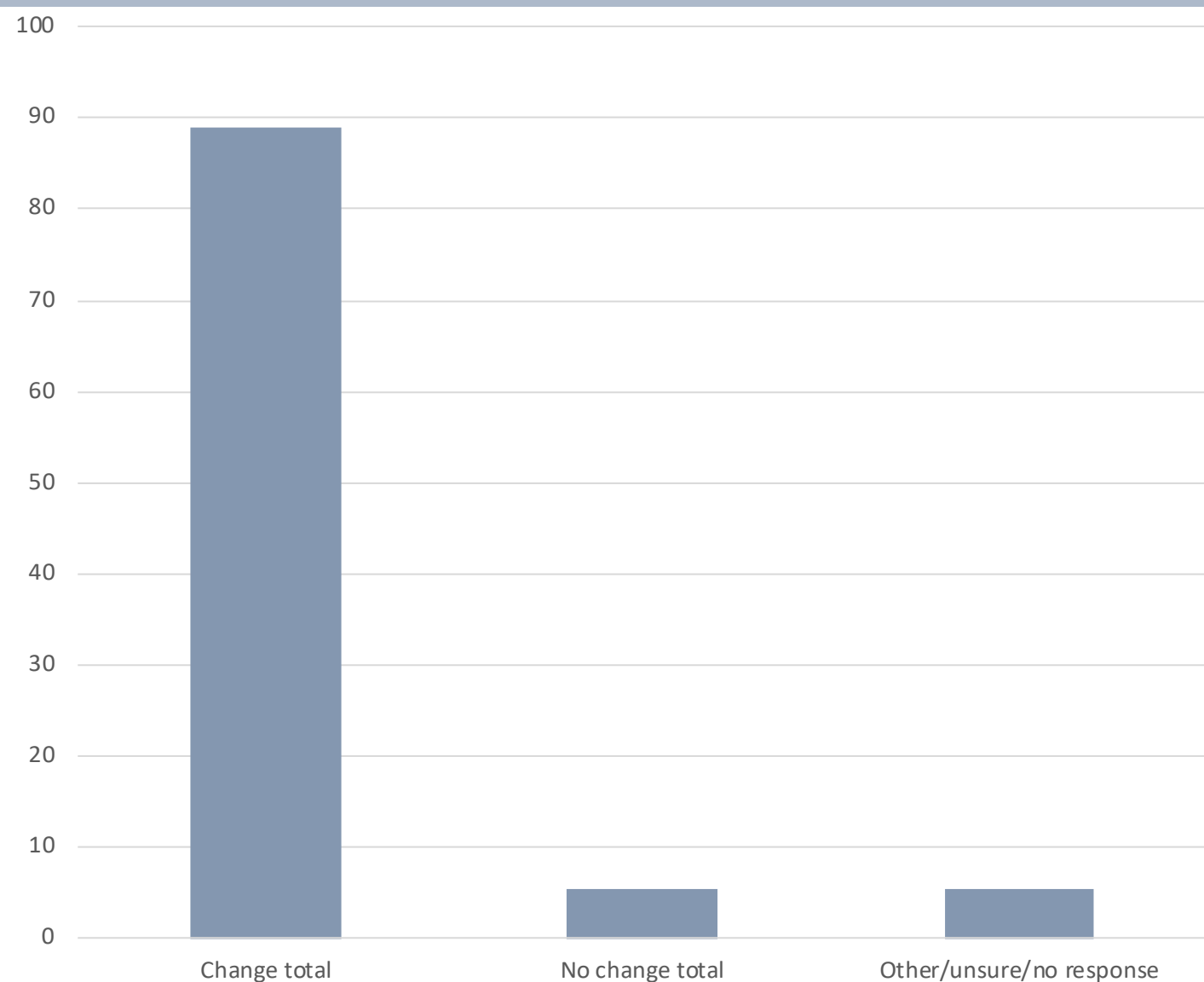
I look at side effects and how they all affect me. Like how often I need to take something, for example. I just want to live my life the most normal as I can. I don't want to be taking pills three times a day. Participant NMO_005

I think really the main thing is the effectiveness of it and whether or not that person understands your condition and is supportive of you. Participant NMO_004

I put all my trust in NAME DOCTOR because so far he's kept me going. He's got me out of trouble a few times, like when I've had an attack and I'm on my way to the hospital, when I get there he's waiting there for me. Participant NMO_007



Section 4



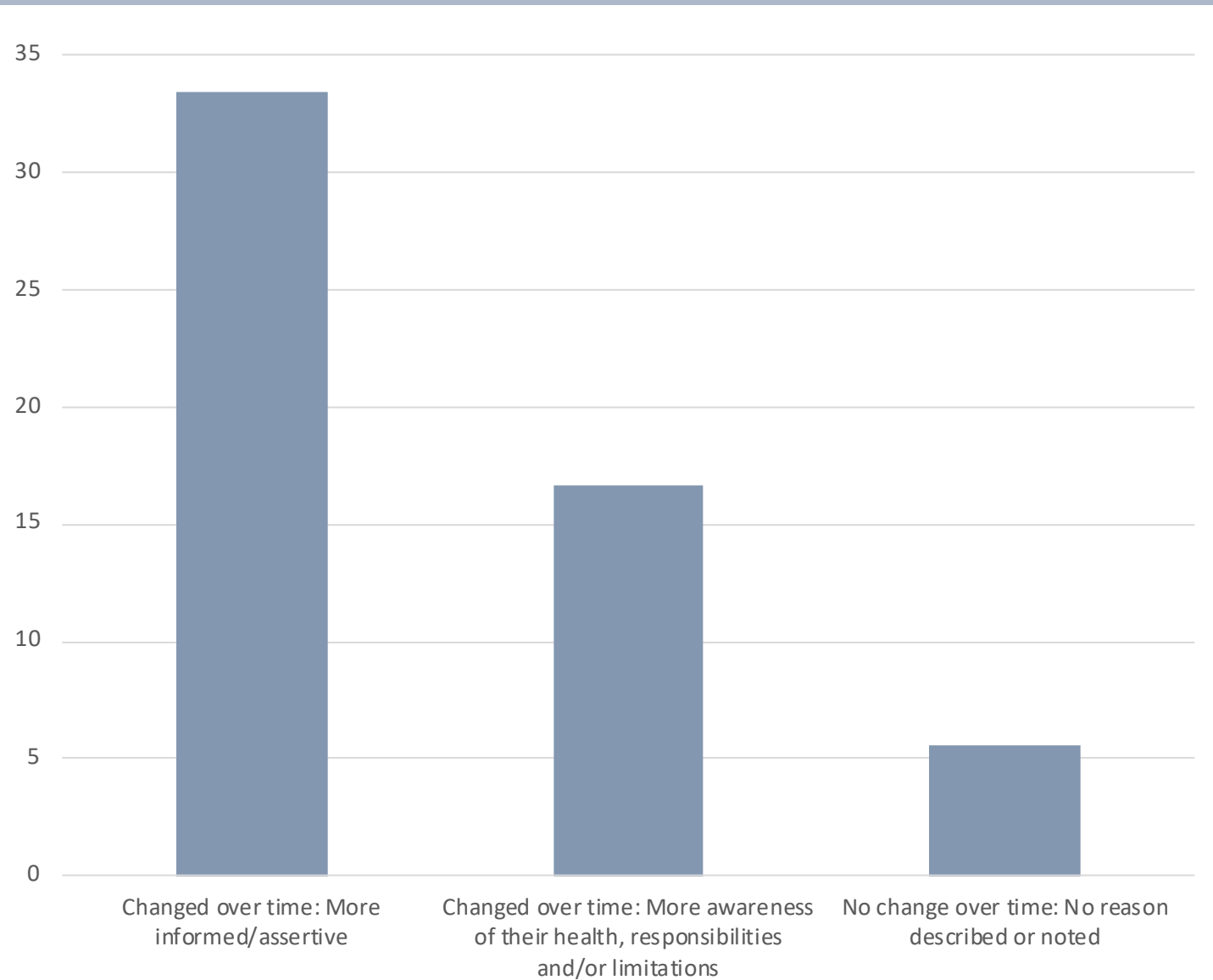
It's changed as I've learned a lot. When it first happens, you get a bit overwhelmed by it all, but I've had to teach myself, learn a lot in the nine years. If you don't learn a lot, you don't know what's happening. Participant NMO_013

No, definitely it has changed. I recently did a deep dive into what NMO is this year. Just previously I feel like you've got to be asking lots of questions and you can't with just your 10-minute session with your specialists. Participant NMO_002

Same way. I think we are quite too early in this journey to have made any other decisions in this. I think if we went 10 years down the track, I think we probably would have changed but now it's just 18 months. Participant NMOCA_003



Section 4



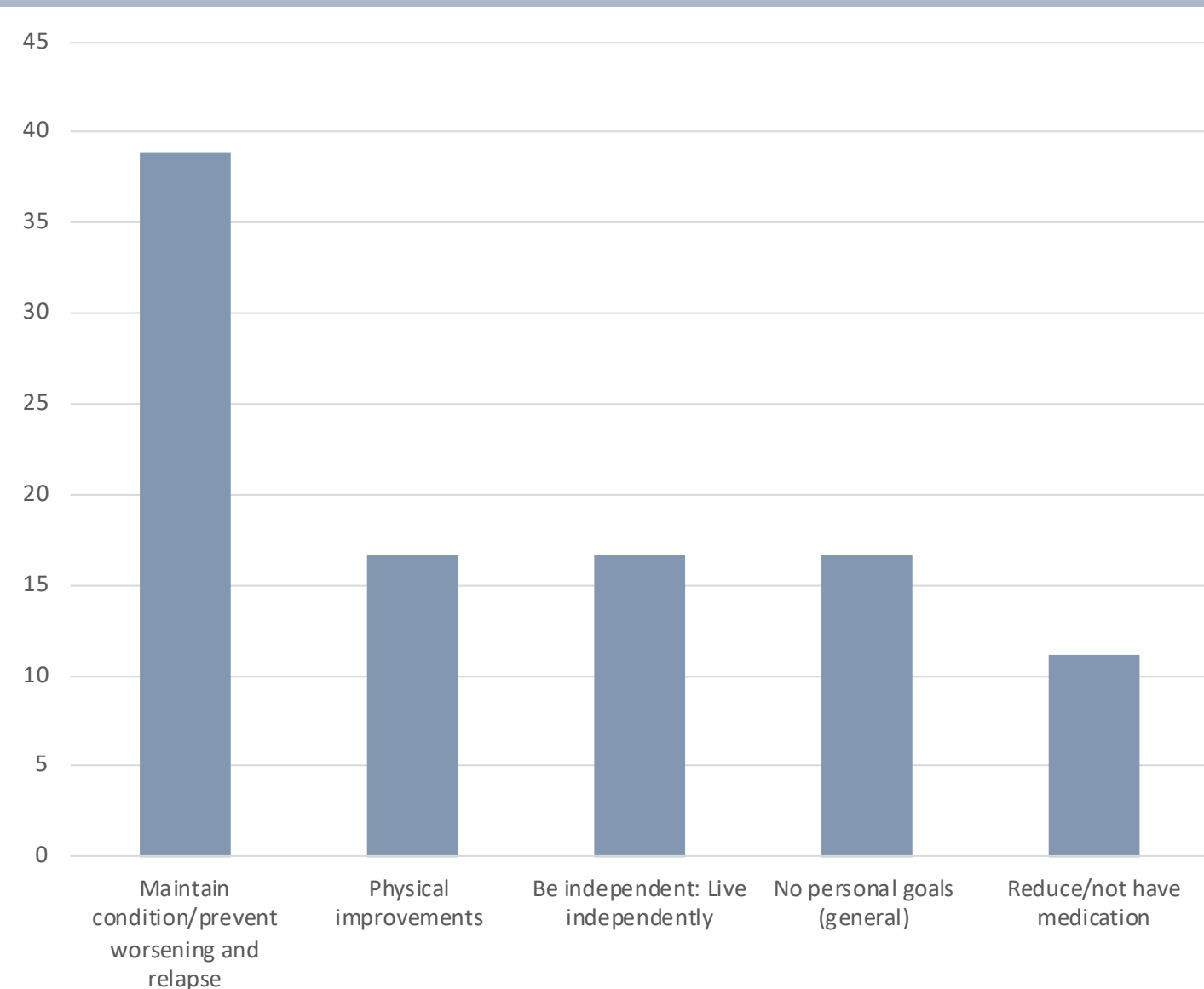
I don't trust doctors as much as I did at the start. I trust my own research more now, definitely. Participant NMO_005

I think we have changed the way we make decisions. This disease is really very much in your face, so that governs how you view things now, to the point where you're concerned about any relapses and so that has changed our lifestyle, I suppose. We're still fairly active but you're aware of this. Participant NMOCA_004

Same way. I think we are quite too early in this journey to have made any other decisions in this. Participant NMOCA_003



Section 4



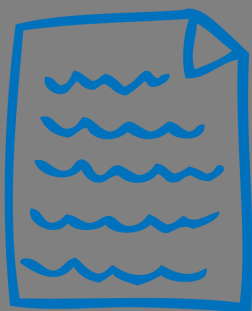
I think he just knows I don't ever want to be in a wheelchair. I don't ever want to be incontinent and I just don't want to be affected by it, which is a bit unrealistic, but that's my goal. Participant NMO_003

The only goals that I have is that I'm registered through NDIS, so my goals are to be able to continue to live independently, and so I have support workers come in to help me. Participant NMO_011

I don't like the side effects, long-term of mycophenolate with the increased chance of skin cancers and lymphoma. I think they're my concerns about being on it long term. I always have this fight with myself, internal dialogue going on. I also talk about it with my MS specialist, I have a fantastic relationship with him. He was invited to my conference as well. Every time I see him, I go, "I wish I could go off them." Participant NMO_004



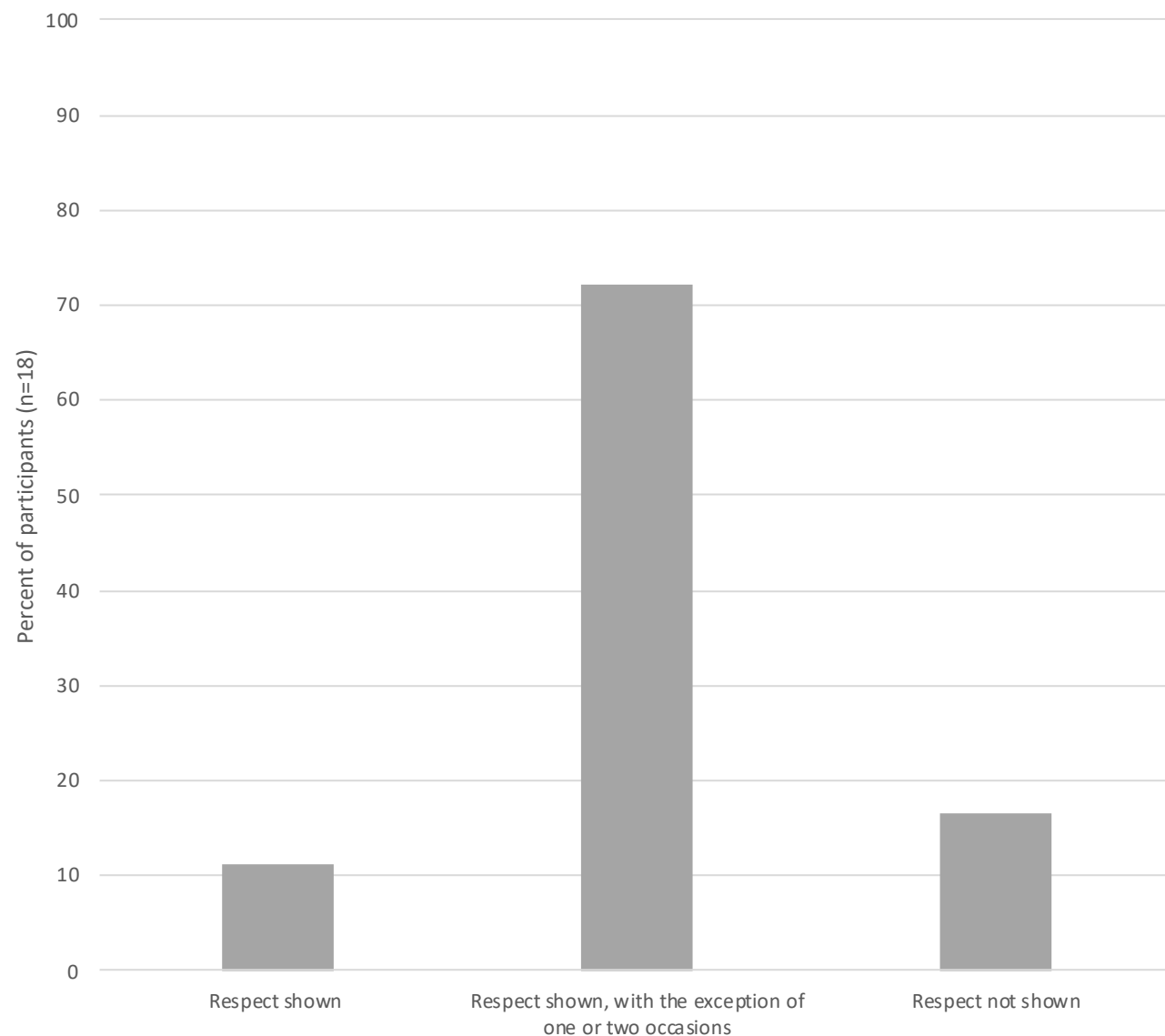
Section 5



Treatment

The treatment section is one of the largest sections in each study. Information is available in relation to the types of treatments people have experienced as well as rating quality of life and effectiveness for each treatment. There is information about the main providers of treatment, access to health professionals and information about which part of the health system participants were treated in. There is information about affordability of healthcare, any reduced income for the patient or their family, an additional costs or changes to employment. There is then also detailed information about the treatments that the participants have experienced, whether they had any side effects, their description of mild side effects and severe side effects, and any complementary therapies that they may have used. Information in relation to access to allied health is also available. Information about what needs to change to feel like treatment is effective, and adherence to treatment is also presented. In this section, there is also information on whether discussions about clinical trials were held with clinicians, and for those who have been on a trial, what their experience was like.





Treated with respect during experience in the health system?

Yes
11% (n=2)

Yes, with the exception of the odd occasion
72% (n=13)

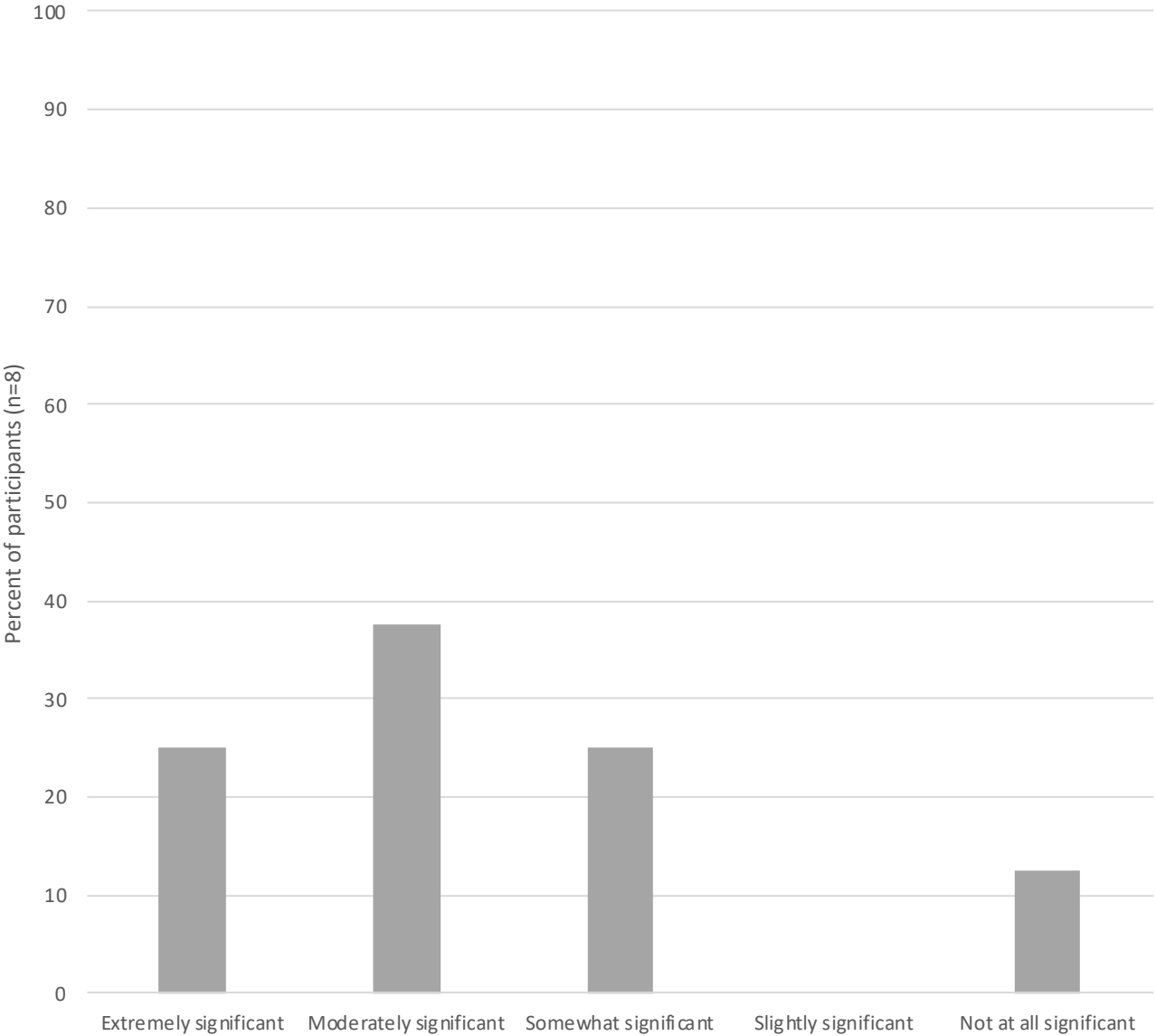
No
17% (n=3)



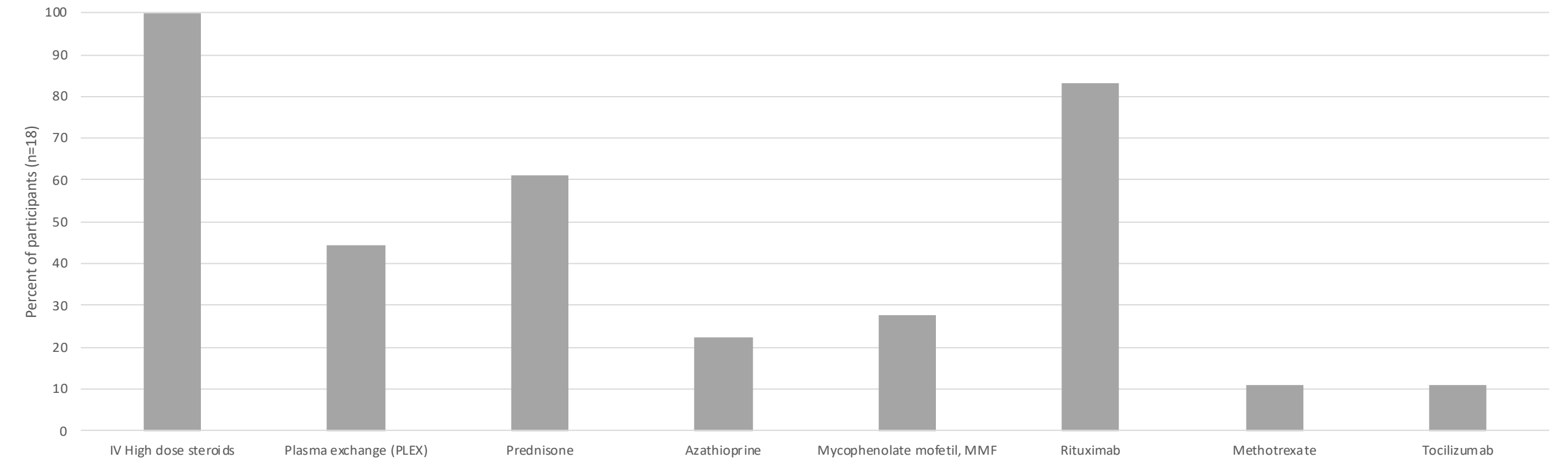
Reduced income (self or family)	Participants with NMOSD	
	Number (n=18)	Percent
No	10	55.56
Yes	8	44.44

Estimated monthly loss of income	Participants with NMOSD	
	Number (n=18)	Percent
\$0	10	55.56
\$500 to \$1999	2	11.11
\$2000 to \$5000	3	16.67
More than \$10,000	2	11.11
Not sure	1	5.56

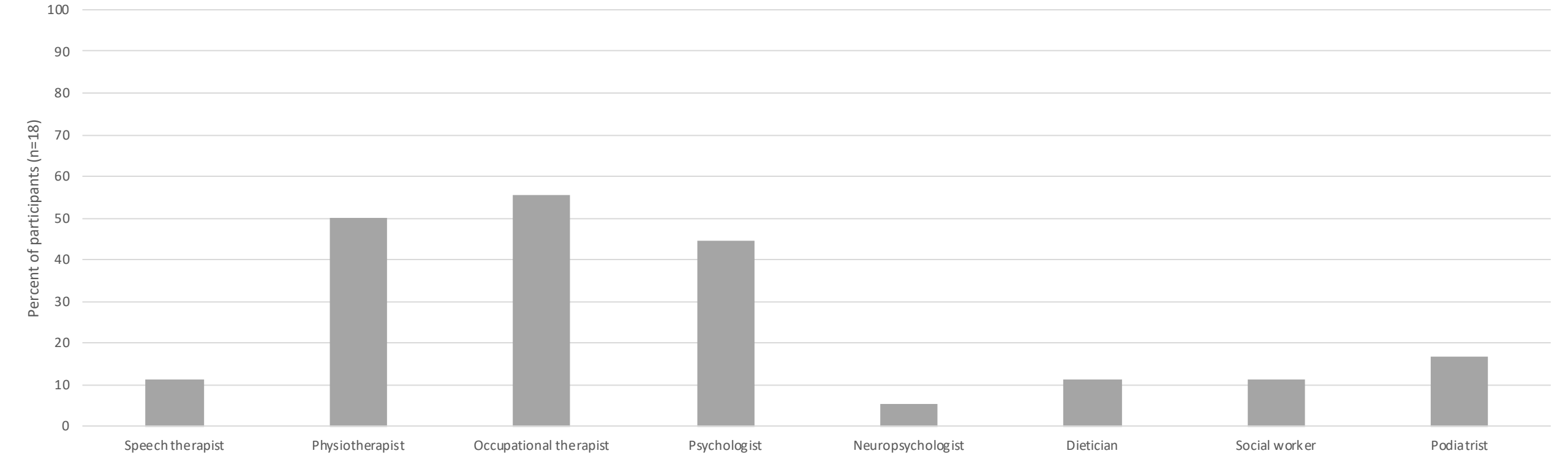
Burden of reduced income	Participants with NMOSD	
	Number (n=8)	Percent
Extremely significant	2	25.00
Moderately significant	3	37.50
Somewhat significant	2	25.00
Slightly significant	0	0.00
Not at all significant	1	12.50



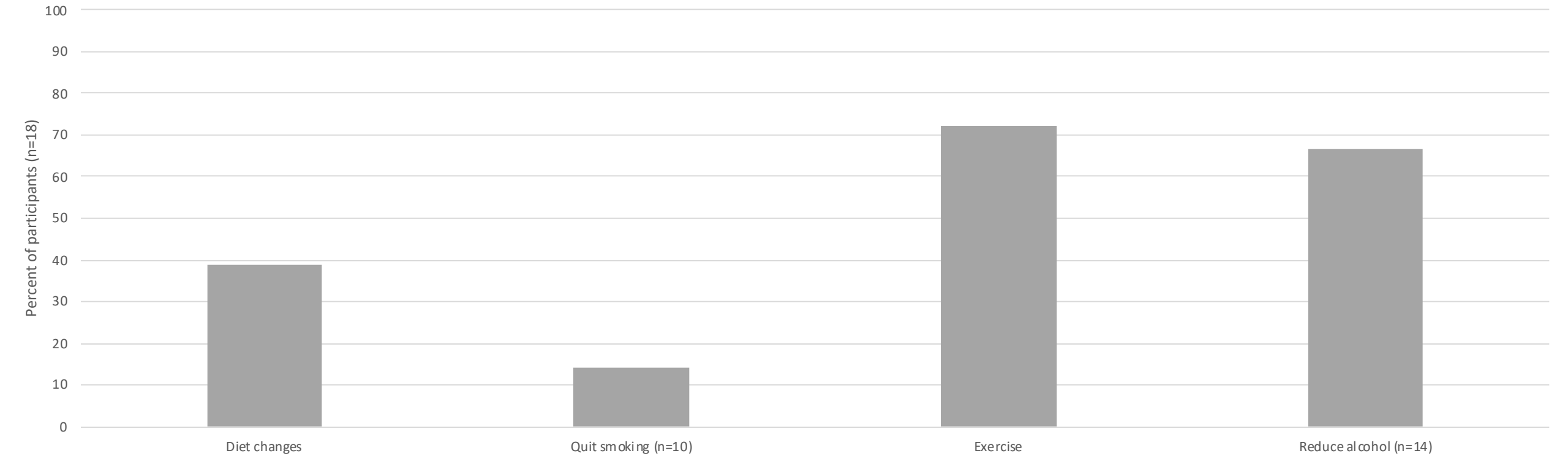
Treatment	Number taking treatment		Participants WITHOUT side effects		Quality of life		Effectiveness	
	Number	Percent	Number	Percent	Median QOL	IQR	Median	IQR
IV High dose steroids	18	100.00	2	11.11	2.00	2.75	4.00	1.00
Plasma exchange	8	44.44	2	25.00	2.50	2.25	4.50	1.00
Prednisone	11	61.11	2	18.18	2.00	2.50	4.00	1.00
Azathioprine	4	22.22	0	0.00	2.50	1.25	1.00	0.25
Mycophenolate mofetil, MMF	5	27.78	0	0.00	1.00	4.00	4.00	3.00
Rituximab	15	83.33	7	46.67	4.00	1.00	4.00	1.00
Methotrexate	2	11.11	1	50.00	3.50	1.50	5.00	0.00
Tocilizumab	2	11.11	2	100.00	4.50	0.50	5.00	0.00



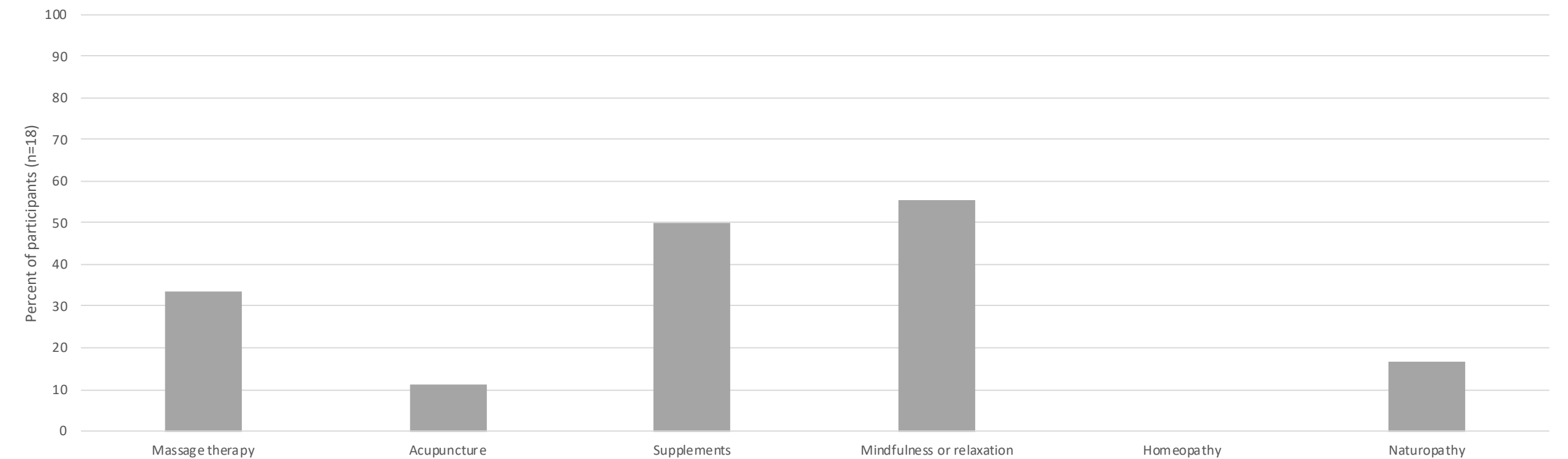
Allied health	Number using allied health		Quality of life		Effectiveness	
	Number (n=18)	Percent	Median	IQR	Number (n=18)	Percent
Speech therapist	2	11.11	2	0.00	4	0.00
Physiotherapist	9	50.00	3	2.00	4	2.00
Occupational therapist	10	55.56	3	2.00	3	0.25
Psychologist	8	44.44	3	1.50	3	1.00
Neuropsychologist	1	5.56	2	0.00	1	0.00
Dietician	2	11.11	1.5	0.50	2.5	1.50
Social worker	2	11.11	1	0.00	3.5	1.50
Podiatrist	3	16.67	4	1.00	3	0.50



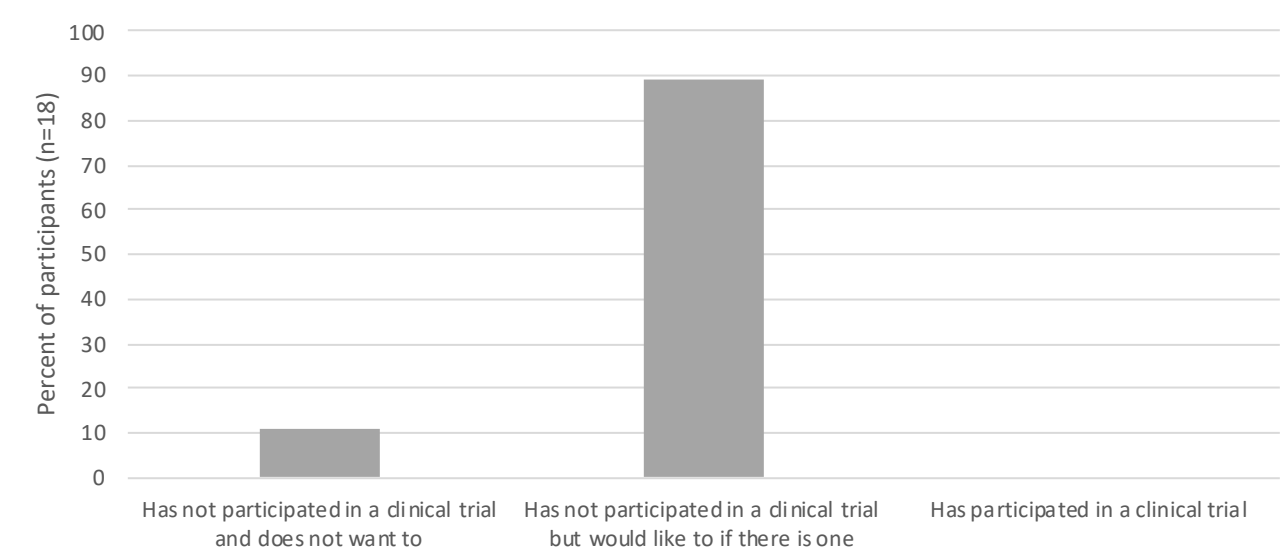
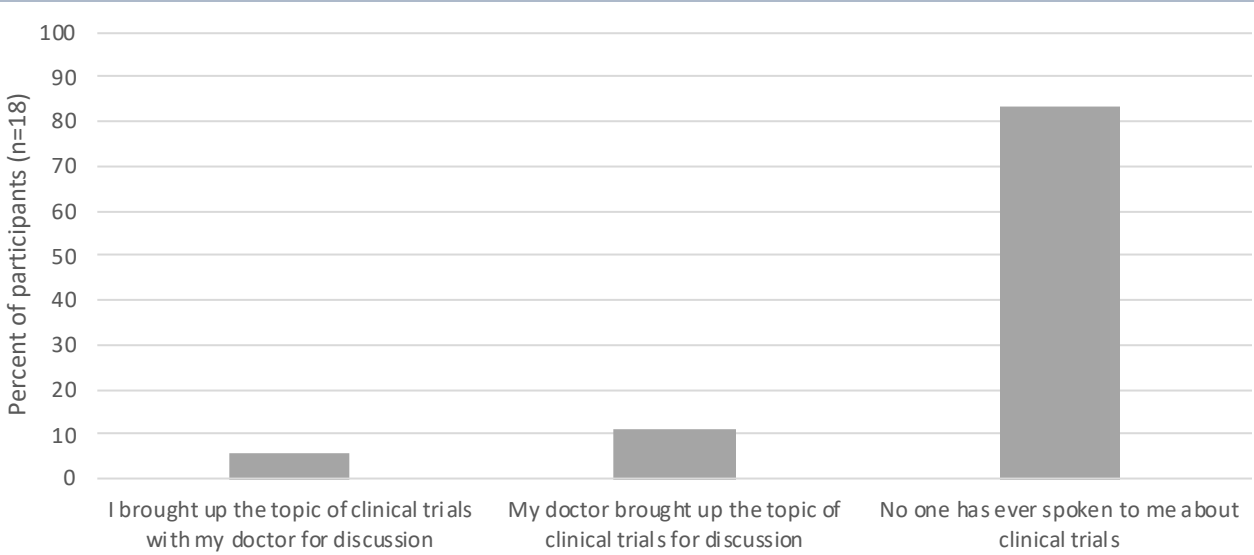
Lifestyle changes	Participants with NMOSD		Quality of life		Effectiveness	
	Number (n=18)	Percent	Median	IQR	Median	IQR
Diet changes	7	38.89	4.00	2.00	2.00	2.00
Quit smoking (NMOSD=7, MOG = 3)	1	14.29	2.00	0.00	5.00	0.00
Exercise	13	72.22	4.00	2.00	4.00	1.00
Reduce alcohol (NMOSD=9, MOG = 5)	6	66.67	4.50	1.00	2.00	2.25



Complementary therapies	Participants with NMOSD		Quality of life		Effectiveness	
	Number (n=18)	Percent	Median	IQR	Median	IQR
Massage therapy	6	33.33	4.00	1.50	4.00	1.50
Acupuncture	2	11.11	4.00	0.00	4.00	0.00
Supplements	9	50.00	4.00	2.00	4.00	1.25
Mindfulness or relaxation	10	55.56	4.00	2.50	4.00	2.00
Naturopathy	3	16.67	3.00	1.00	3.00	1.00

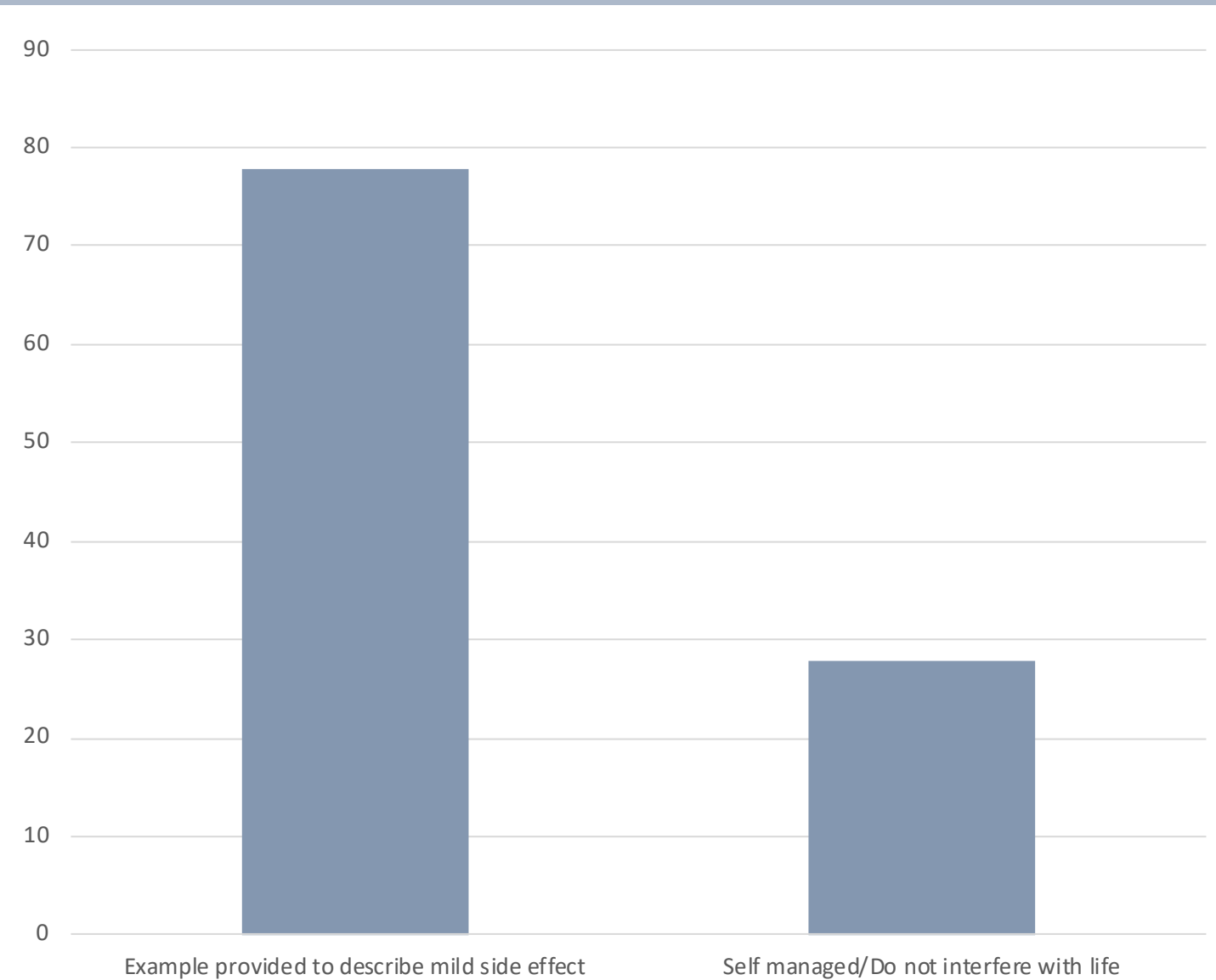


Clinical trial discussions	Participants with NMOSD	
	Number (n=18)	Percent
I brought up the topic of clinical trials with my doctor for discussion	1	5.56
My doctor brought up the topic of clinical trials for discussion	2	11.11
No one has ever spoken to me about clinical trials	15	83.33



Clinical trial discussions	Participants with NMOSD	
	Number (n=18)	Percent
Has not participated in a clinical trial and does not want to	2	11.11
Has not participated in a clinical trial but would like to if there is one	16	88.89
Has participated in a clinical trial	0	0.00

Section 5



The mild side effects are the spasms. You get heat intolerance. That's another side effect. I have heat intolerance. I find that once I heat up, it's very hard for me to cool down. Participant NMO_004

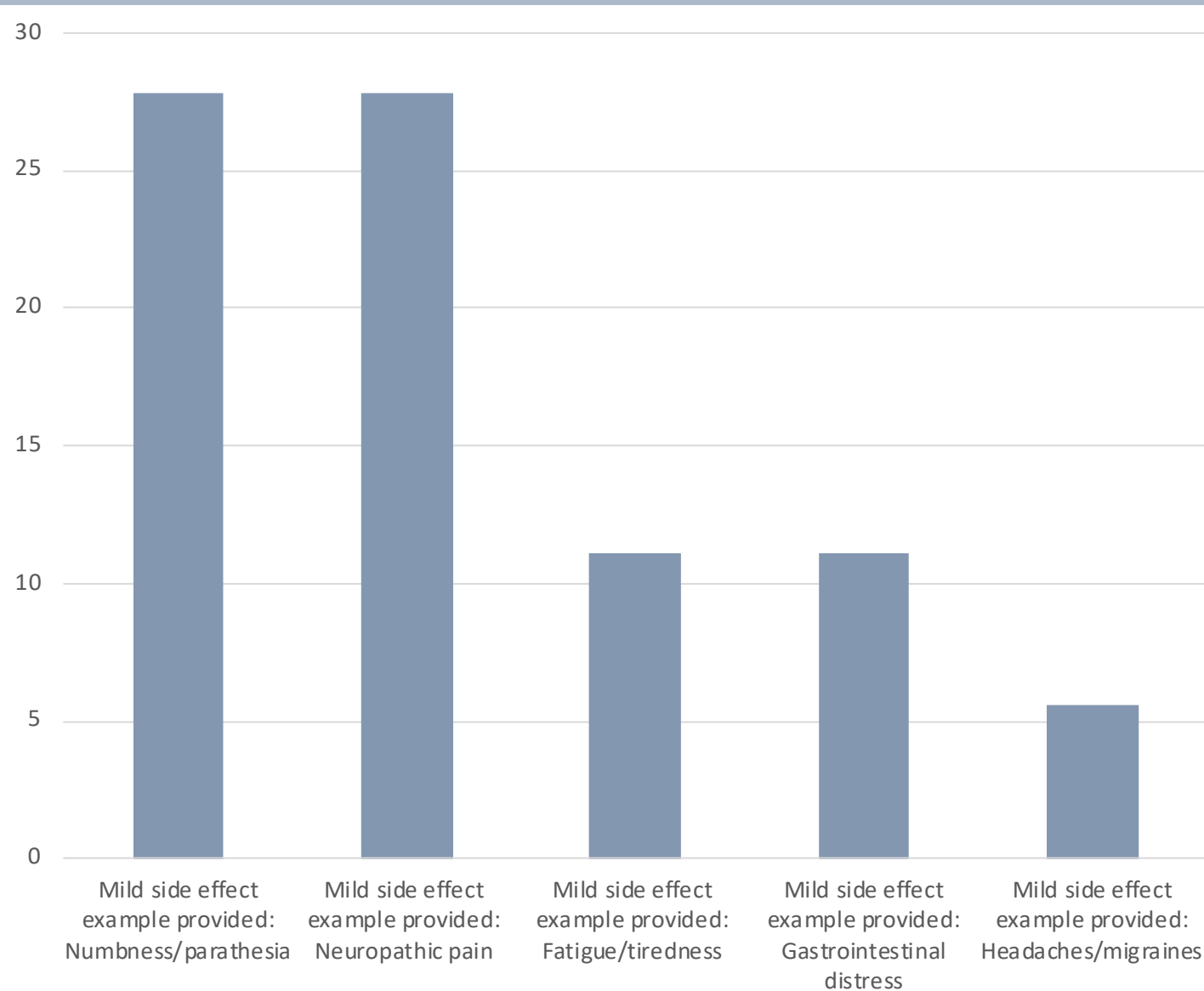
I don't know. If I could keep working or keep doing the things that I enjoy even with the side effects, I'd say they're kind of mild. Participant NMO_010

For me, mild is something that I can live with and I can deal with. Participant NMO_005

Mild side effects to me is something that you can take a pill for and it disappears or it eases, so nausea I can take an anti-nausea tablet and it alleviates it. Participant NMO_017



Section 5

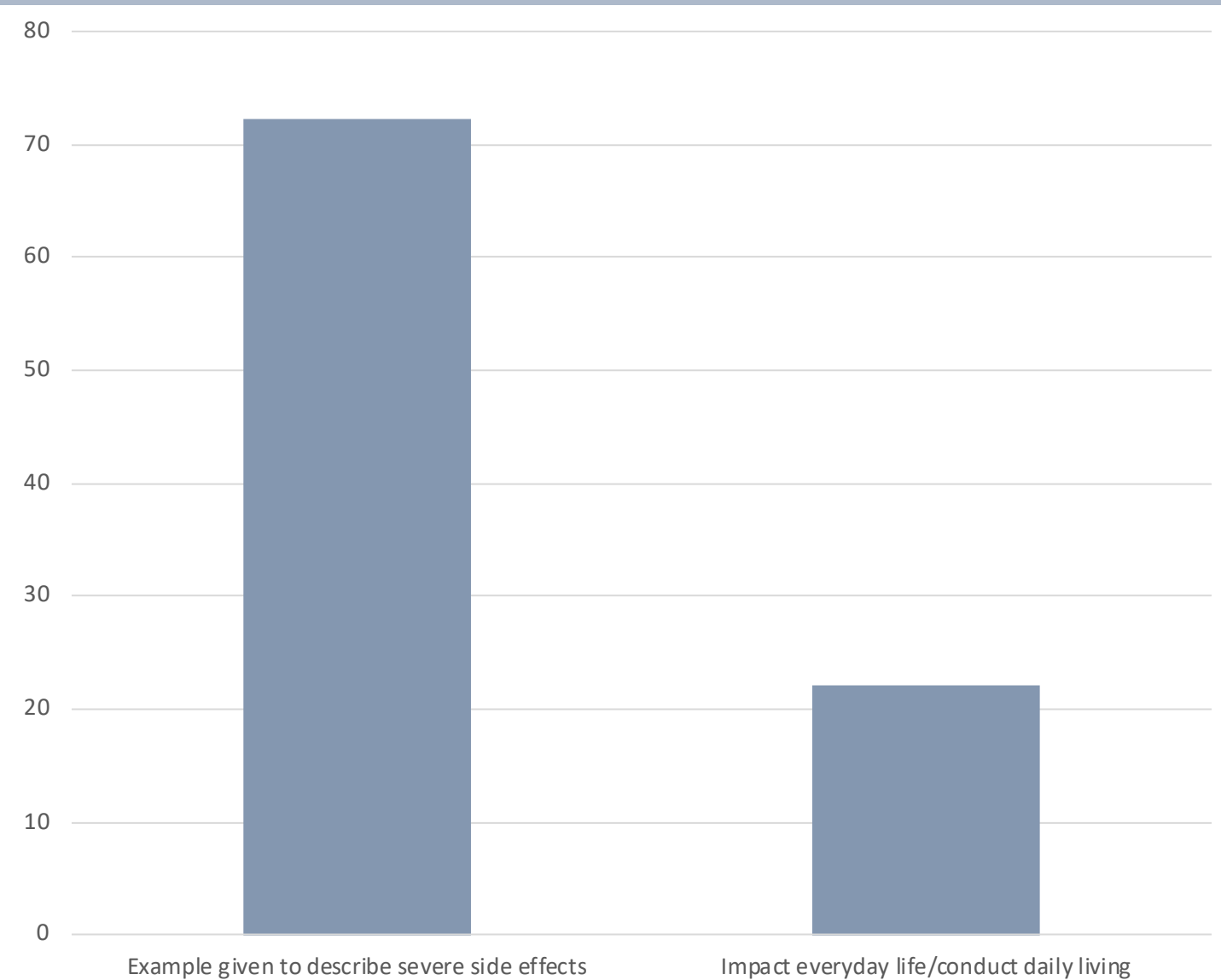


Pins and needles. If they are just locally that's a mild side effect as well as-- I think that would be the only-- Then there are some kind of more sharper pains every now and then but they are very seldom but they take place. I would put them also in the mild category. Participant NMOCA_003

For me, mild is sometimes or probably every day, say, I might get a quick sensation of a burning rash on the sides of my body, just in about a three or four-inch square and it will just be a little quick burn, and then it goes. On my left side, it's like I've still got the socks on and my left side's tight, and I get a little bit of just slight pain but nothing that bothers me at all. I just know that it's still there every day on my left leg. What else? Yes, that's my mild ones. Participant NMO_015



Section 5



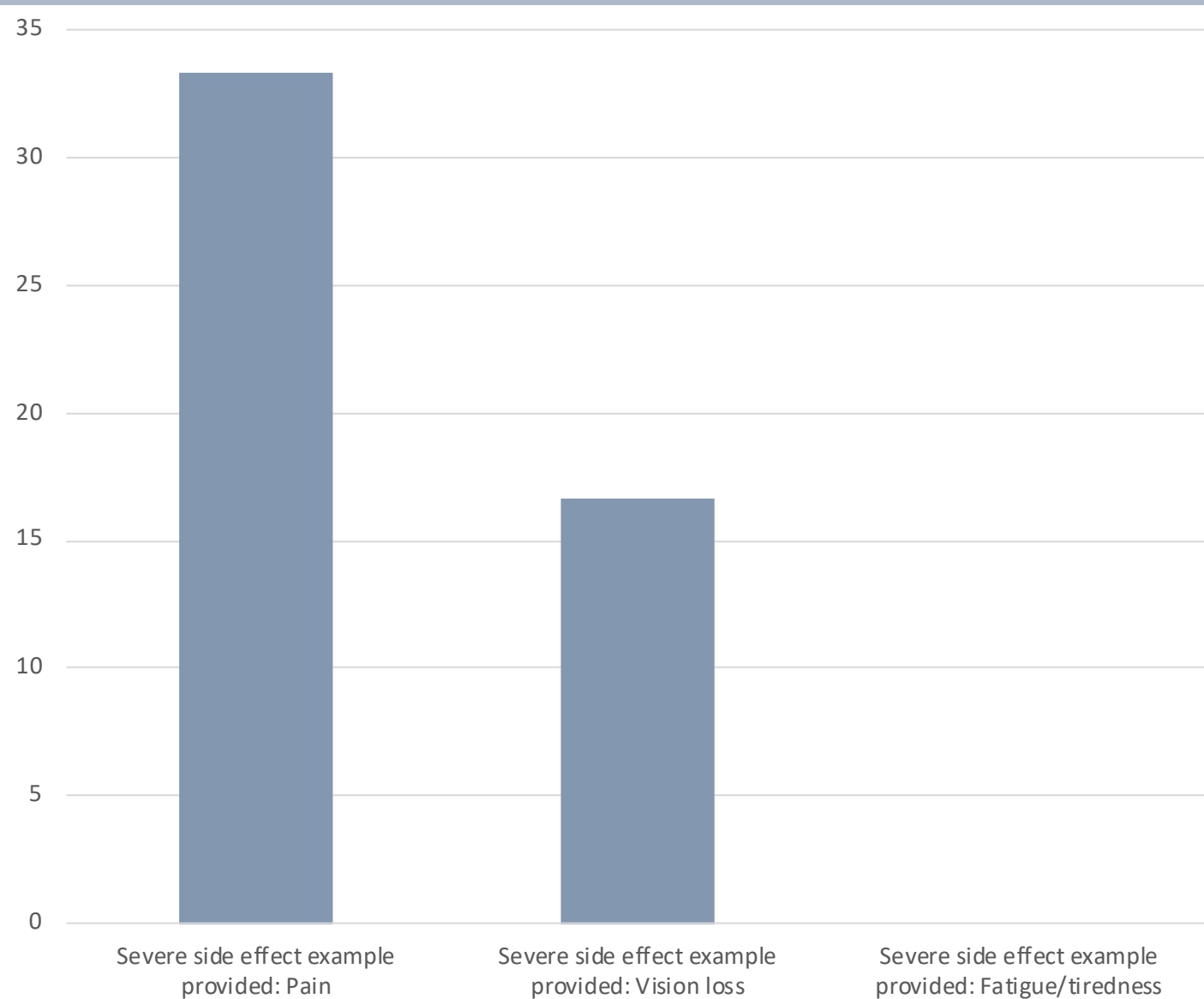
For me, severe would be something I can't live with. For example, I'm swelling up from my migraines, not being able to open my eyes in the sunlight, things like that. Like being really severely allergic to the sun on some of the medications where I'd go out, for example, to put the washing out, or for taking the washing down, and I'd be covered in a really painful rash. Participant NMO_005

Well, the opposite. The side effects would just be interfering, or if the side effects that are worse than what we were trying to manage, that would be severe but if I couldn't go about my normal day or enjoy things in life, then they would be pretty severe side effects. Participant NMO_010

It's where you're just incapable of living your normal life. Participant NMO_014



Section 5



Pain. Pain will be the burning pain. To me, that's severe. Participant NMO_001

I had double vision that I couldn't cope with. Not vomiting. I couldn't walk straight and severe headache. Did not cope well with any of that. Participant NMO_008

I think the loss of vision was obviously a very scary situation to have to deal with, and at the time, not knowing what was causing it, was even more daunting. Participant NMOCA_004

Fatigue, just overwhelming exhaustion, and paralysis from the neck down, and the pain behind his eyes at different stages. Participant NMOCA_002

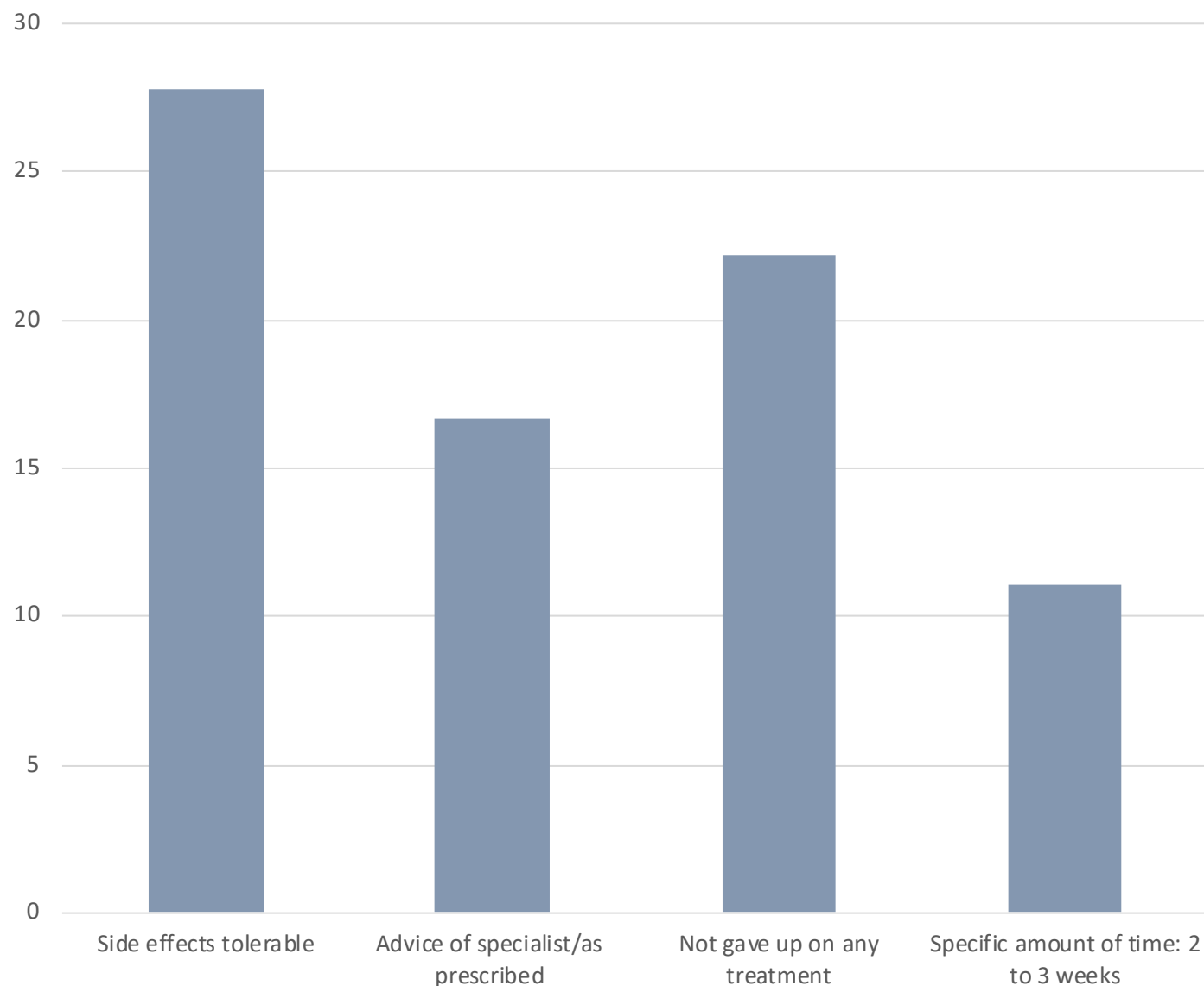


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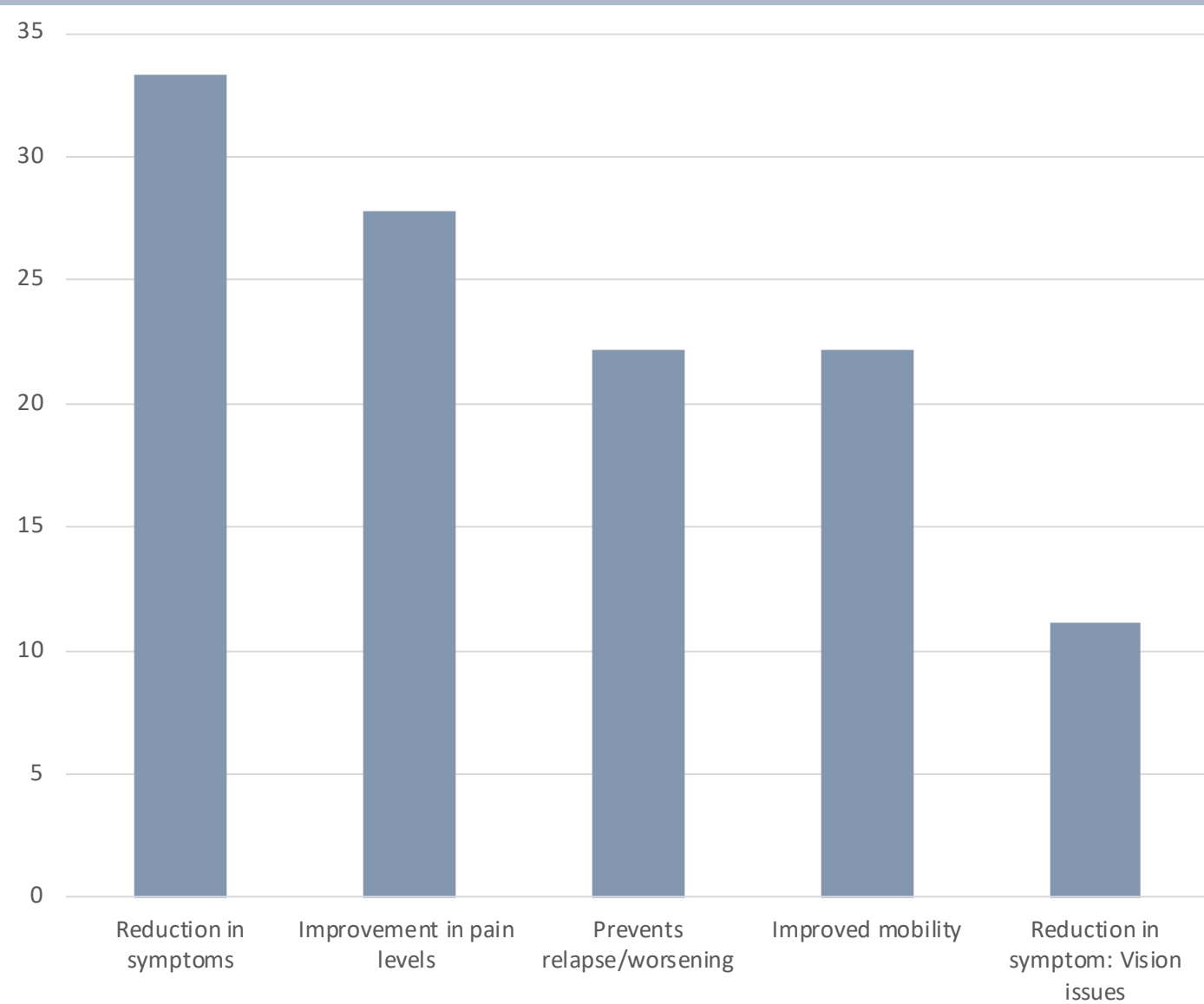
I usually know fairly quickly. I've given it a few weeks, probably longer sometimes, unless it makes me really sick. For instance, I know that I can't use Lyrica. I've tried and it just does not agree with me. Participant NMO_011

At the moment I've been sticking to whatever medication was given. I have no problem taking it. Participant NMO_001

I probably, I'd wait until I then speak to the doctor and then if they believe that that-- I tell them what like I was telling them what was wrong with me with the gabapentin and that's when we decided to change. Participant NMO_006



Section 5



No. I'm at that point in my diagnosis where I'm not really expecting any more improvement. I'd like my bladder to work better. Participant NMO_010

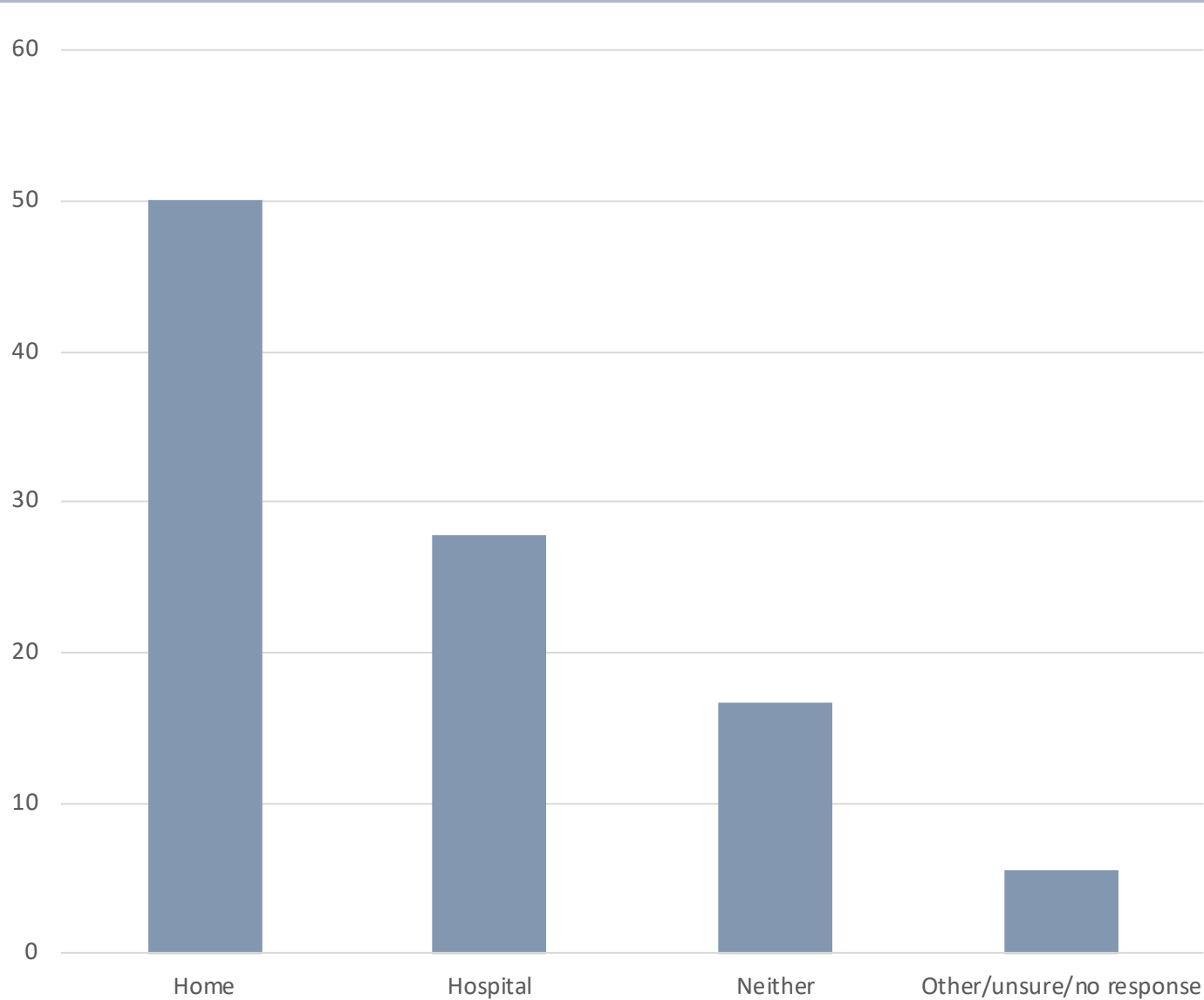
Well, I suppose being able to move without pain. Being less stiff. Medication treatments only do like pain and stuff and just stop the flares. Participant NMO_006

For me, for the treatment to work, I think rituximab whether it works then if I don't relapse then I will believe it worked. Otherwise, no. [laughs] I'm still yet to see what will happen next. Participant NMO_001

Basically, yes, when I'm not having a relapse, it's a good day. Participant NMO_003



Section 5



I would prefer at home because it wouldn't interrupt my life as much. Participant NMO_010

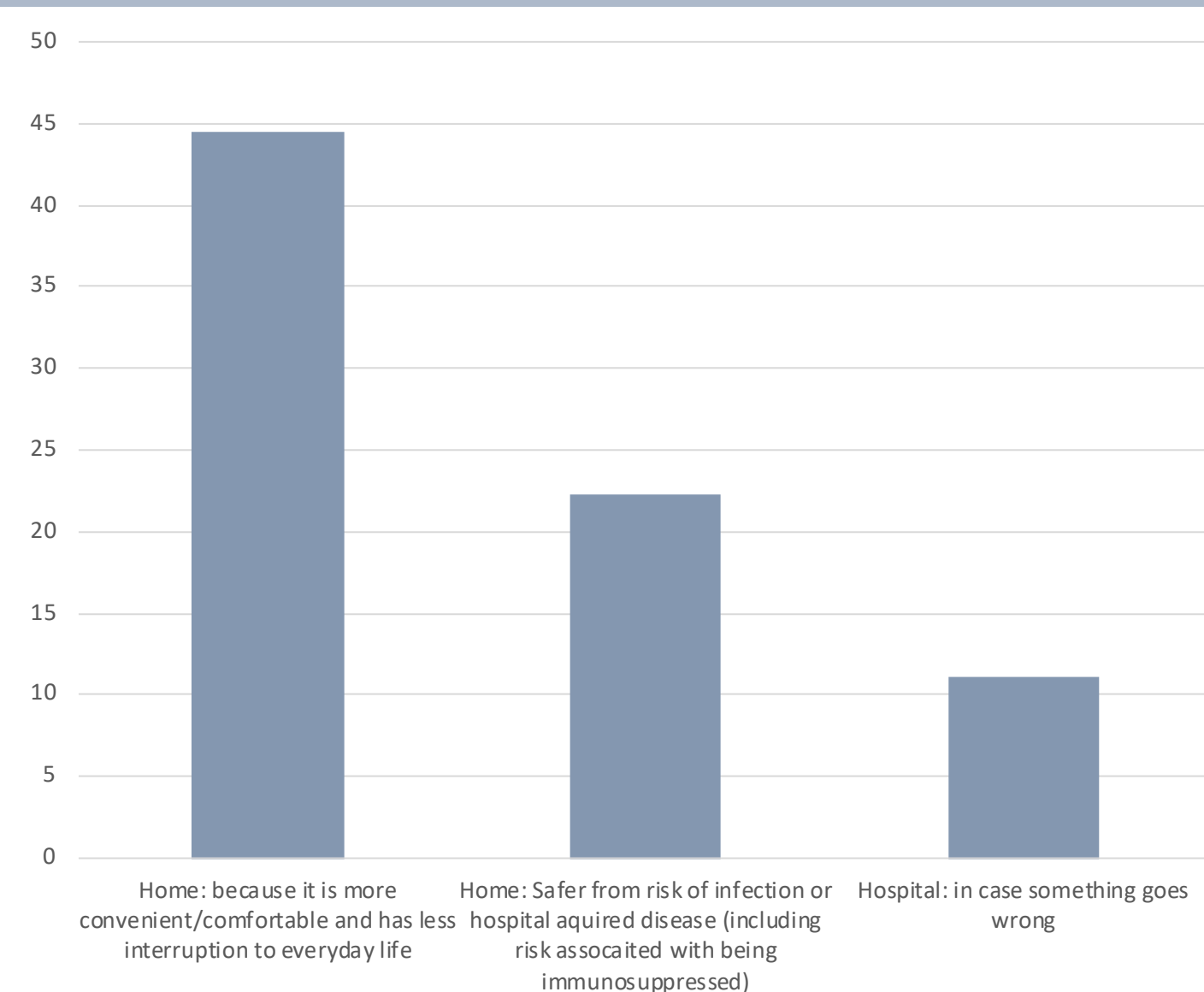
At home, easy, because I'm in my own environment. I can just rest afterwards. Also because my immunity is reduced, it's also going to be safer for me to be at home rather than at the hospital. Participant NMO_011

I think at the hospital because if anything happens, what you might not think will happen, you've got the medical people that know [laughs] compared to at home. Participant NMO_012

I think the hospital I would prefer because I think you just don't know with the reactions. I think it's good, if it's a new treatment, just to see how it goes. Participant NMO_015



Section 5



I'd probably prefer it at home because I can't drive, so it would just be easier for me, because I won't have to-- My mum has to take a day off work, or my brother has to take a day off work, or my dad, to drive me. I guess it would be more just easier for everyone around me. Participant NMO_005

Obviously if you're at home, you're not surrounded by other people that are sick. Participant NMO_008

I think the hospital I would prefer because I think you just don't know with the reactions. I think it's good, if it's a new treatment, just to see how it goes. Is there going to be any side effects? Just to keep that record. Participant NMO_015



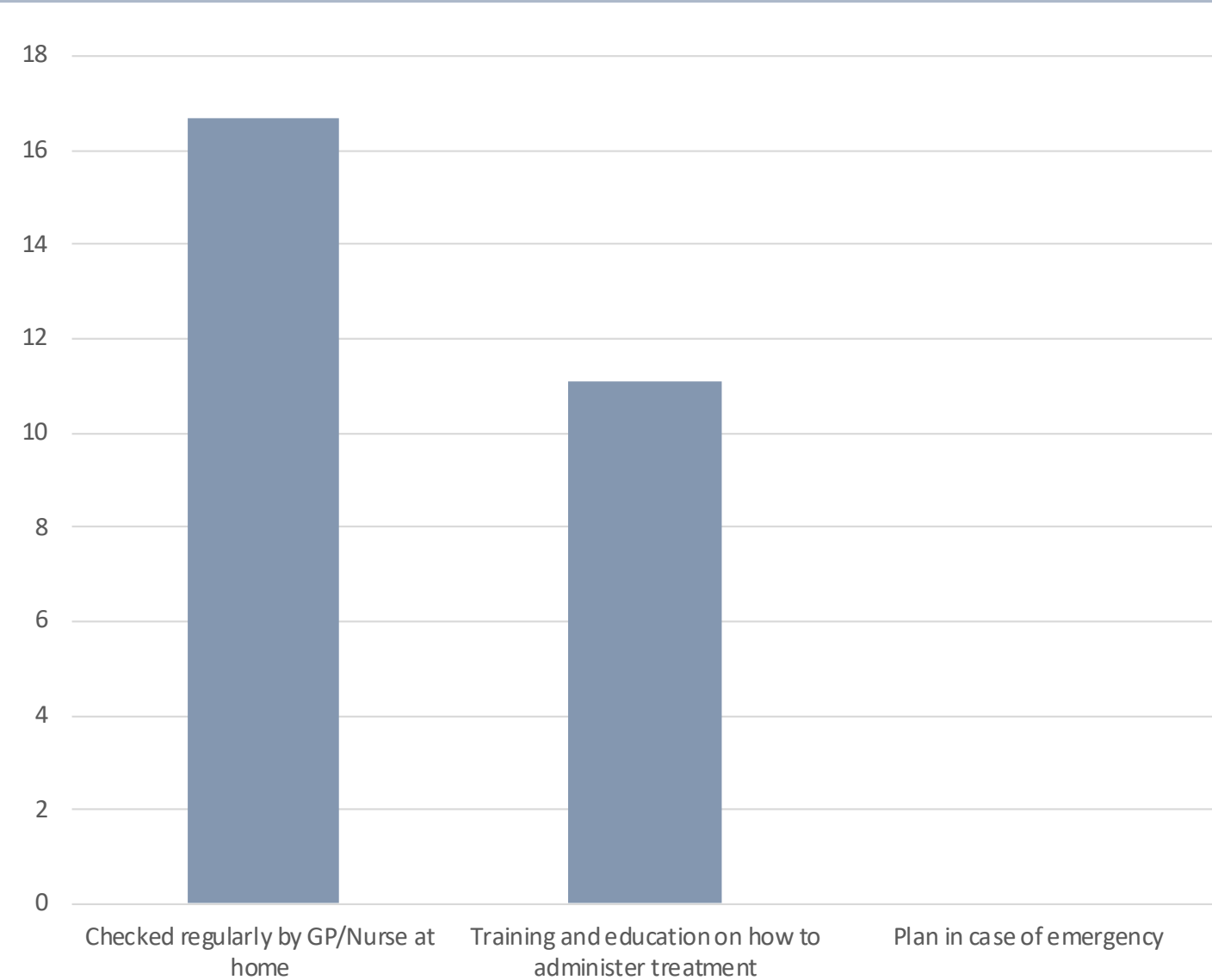
Section 5

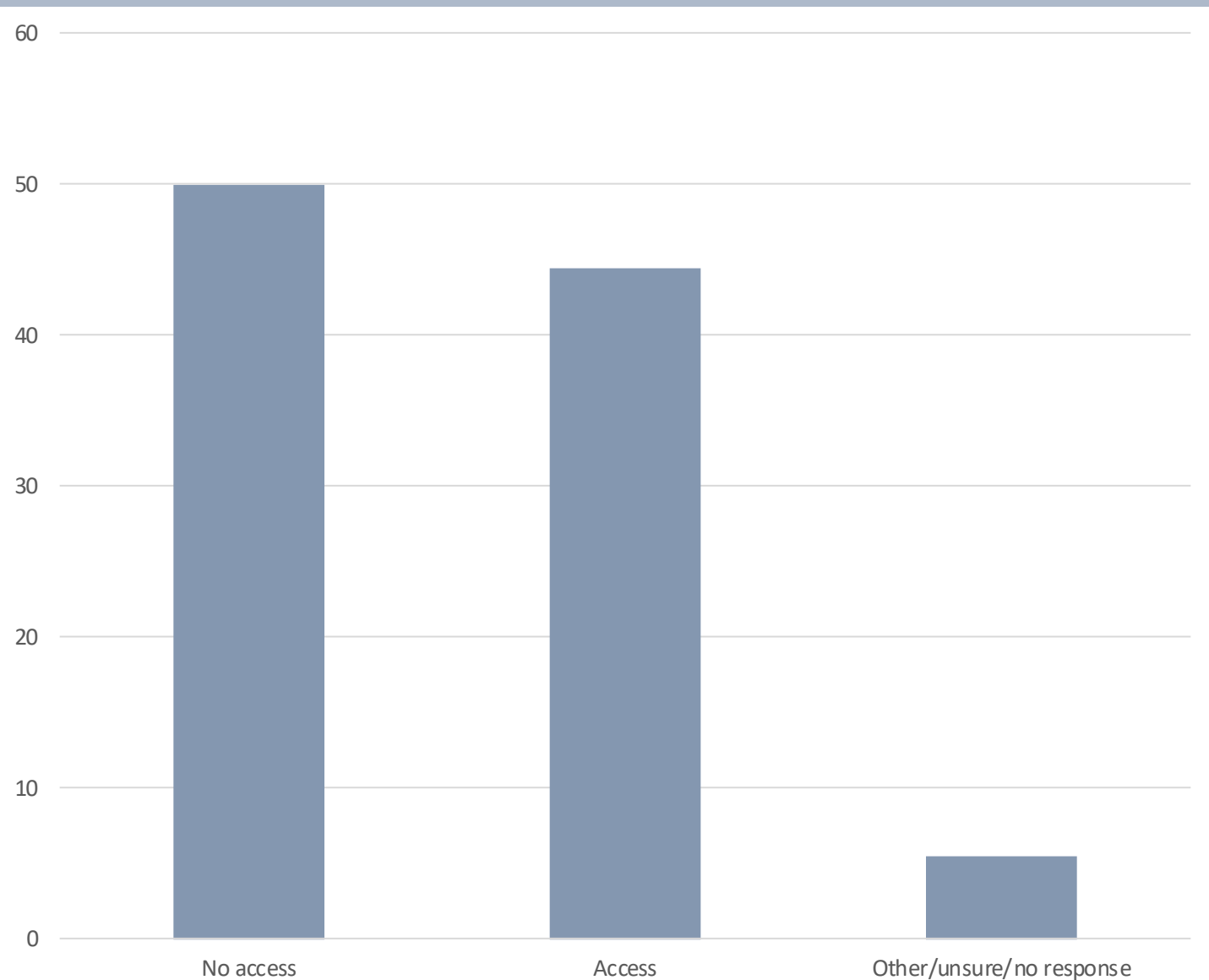
I think the only way is to have a nurse or a doctor around. Participant NMO_001

If there was a nurse or whatever that was there with you just to make sure you were doing it correctly. Participant NMO_012

I don't know about anxiety because before I would agree to it, I would've done all my research. [laughs] I have probably a good understanding of it and probably maybe some trials at hospital prior to doing it at home. Participant NMO_015

Just the training and support in just knowing that you are administering it correctly. I think as long as I knew what I needed to do I'd be comfortable enough. Participant MOG_008





No, don't think so. Participant NMO_012

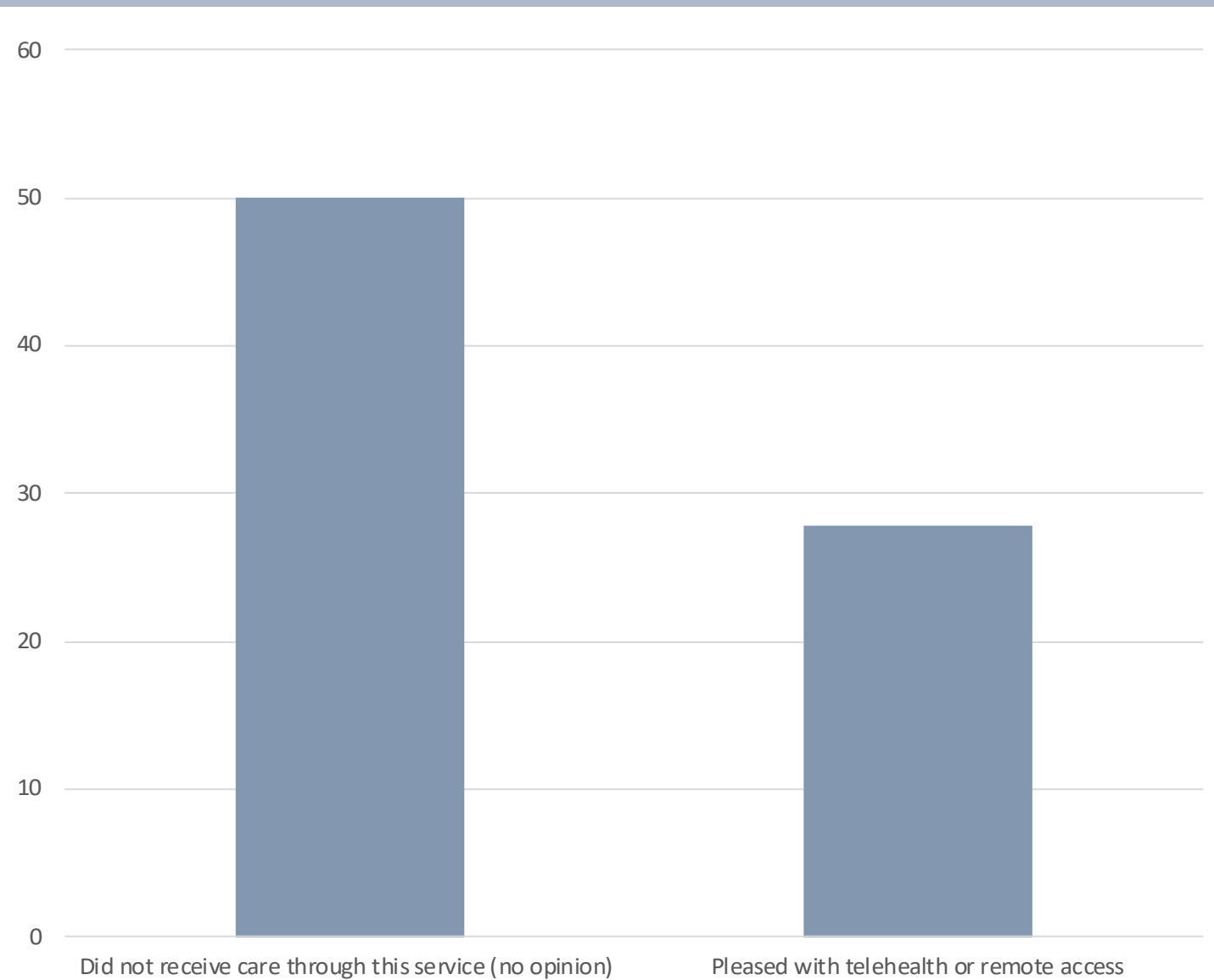
All of our conversations have been via phone really. Participant NMOCA_002

I did psychologically, a psychologist when COVID was on. I did telehealth and I also had two, three sessions with an OT who was a specialised OT for driving assessments because I needed to apply for hand controls. She did assessment on like a Zoom. NMO_006

Yes, we had like for her haematology and I think it was gynaecology because some of them are not often, like haematology is once a year, and then because it was during the COVID, we had to have it on telehealth, those calls. Participant NMOCA_006



Section 5



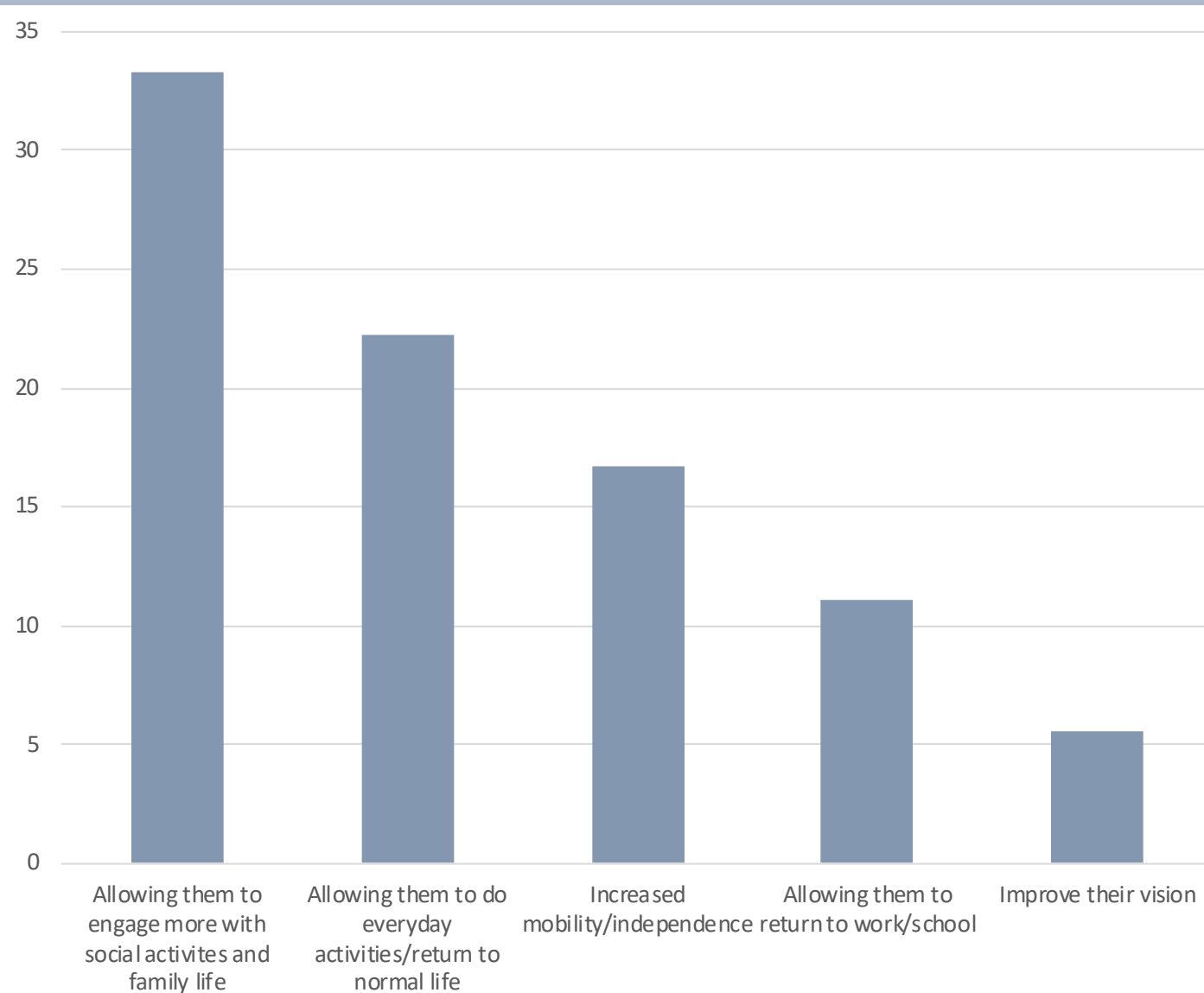
Oh, very good and very easy. Convenient and easy. Participant NMO_001

Yes, that's been really good. The first time I did it, it was a little bit difficult, sort of getting used to logging in and all that sort of stuff, but it was fine. Participant NMO_009

Just recently, I did a lot of physio through telehealth with COVID. I've had specialist appointments, which I had to go. It's good. No problems. Participant NMO_010



Section 5



If I didn't have fatigue, I would probably be able to spend a lot more energy with my children. There's some days where I just come home from my uni and go straight to bed at like 4:00 O'clock, and my partner kind of has to pick up the slack a lot just because I don't have the energy. Participant NMO_003

Just live my normal life. Participant NMO_014

That I can still see or I can still walk. It's just those things. I'm grateful for that I can still see something. As well as still walk and be able to pick up things. Participant NMO_012

Well, obviously, I haven't been able to work. I can't work because I don't have the stamina anymore. Even one phone conversation will exhaust me. The ability for treatment to give my life back to me. Participant NMO_004



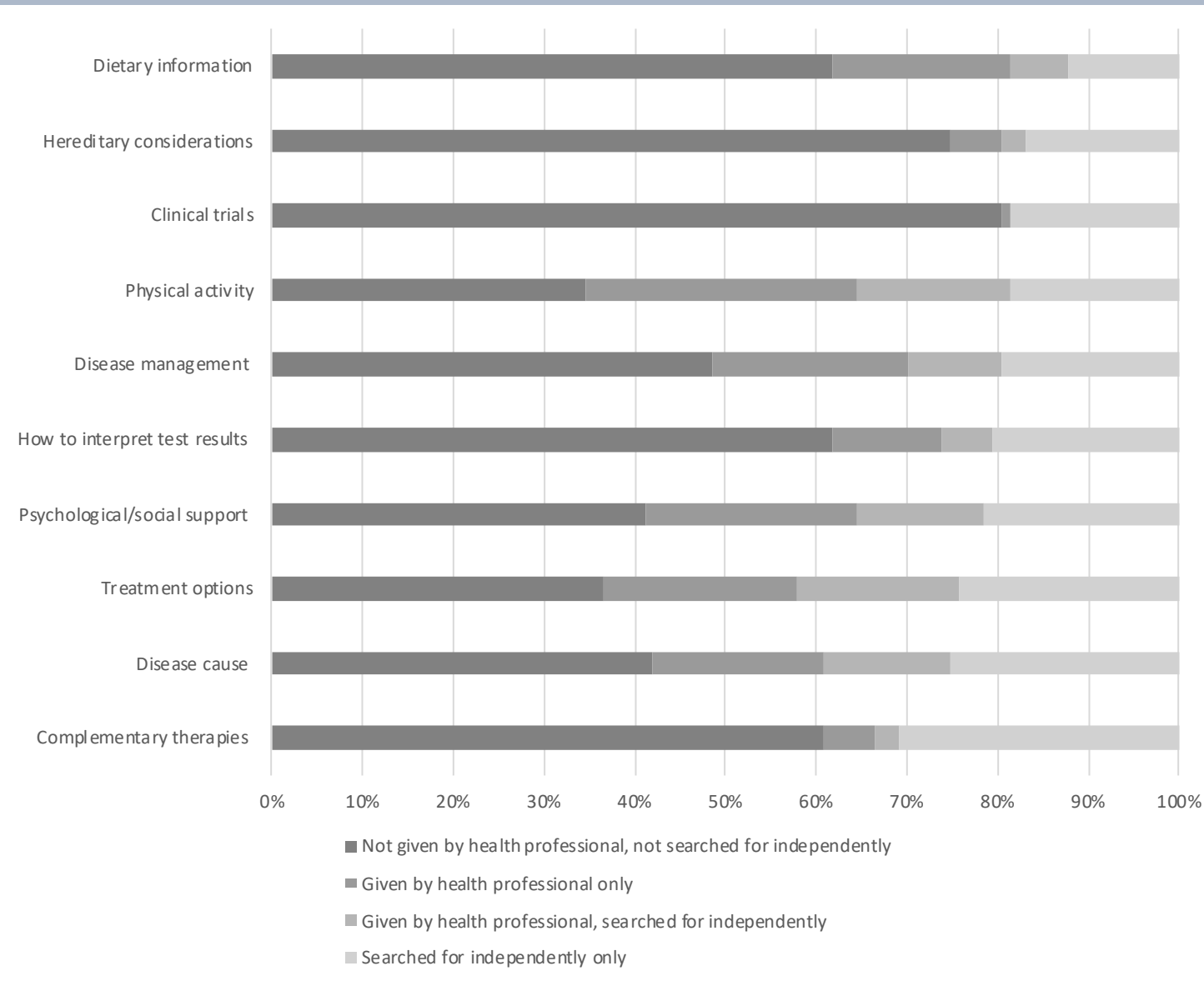
Section 6



Communication
&
Information

This section report access to information, information that was helpful and information that was not helpful, when participants feel they were most receptive to receiving information, information preferences, information topics for which information was received or searched for, as well as when it was received and additional information was required. This is also where there is information about healthcare professional communication and participant's knowledge and confidence in managing their own health using the Partners in Health tool.





Information given and searched for

Treatment options, Physical activity, Psychological/social support, and Disease cause

Information given and not searched for

Physical activity, Psychological/social support, Treatment options, and Disease management

Information not given and searched for

Complementary therapies, Disease cause, Treatment options, and Psychological/social support

Information not given and not searched for

Dietary information, How to interpret test results, Hereditary considerations, and Clinical trials



Partners in health scale (n=18)	Mean	SD	Possible range	Quintile
Partners in health: knowledge	23.00	5.39	0 to 32	4
Partners in health: coping	11.50	5.94	0 to 24	3
Partners in health: recognition and management of symptoms	17.72	4.07	0 to 24	4
Partners in health: adherence to treatment	12.89	2.68	0 to 16	5
Partners in health: total score	65.11	13.87	0 to 96	4

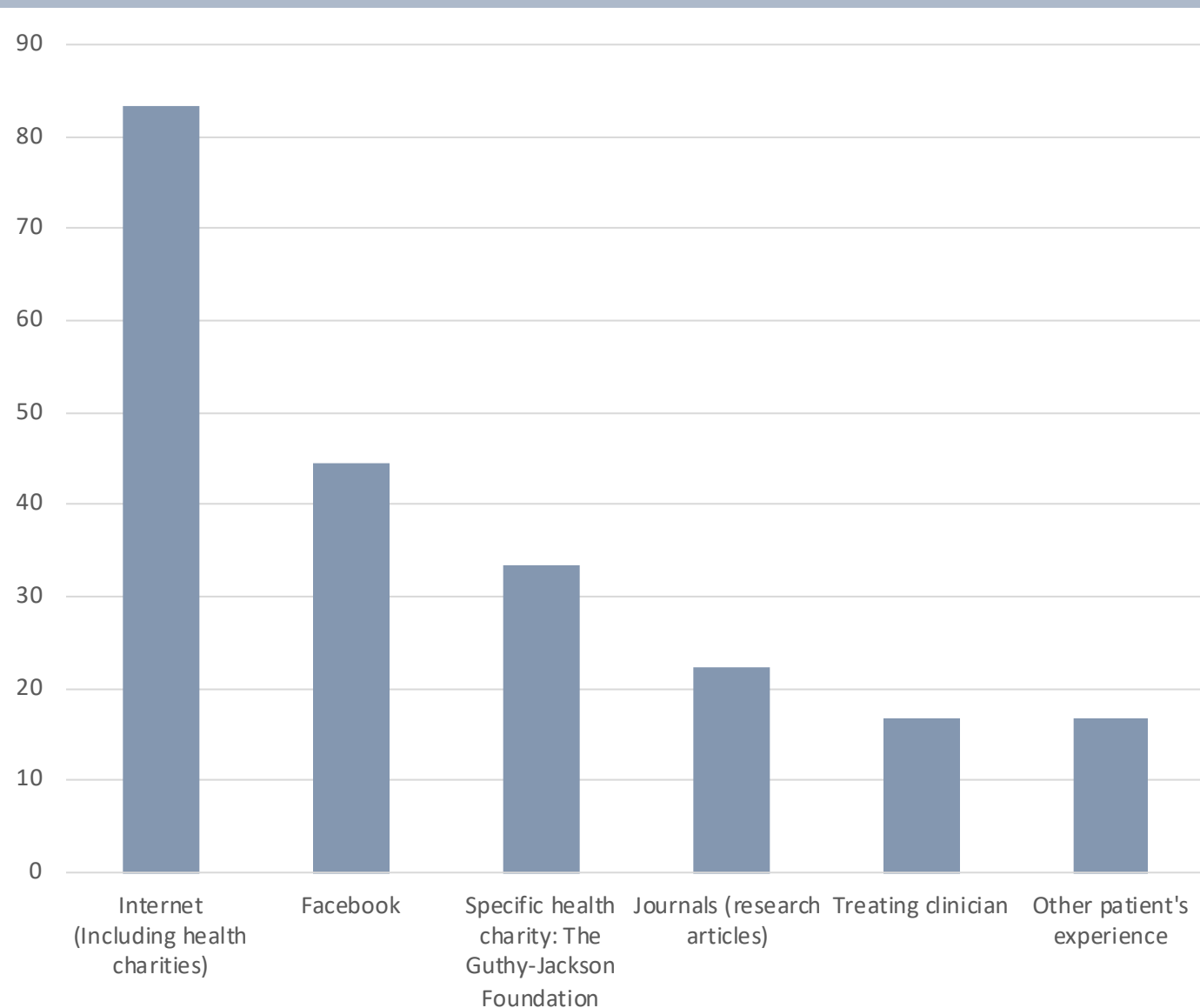
The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. **On average participants in this study had excellent overall knowledge, coping and confidence for managing their own health.**

Section 6

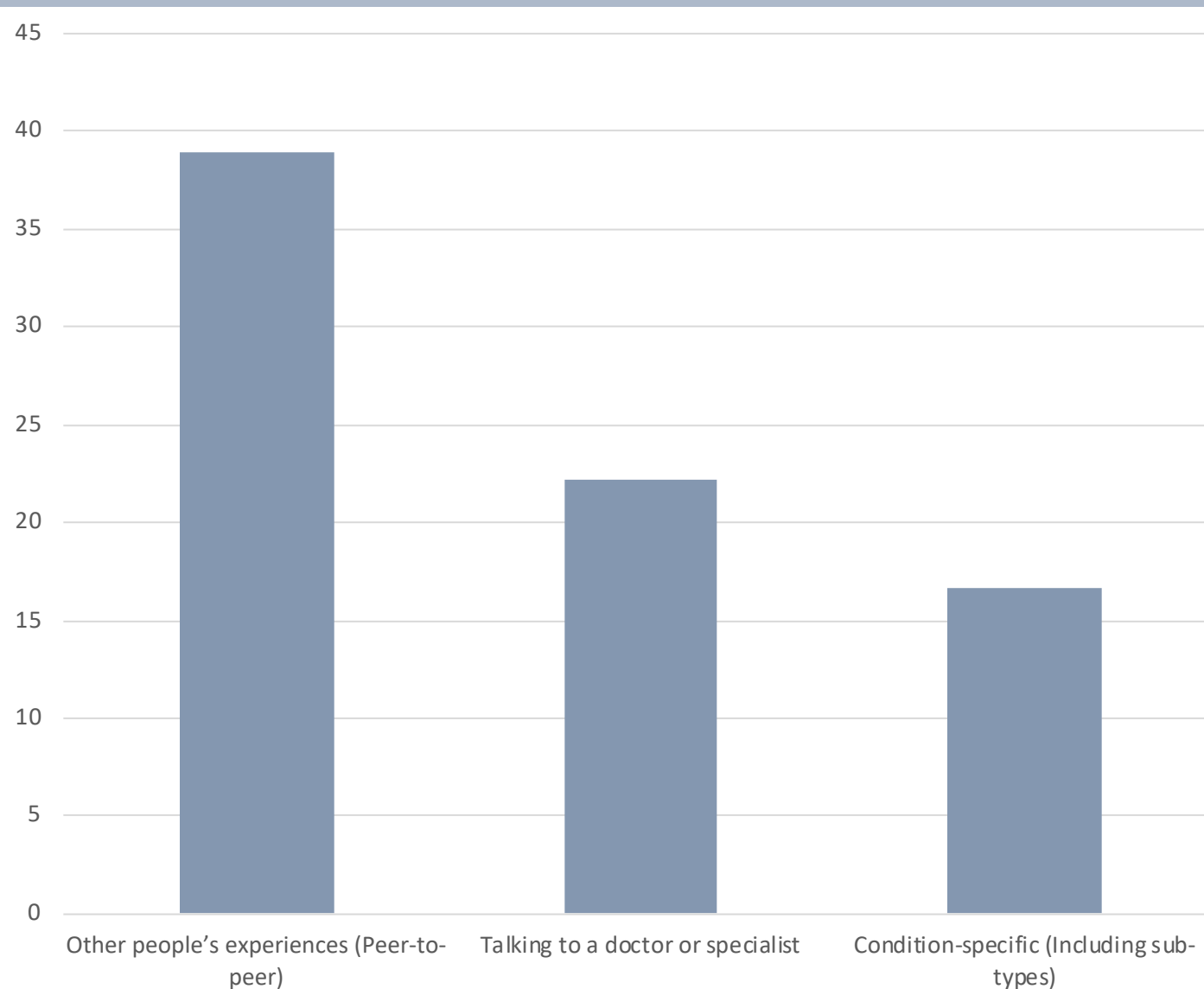
Mainly Google. I sought out possible causes. I sought out whether vaccines have anything to do with it. That's just recent. I sought out diets that might be good. That's just recent too. Participant NMO_002

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

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



Section 6

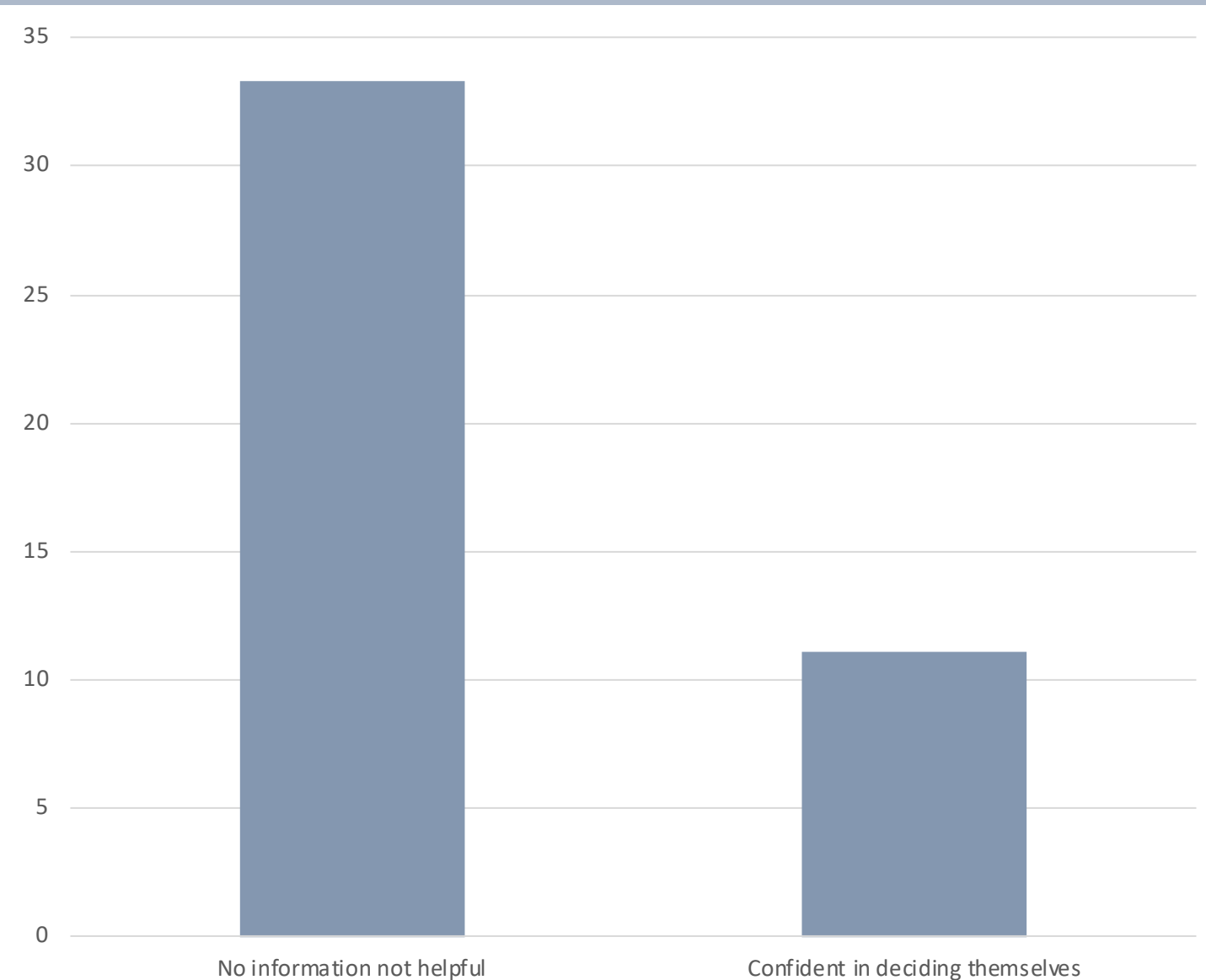


Knowing that there's somebody else with it was quite good. That was the best thing for me initially. I suppose it was knowing that people don't die from it. Some people have died from it but it's not the predominant type thing. That there is other people that have been in this situation and it was good 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

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



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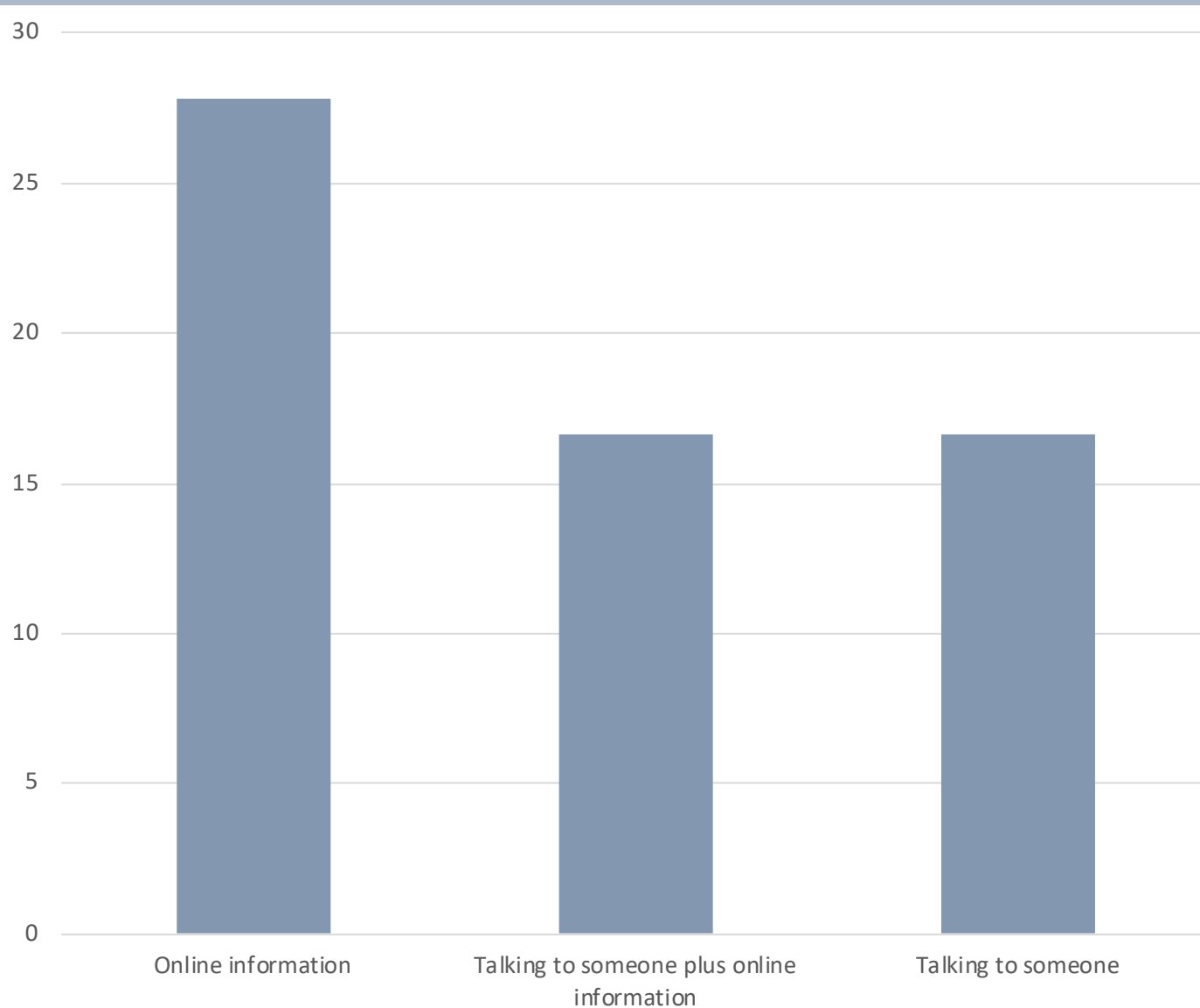
No, not really, especially the Facebook page that everything's positive, I think it's run by two nurses on there as the admin and they watch what everyone says, but yes, everything's been good.. Participant NMO_009

No, not really. 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



Section 6



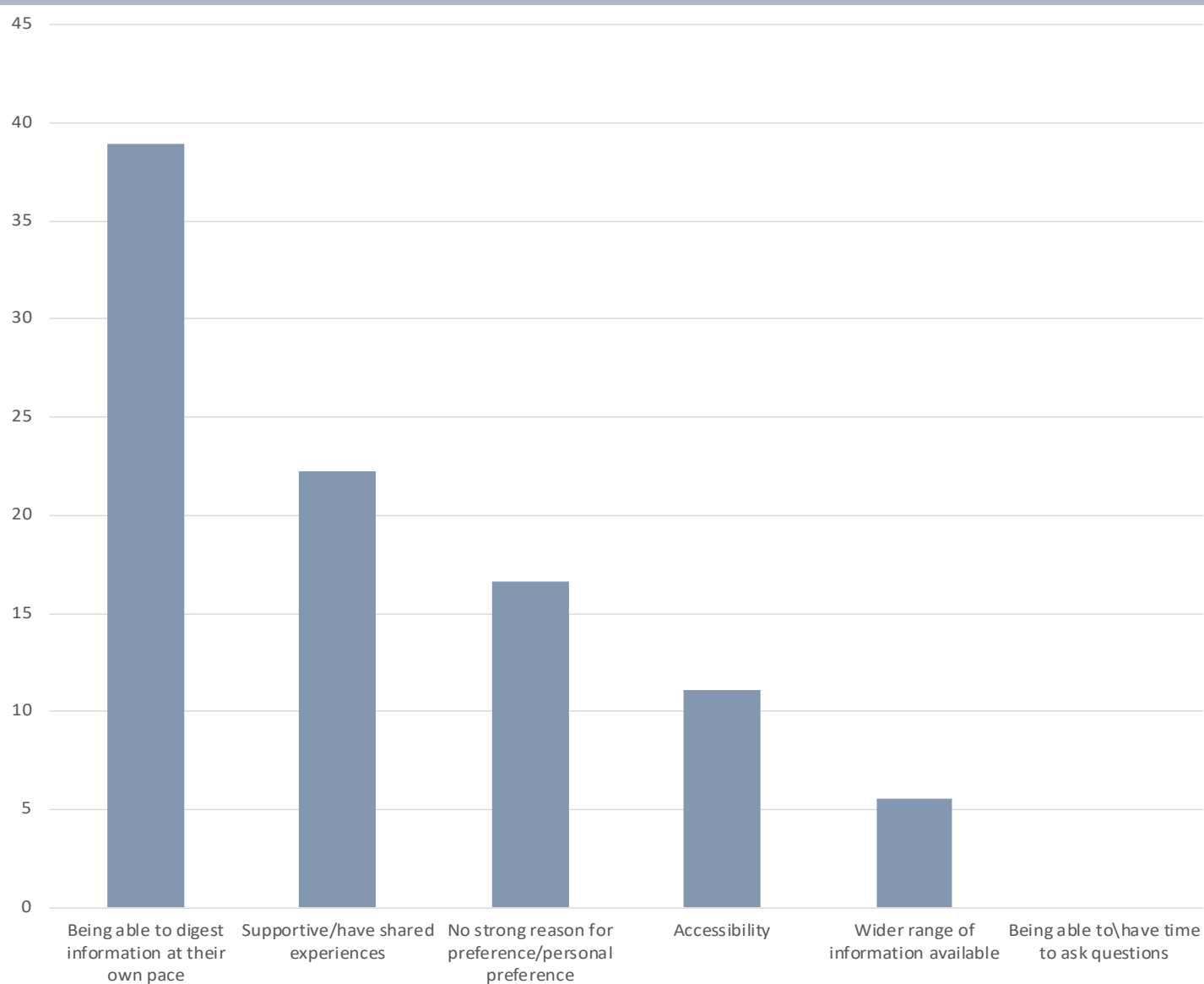
I like to read online because I like to do it in my own time where I can take breaks and stuff if I'm upset by something. I haven't had a lot of good experiences talking to my specialists or doctors about NMO, but I don't really get much information on it. Participant NMO_010

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

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



Section 6



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

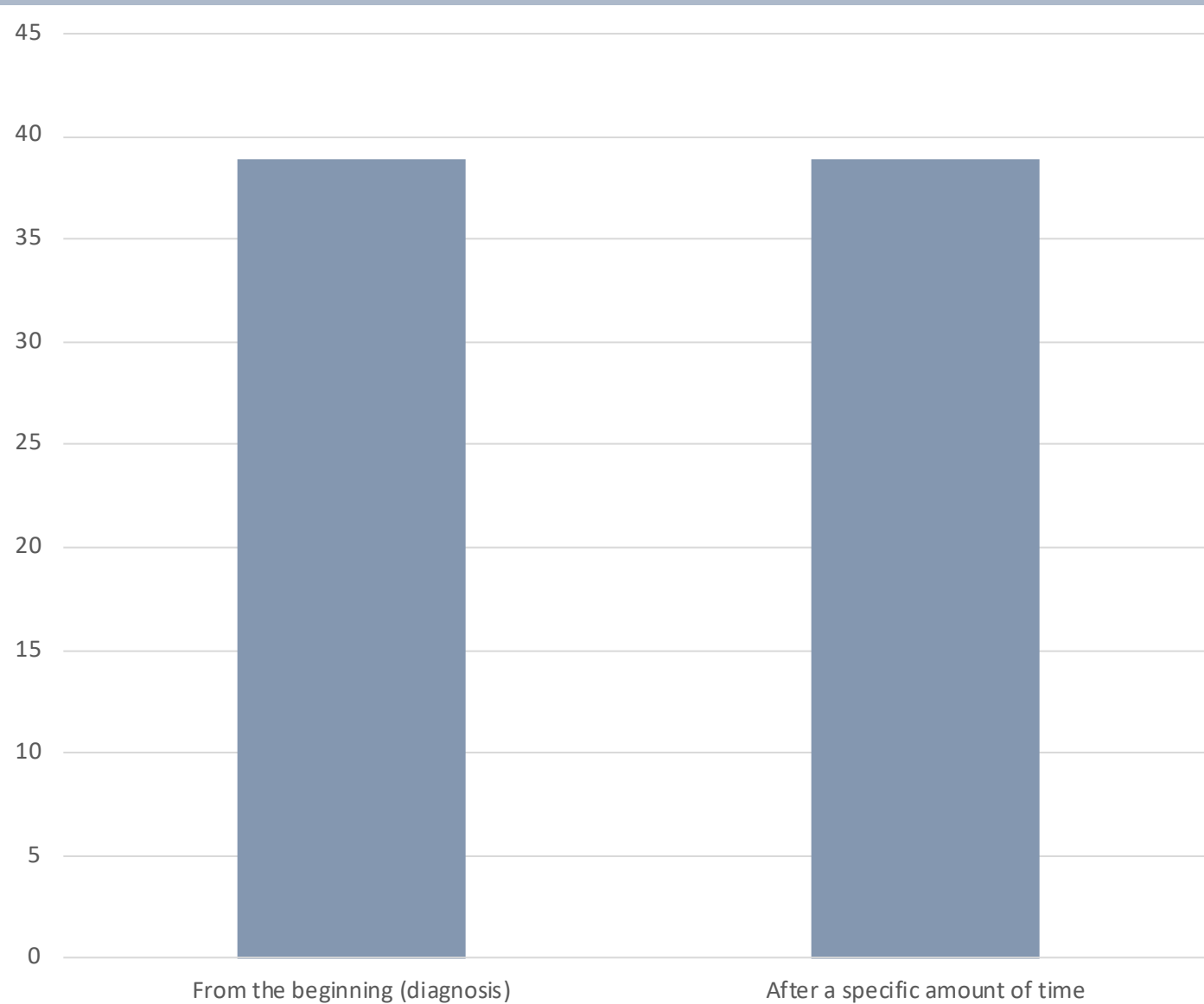
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Online is brilliant if you can read it and print it out and just have readily access to it. Participant NMO_014



Section 6



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 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 NMOCA_005

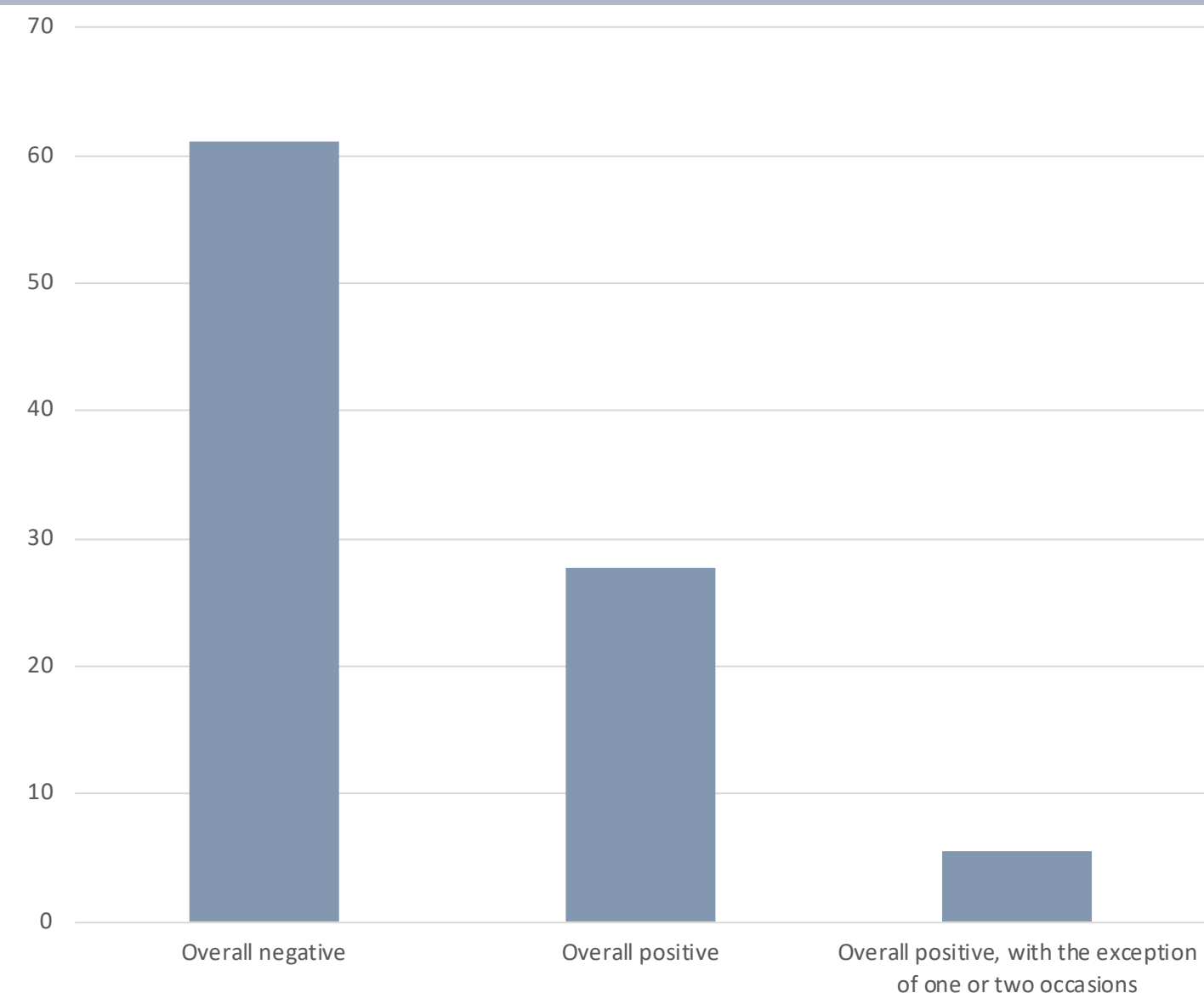


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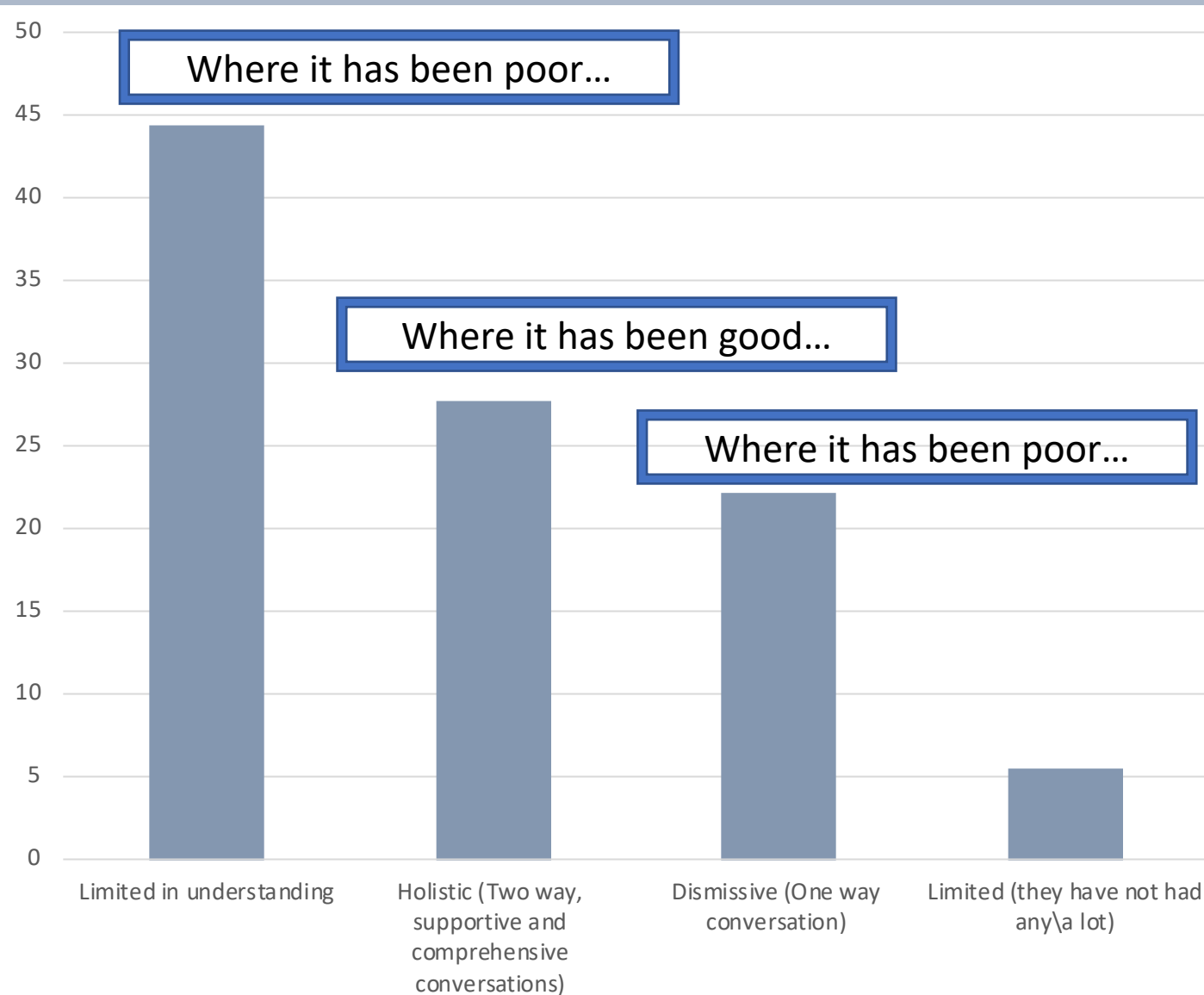
Very little knowledge out there and lack of discussion more than anything. I felt like saying to my GP, "Have you actually Googled my disease and read anything about it?" Participant NMO_014

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

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



Section 6



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

Being good with my immunologist. It's great to have some in-depth discussions. Participant NMO_002

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



Section 7



Care
&
Support

A Care Coordination questionnaire tool is used and reported in this section to demonstrate how people have been able to navigate the health system. There is also information about the care and support people have received, including from the charity sector.



Care coordination scale (n=18)	Mean	SD	Median	IQR	Possible range	Quintile
Communication	30.94	8.54	29.50	6.00	13 to 65	2
Navigation*	20.56	4.84	21.50	5.00	7 to 35	3
Total score*	51.50	11.16	52.00	13.50	20 to 100	2
Care coordination global measure*	5.67	2.20	6.00	2.00	1 to 10	3
Quality of care global measure	6.00	2.50	6.00	3.75	1 to 10	3

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

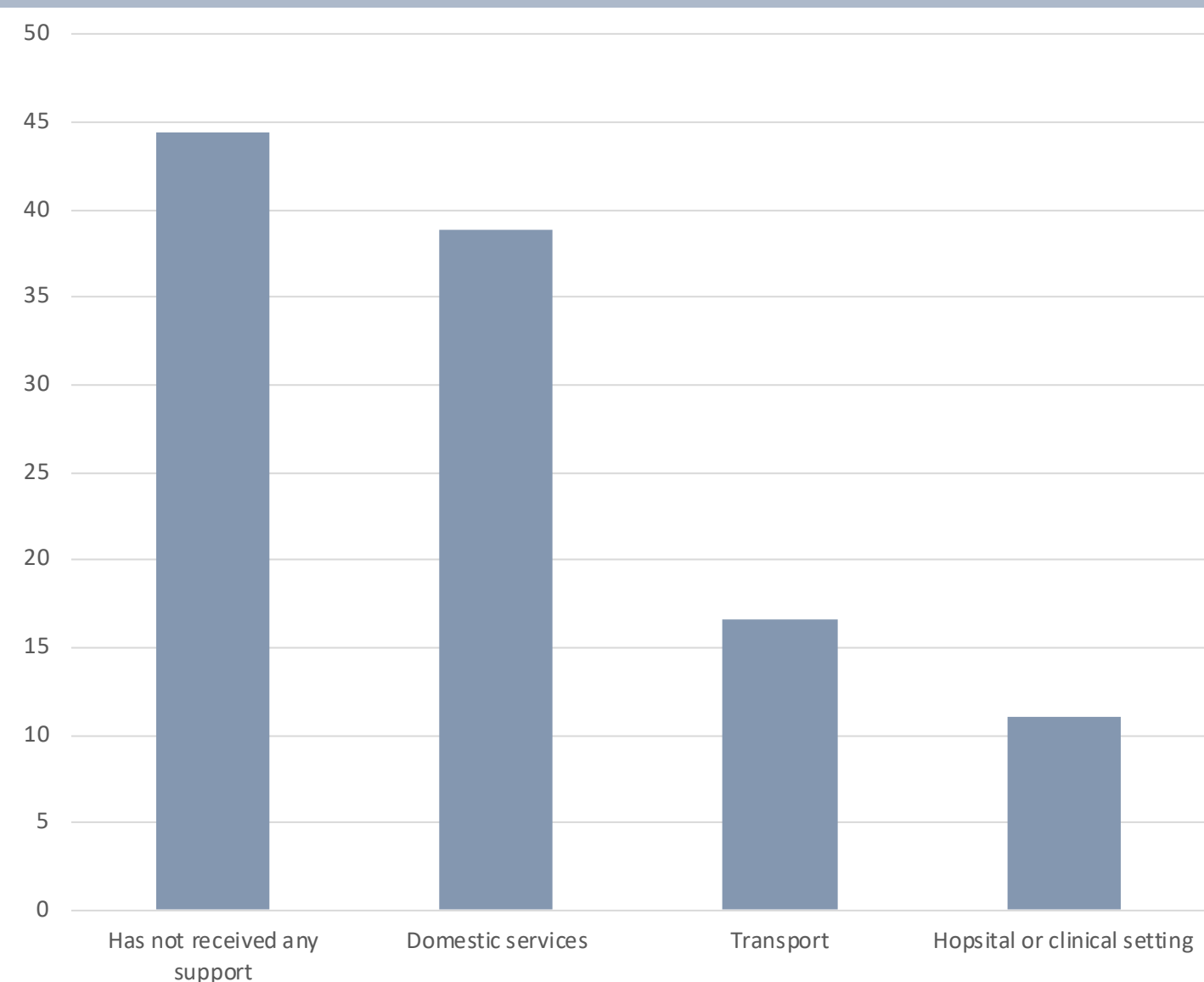
The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. **The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.**

Section 7

None, from nowhere. Participant NMO_003

Only through NDIS. I get a gardener, I get a cleaner once a fortnight. I get my exercise physiology through NDIS. NDIS has really been my lifesaver. Participant NMO_004

They have been quite good, but seeing that we've had COVID, I only had one to two weeks of going out shopping and feeling like I was normal again, and then bloody COVID hit. [laughs] I haven't really been able to get out and about, but they have been taking me to my hospital appointments and doctors' appointments. The transport, it's really good having that service there. Participant NMO_012



Section 8



Quality of Life

In this section, information is available in relation to the impact that the condition or disease has on quality of life, regular activities to maintain mental health, regular activities to maintain physical health, impact on relationships, impact on family and relationships, cost considerations. The Fear of Progression tool is used and reported here to describe the level of anxiety that participants may have in relation to their condition.

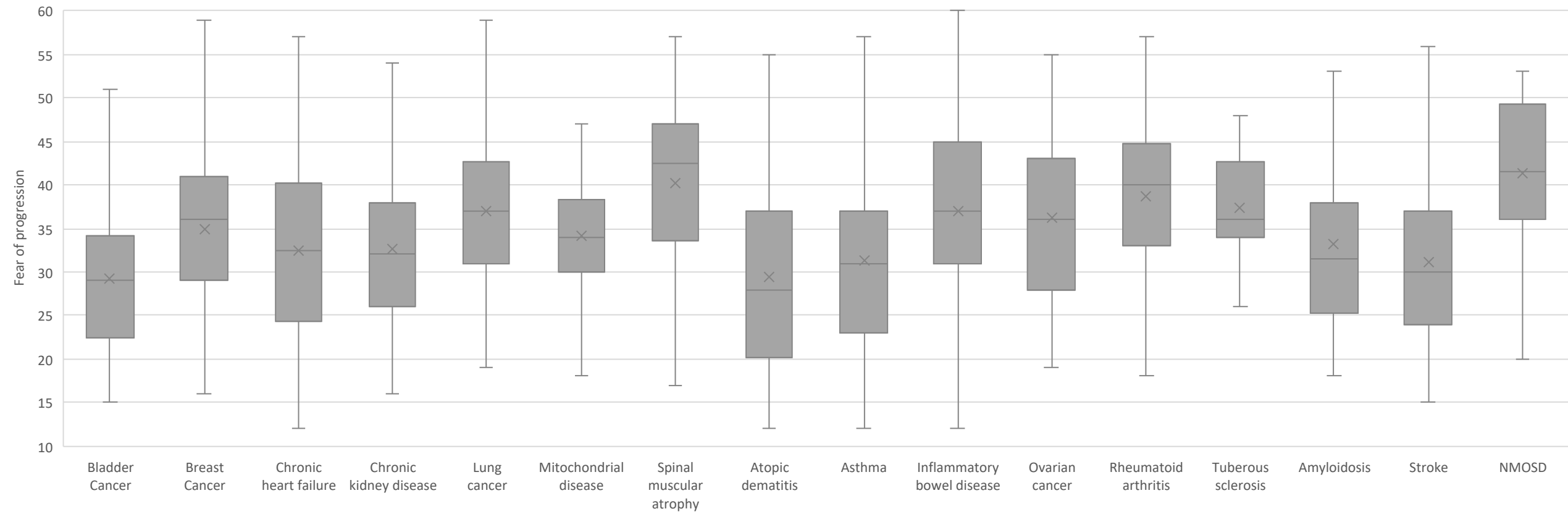


Fear of progression	Mean	SD	Possible range	Quintile
NMOSD (n=18)	41.33	8.90	12 to 60	4

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. **Overall, the cohort had a median total score of 41.33 (IQR = 8.90), which corresponds to high levels of anxiety.**



Fear of progression



Fear of progression

PEEK study	NMOSD
Bladder cancer	0.0003*
Breast cancer	0.0143*
Chronic heart failure	0.0058*
Chronic kidney disease	0.0019*
Lung cancer	0.0894
Mitochondrial disease	0.0066*
Spinal muscular atrophy	0.6878
Atopic dermatitis	0.0004*
Asthma	0.0011*
Inflammatory bowel disease	0.1387
Ovarian cancer	0.0796
Rheumatoid arthritis	0.3032
Tuberous sclerosis	0.1492
Amyloidosis	0.0085*
Stroke	0.0006*

Pairwise comparisons using Wilcoxon rank sum test with continuity correction

NMOSD significantly higher fear of progression scores (more anxiety) compared to:

- Bladder cancer
- Breast cancer
- Chronic heart failure
- Chronic kidney disease
- Mitochondrial disease
- Atopic dermatitis
- Asthma
- Amyloidosis
- Stroke



Fear of progression

Fear of progression (n=18)	Never to sometimes		Often and Very often	
	N	%	N	%
I become anxious if I think my disease may progress	13	50.00	13	50.00
I am nervous prior to doctor's appointments or periodic examinations	16	61.54	10	38.46
I am afraid of pain	18	69.23	8	30.77
I have concerns about reaching my professional and/or personal goals because of my illness	8	30.77	18	69.23
When I am anxious, I have physical symptoms such as a rapid heartbeat, stomach ache or agitation	20	76.92	6	23.08
The possibility of my relatives being diagnosed with this disease disturbs me	14	53.85	12	46.15
It disturbs me that I may have to rely on strangers for activities of daily living	14	53.85	12	46.15
I am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	4	15.38	22	84.62
I am afraid of severe medical treatments during the course of my illness	16	61.54	10	38.46
I worry that my treatment could damage my body	12	46.15	14	53.85
I worry about what will become of my family if something should happen to me	8	30.77	18	69.23
The thought that I might not be able to work due to my illness disturbs me	12	46.15	14	53.85
If I am on a treatment and it is working well for me (limited side effects, no progression of disease), I worry what will happen if I stop treatment	14	53.85	12	46.15
I become anxious if I am not experiencing any side effects of treatment as it makes me think that the treatment isn't working	25	96.15	1	3.85

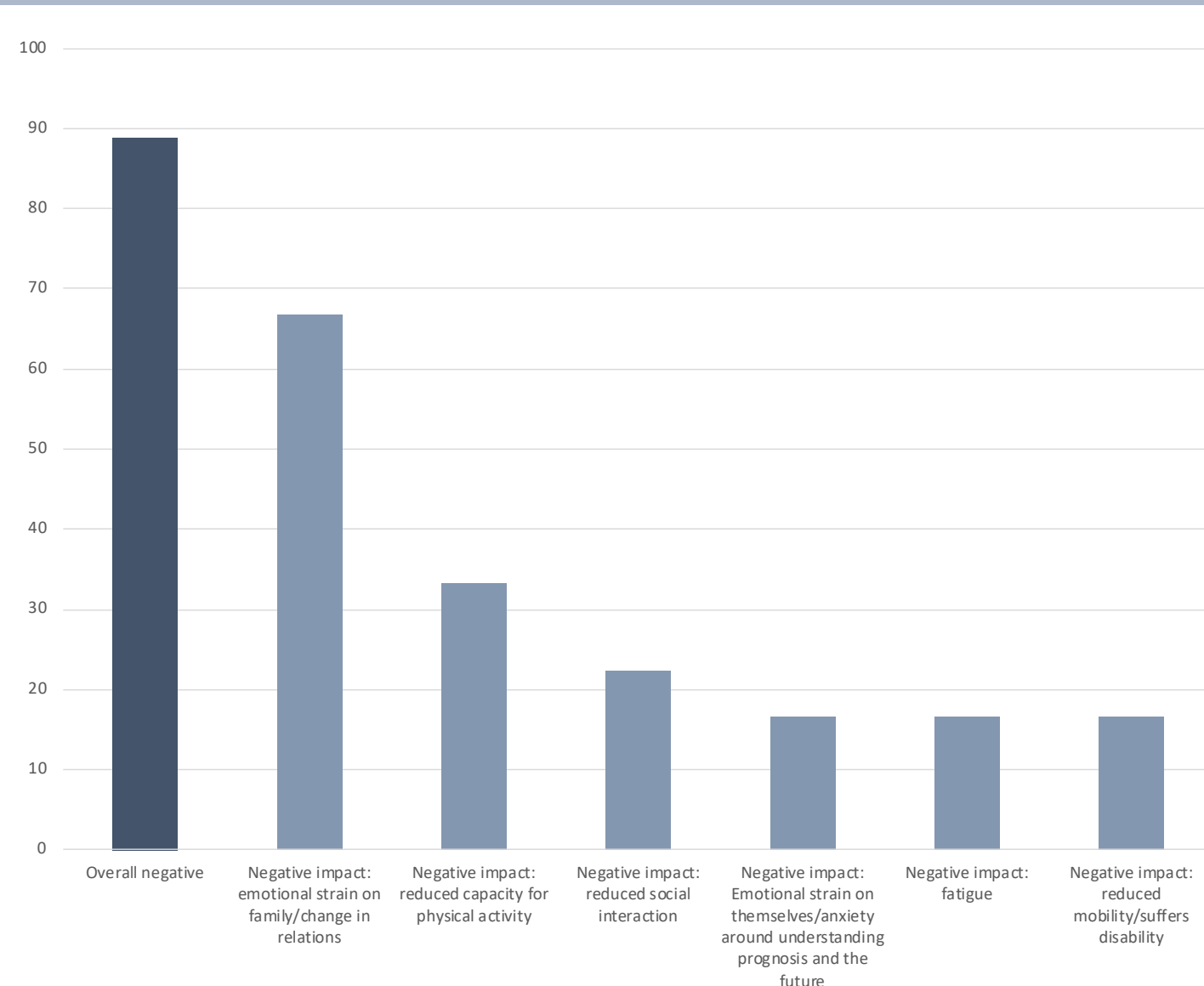


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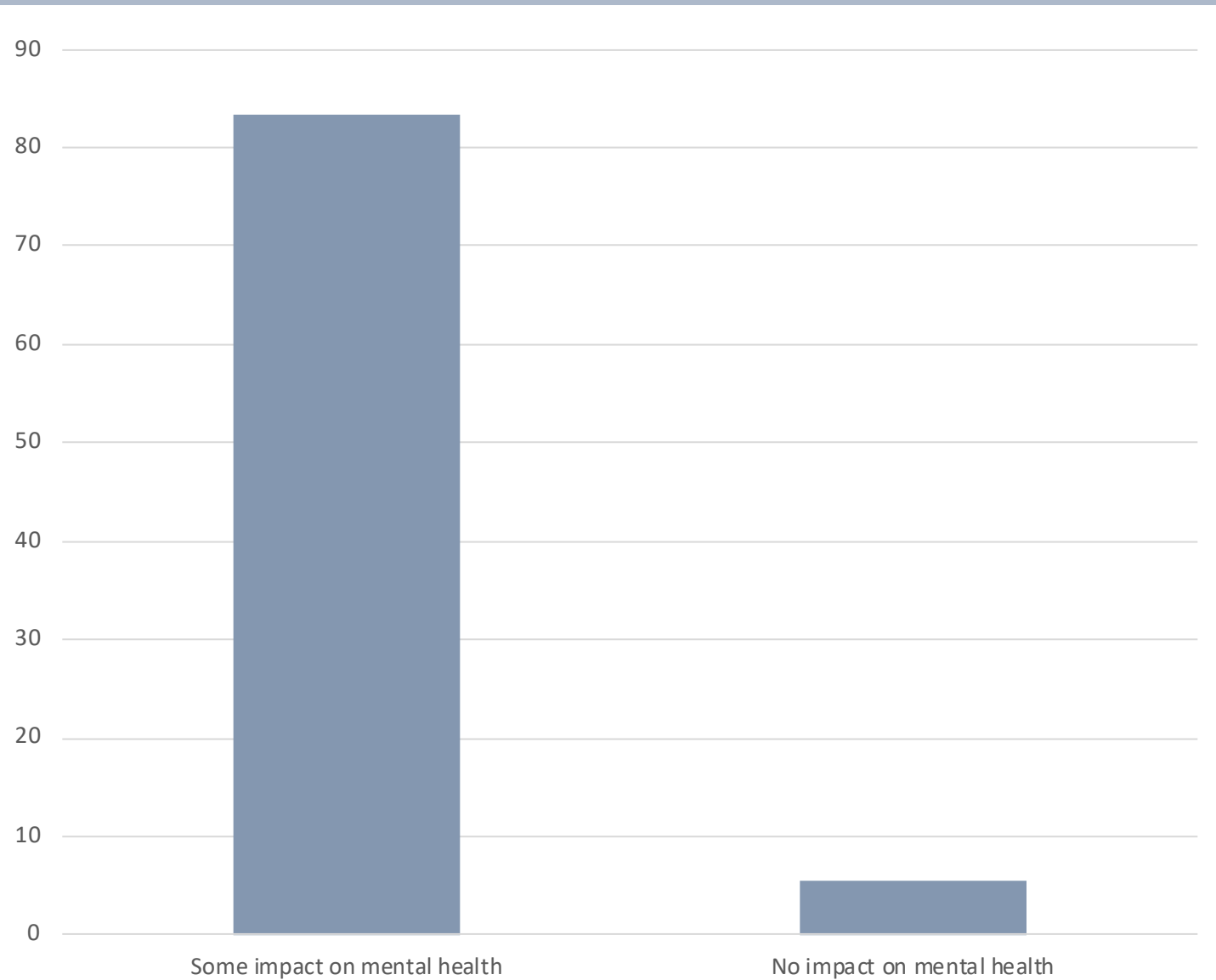
Sure. Pretty much I can't do the things as much, like the housework and all of those things. Looking after my son and enjoying time with him, but having said that, it's just the stress of it as well on the family. I have been sick for quite some time so it's been quite difficult in that regard. Participant NMO_008

My quality of life is that I have to now depend on everybody, where before I was very independent. Participant NMO_013

It has because they're always, when we go anywhere, it's, "Be careful here. Be careful here. There's a bump on the footpath. Watch out you don't fall over." They're always like, "Am I all right?" To see that I haven't fallen over and things like that. Participant NMO_007



Section 8



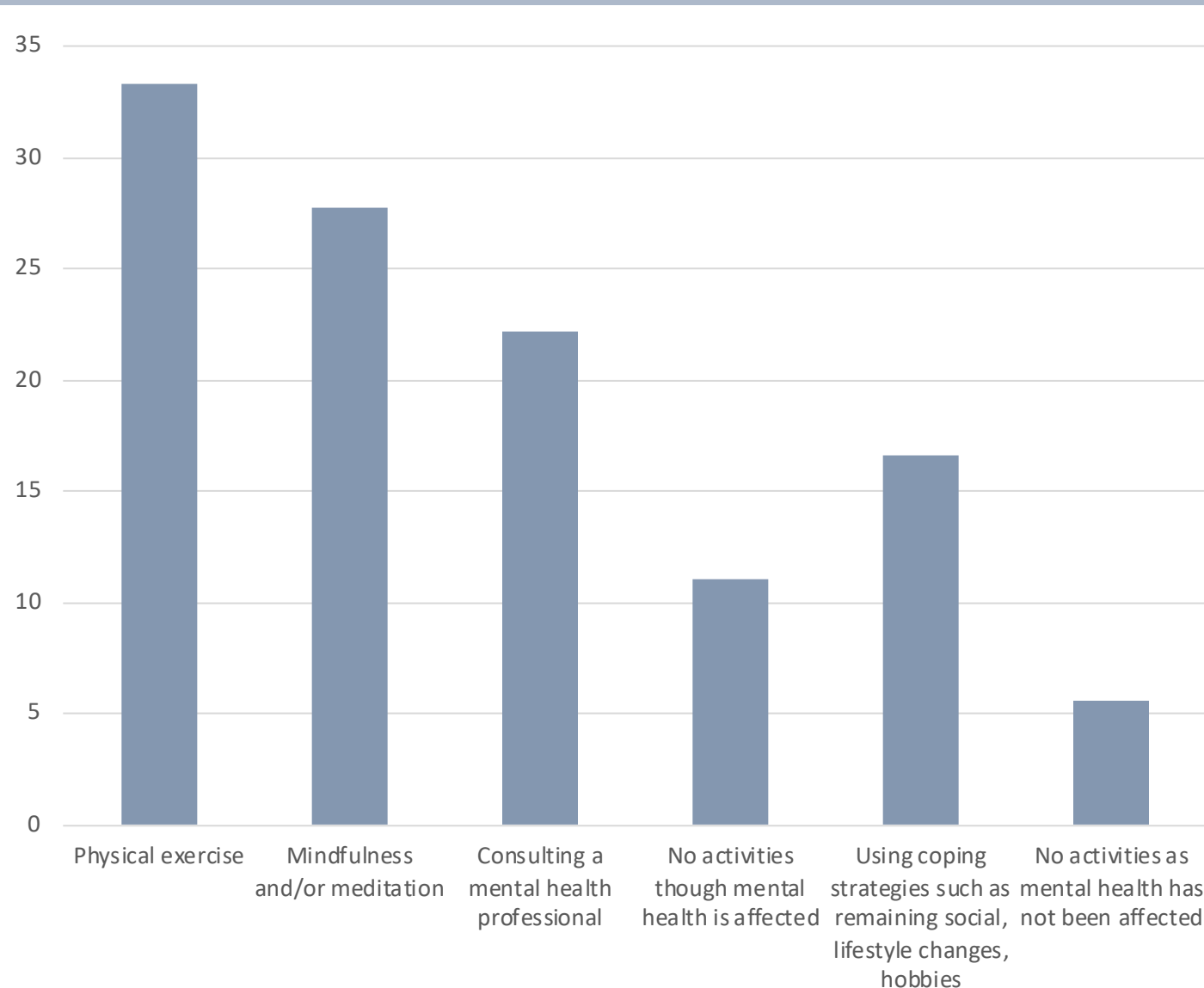
When I first got sick with all this, it was horrendous. I would have cried every day and I didn't really know what to do about it. It took a few years for me to accept that. Participant NMO_010

It's quite depressing sometimes, especially when I get to the stage where it spasms up my whole body. I've got to lay on a bed and then my mind's telling me, "You got to get up. You got to get up. You can't lay in bed" type thing. Participant NMO_013

I don't think it's affected either of us I don't know how it's changing if symptoms become more severe, but I think he's just taking it day by day and just trying to do the best we can, but so far we have been fine. Participant NMOCA_003



Section 8



Exercise and trying to keep my life as normal as I can, when I can. Participant NMO_001

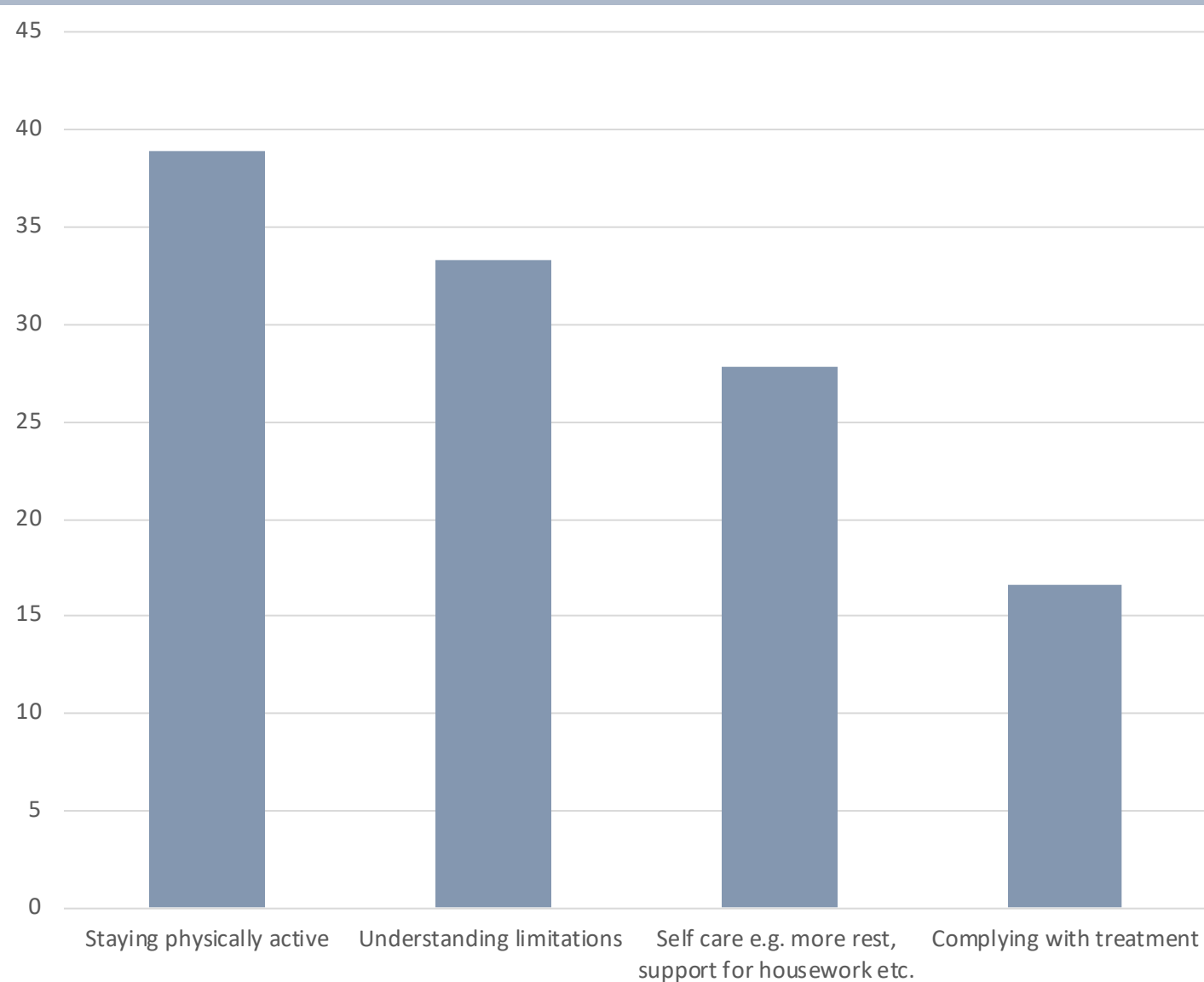
I do see psychologists. I do see my psychologist and I do mindfulness meditation. I've been meditating for quite a long time and trying to do something that I enjoy every day. Participant NMO_001

It completely effects your mood. Like I have massive mood swings that I can't control, and it's just difficult because everyone's moving forward with their lives around me, and I feel like I'm stuck. Participant NMO_005

To look after my mental health, I pretty much just put music on and drown my own thoughts. Participant NMO_012



Section 8



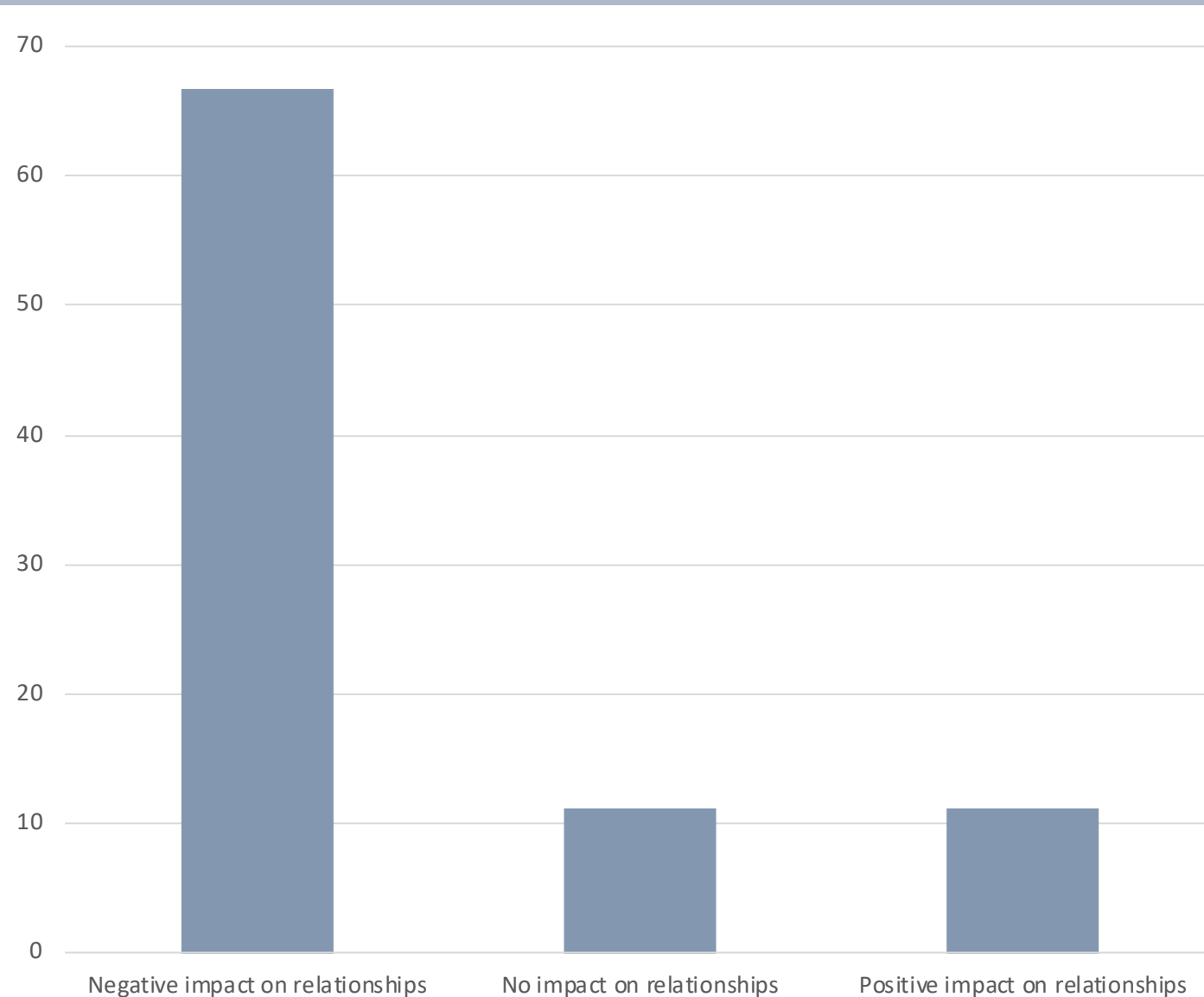
I go to the gym. I try to go to the gym every day, but some days I guess I can't. I just try and live a normal life, and I just try and disregard that I have this condition basically, yes. Participant NMO_003

I have to manage my body, so I have to listen to what my body says. If I push my body too much, it will get worse. Participant NMO_013

Pretty much, if I want to do something in particular, I might just go down the street and just have a bit of a look at the shops. I will make sure that I lay down and just rest, not be stressed, or anything like that, but just rest on the lounge. I don't have to sleep but that's the only way. I've got to really rest every bit of my body, to know, "Okay, I've got to find that energy to reach out to be able to go and do that." That's the only way that I can function. If I know something's coming up that I have to go to, but sometimes it doesn't always help. Participant NMO_012



Section 8



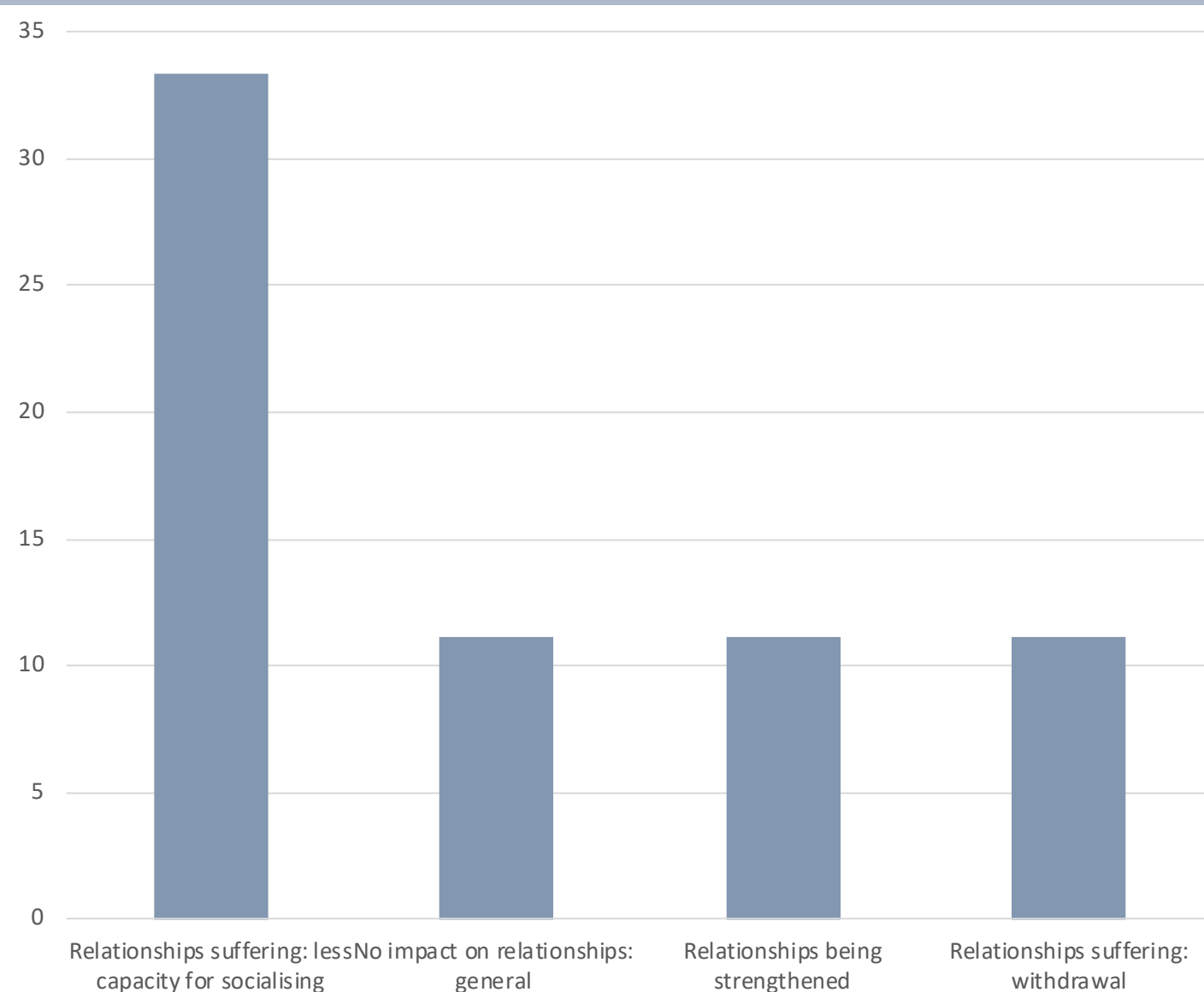
Yes, definitely. I've lost friends over it because people don't understand it. I lost my husband. It definitely affects relationships and it's definitely affected the quality of my life. Participant NMO_004

No, not at all. My friends know and they're 100% supportive. They regularly ask, "How are things going?" Participant MOG_007

No. I think it's made it stronger. I think it's made me a stronger person, and I think it's made our relationships stronger, and I think you have a different outlook about life, and about any worries that were insignificant. I just let it go now, because it's not worth it. Participant NMO_017



Section 8



My family, yes, a little bit, I used to spend a lot of time with my nephews and nieces looking after them, and now I just don't have the energy to do that. I think my family understands that I don't have the energy, that I'm not just avoiding them or whatever. Participant NMO_010

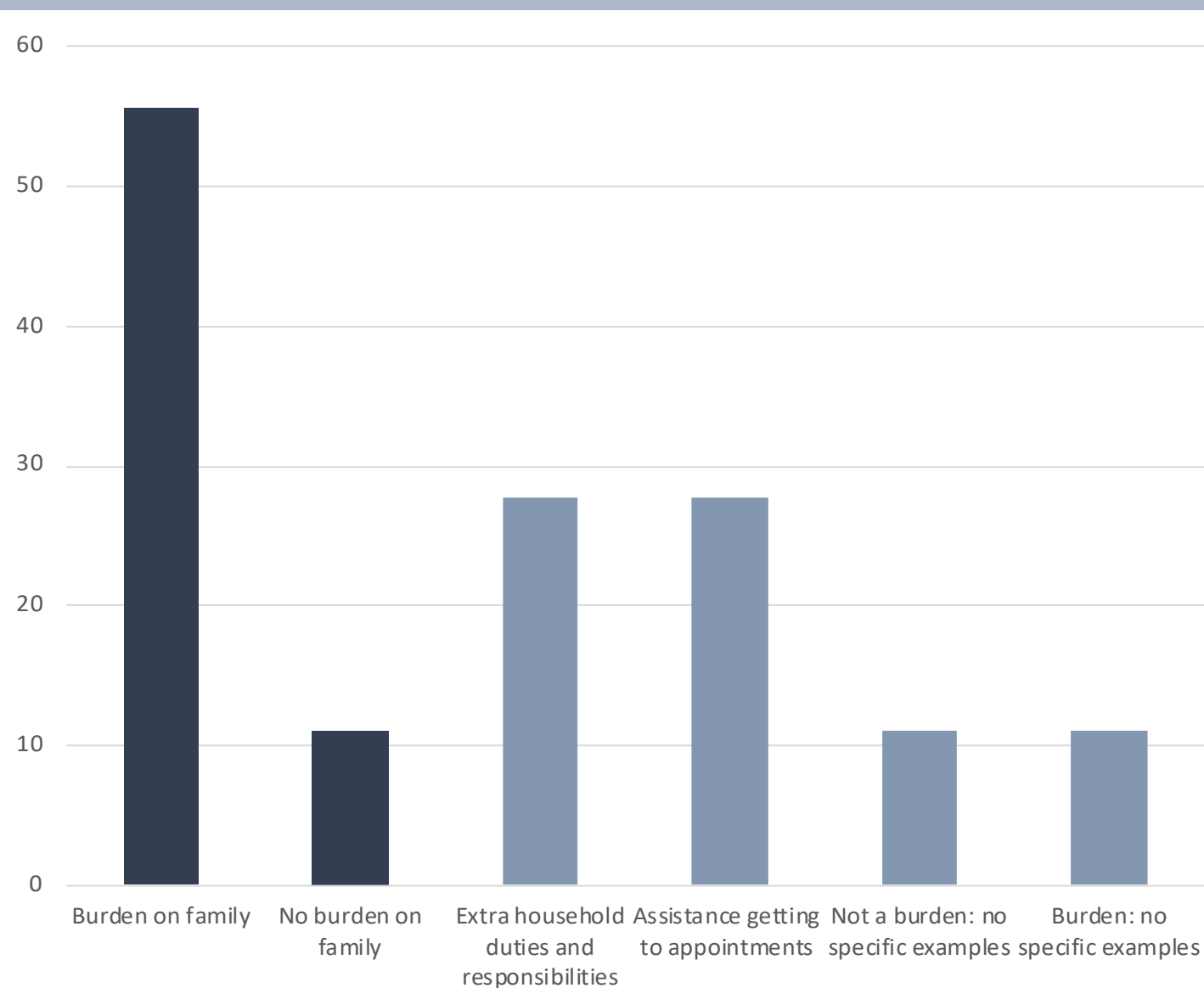
No. Participant NMO_015

I think more good than bad. Everybody has been very supportive including at his work. Participant NMOCA_003

I think so. Some friends, they just don't want to hear. If you just need to get something off your chest, or whatever, that's something about you, what you're feeling, some people just go, "All right. Here she goes again." Participant NMO_012



Section 8



Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Participant NMO_005

That's an interesting question. It's a different direction for our family, there's no doubt about that. As far as a burden, it's the cards we've been dealt, so we make the best of that. No one is annoyed at providing any assistance with that.. Participant NMOCA_004

It is. Yes. It's probably a burden on my husband, because when I have different treatments, obviously you can't drive after treatments or different things. He has to-- because he still works. Participant NMO_013



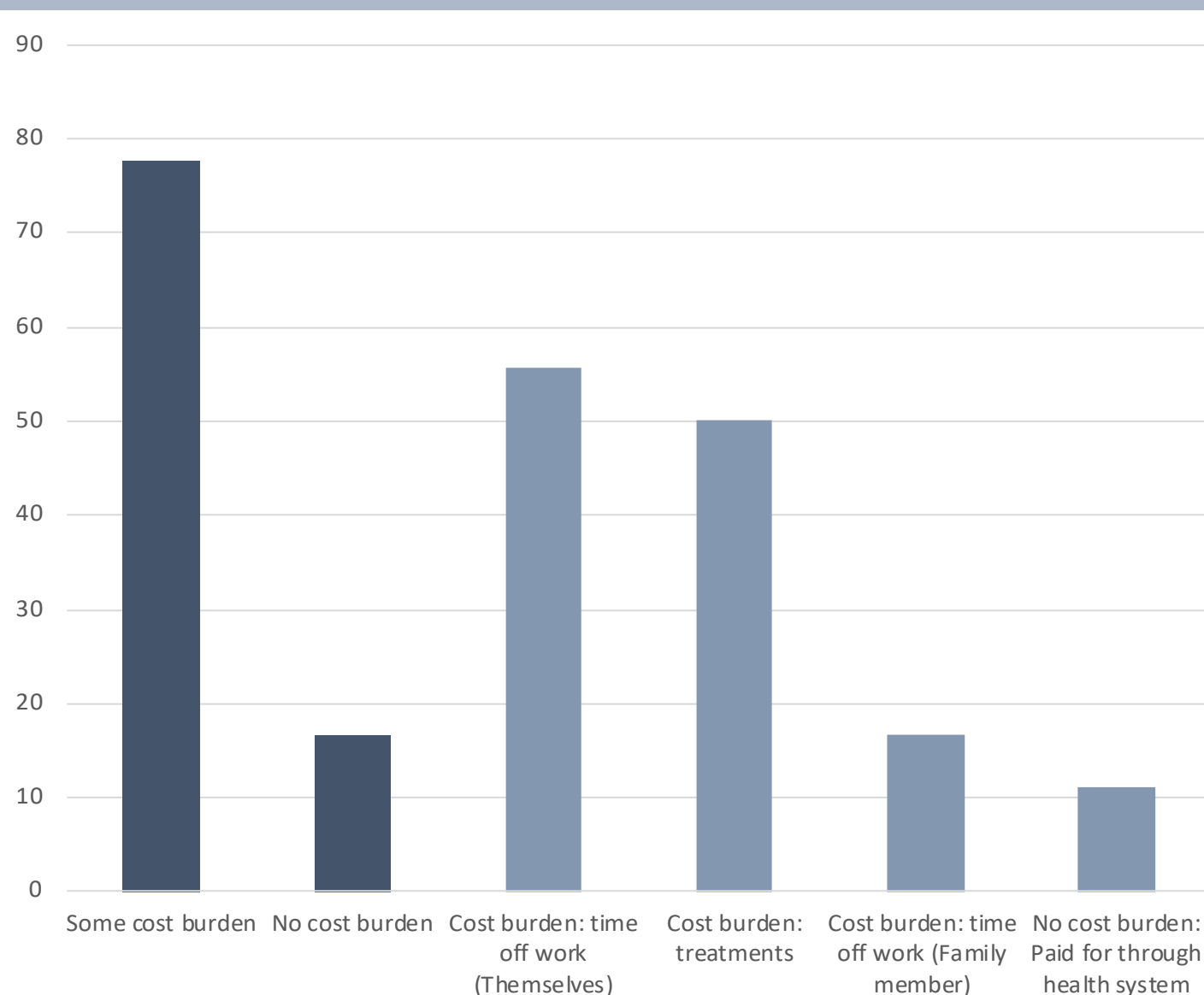
Section 8

Obviously, I lost my job, my career, so that was pretty big financial burden. Participant NMO_003

Oh. I've lost my job. I don't work now. That's had a huge impact on our lives. My husband is working two jobs to keep the house, the mortgage and all those kinds of things. Participant NMO_006

I've really had no cost associated with it because I've gone public the whole time. Even my MRIs are all done at a hospital, I don't pay for them. Participant NMO_017

I was just sent to the neuro physio and I didn't have to pay for that, but all the medications and everything I had to pay for. Participant NMO_010



Section 9

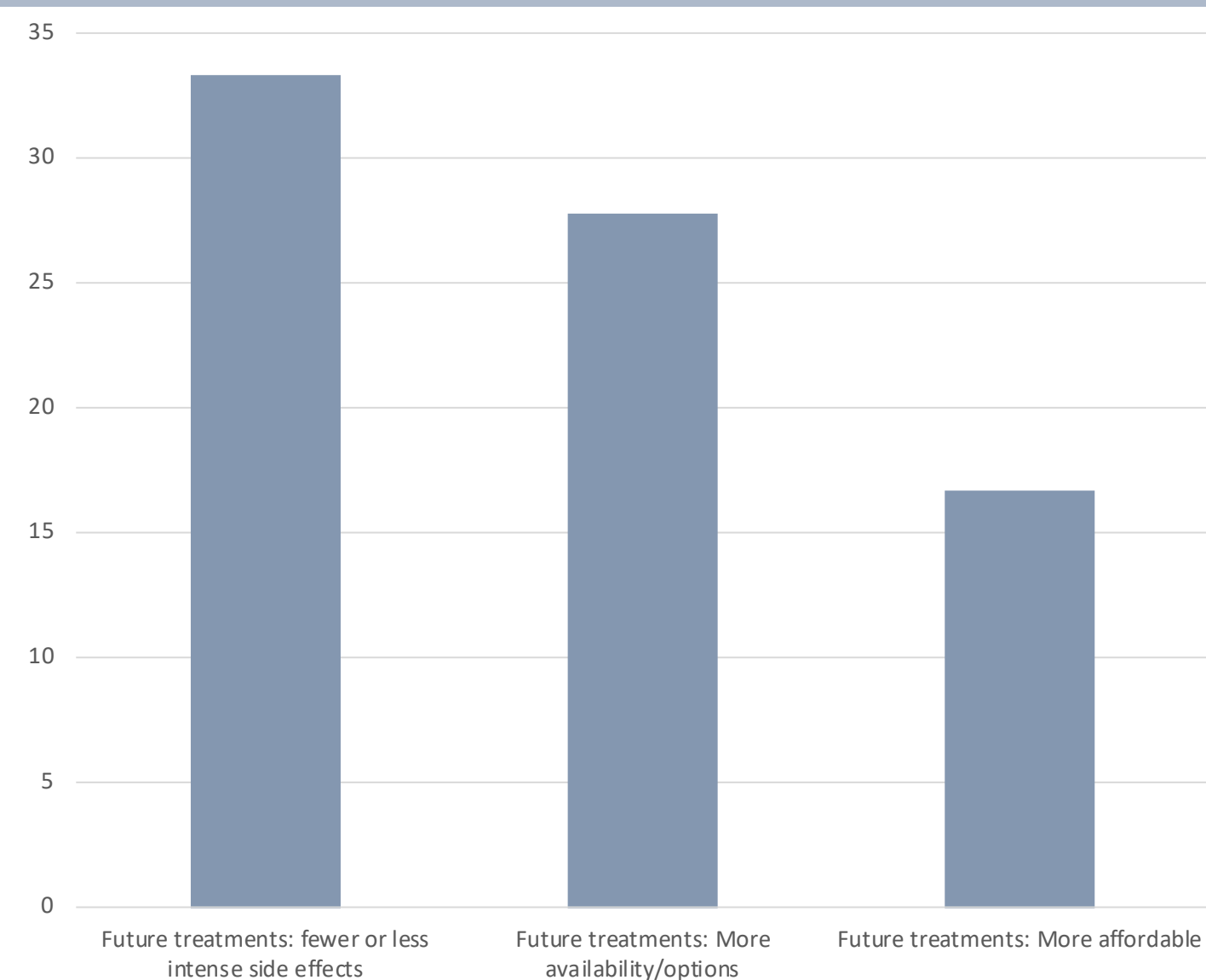


Expectations & Messages to Decision-Makers

By the time participants are asked questions about their expectations of the future, they have had the chance to talk about everything that they have been through. It means that they have been able to reflect on what worked for them and what was potentially not so great. In this section there is information about what participants would like to see from future treatments, information, care and communication. We present the cohorts message to decision-makers about their condition and the values that are important to them when they make decisions about treatment and care. In this section there is also information about what people have been grateful for.



Section 9



Well, less side effects would be fantastic. Participant NMO_016

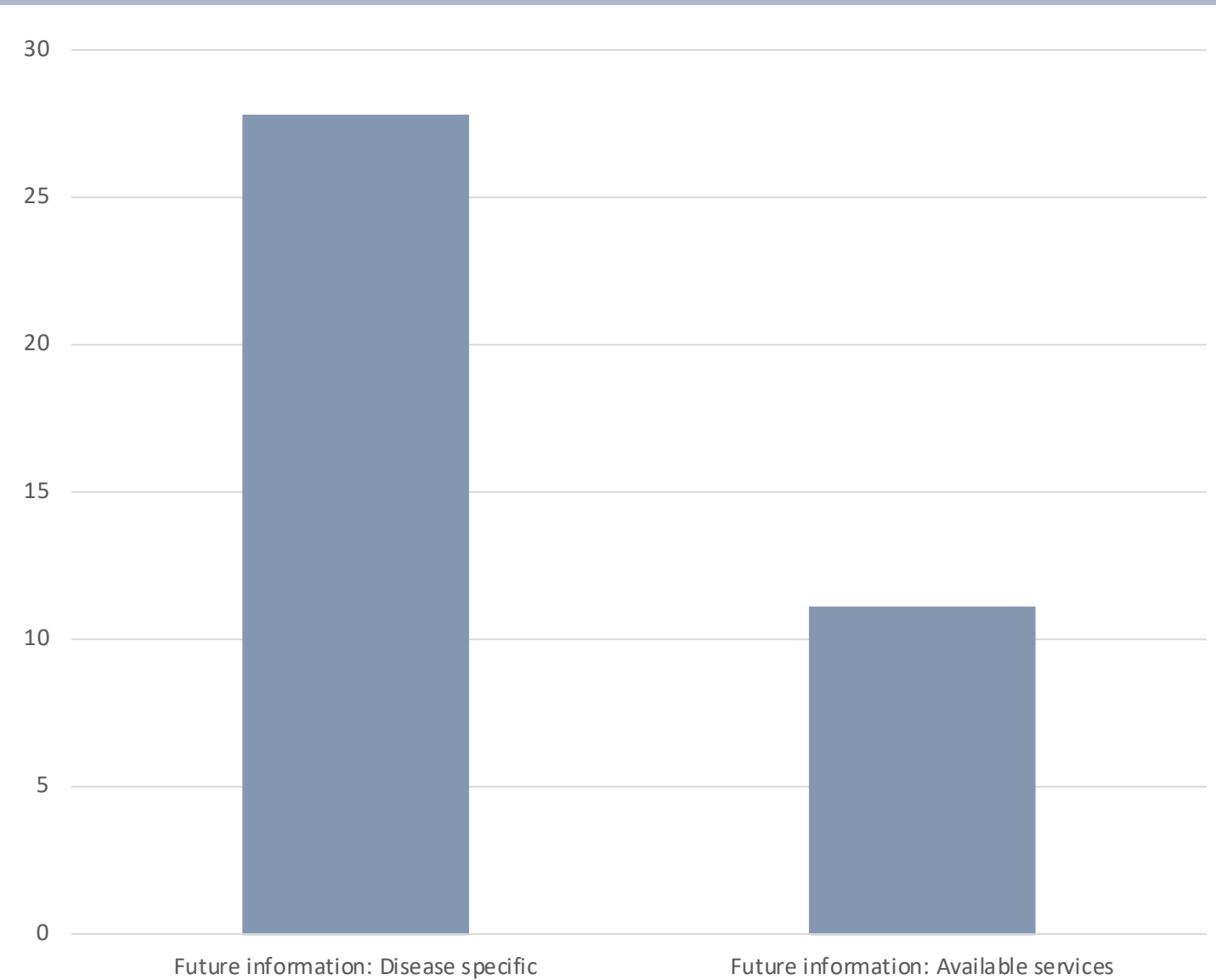
An injection would be great, or transfusion is fine, and a lot more affordable on the PBS would be amazing and more options because I feel like I don't have any options. Participant NMO_003

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

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



Section 9



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

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

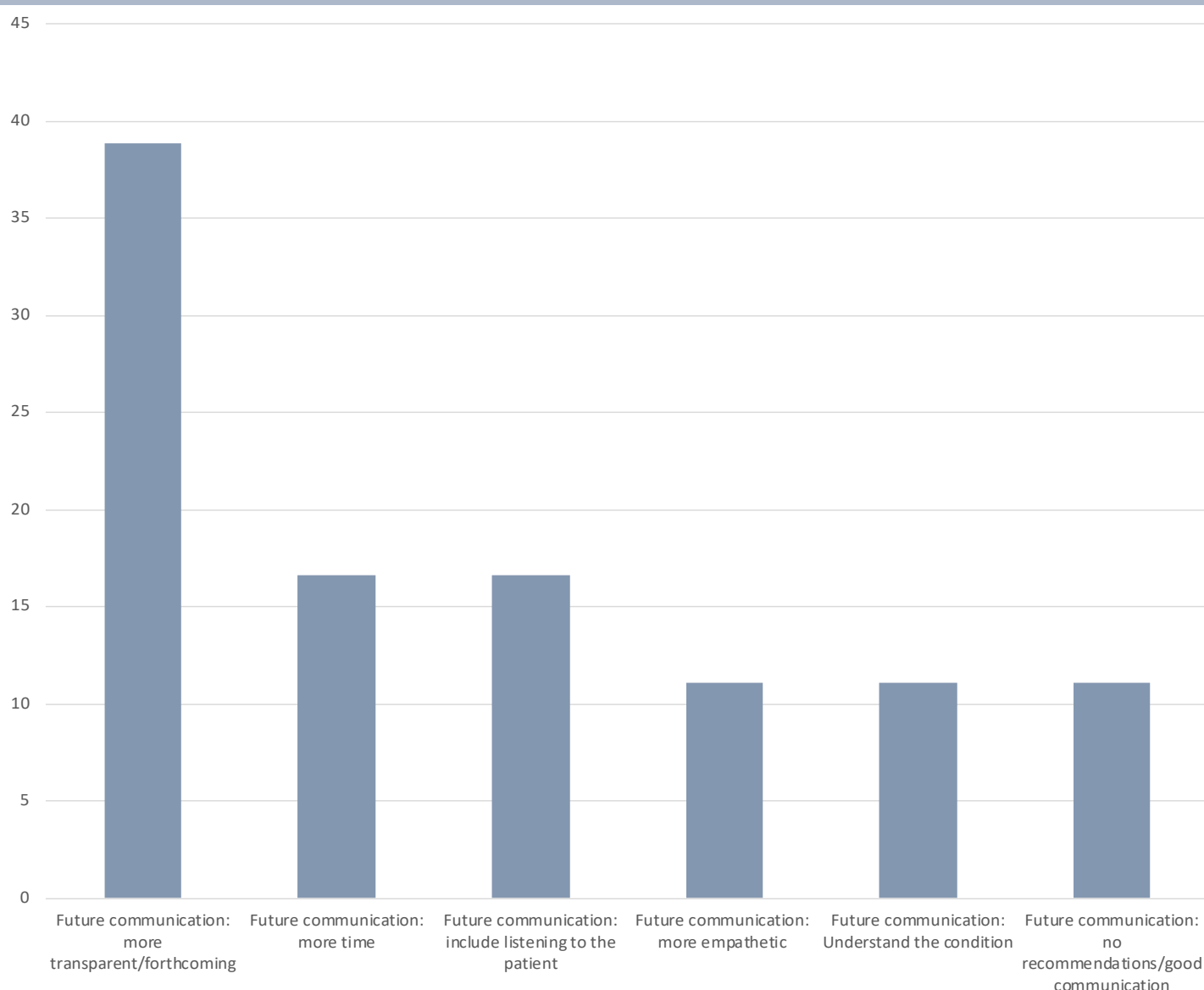


Section 9

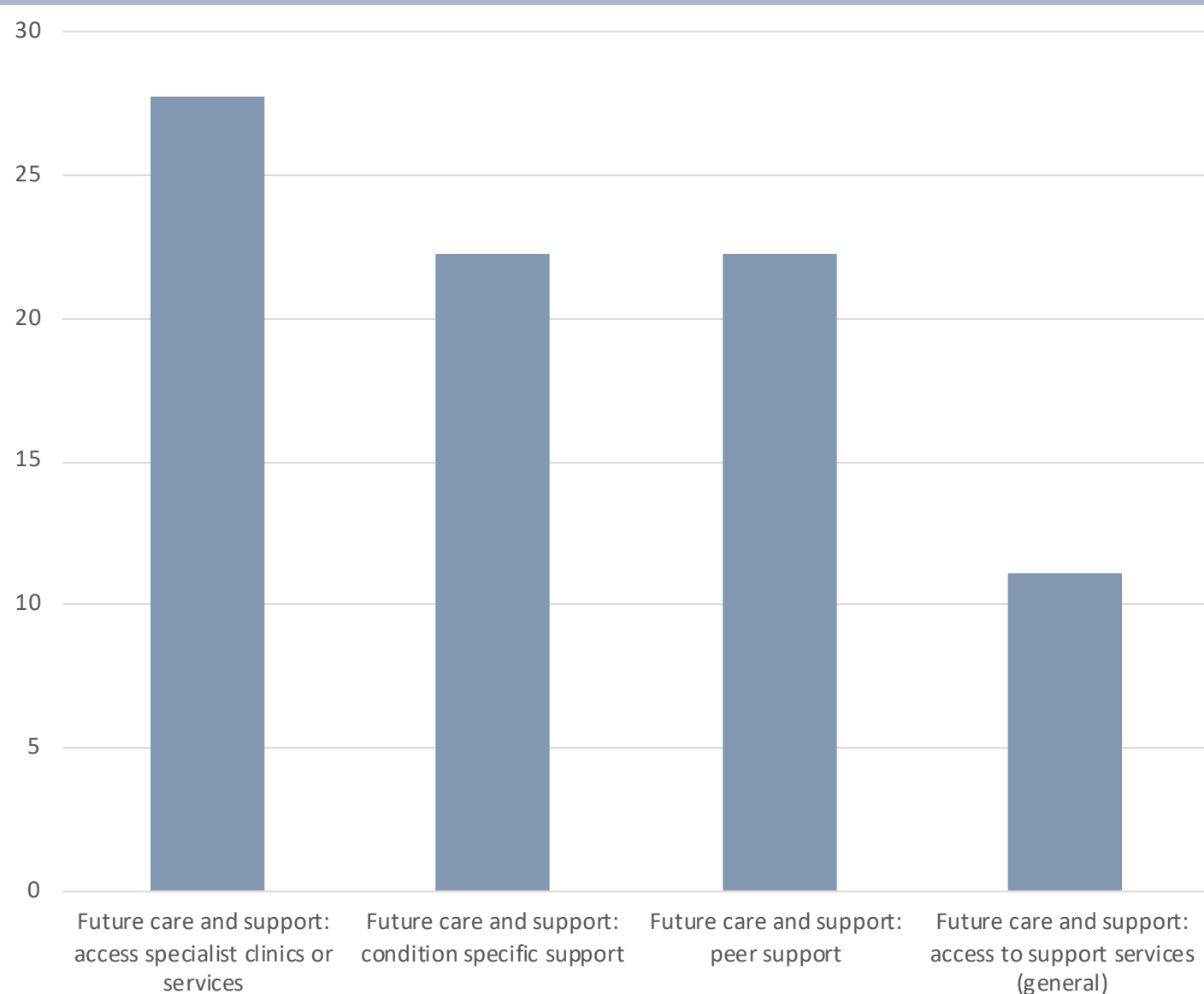
Some dialogue would be very nice, even if they just say like, actually tells you, "This is how we've come about the diagnosis and this is what it means. These are the testing that we've done." Just the information about your health that should be available to you. Participant NMO_014

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



Section 9



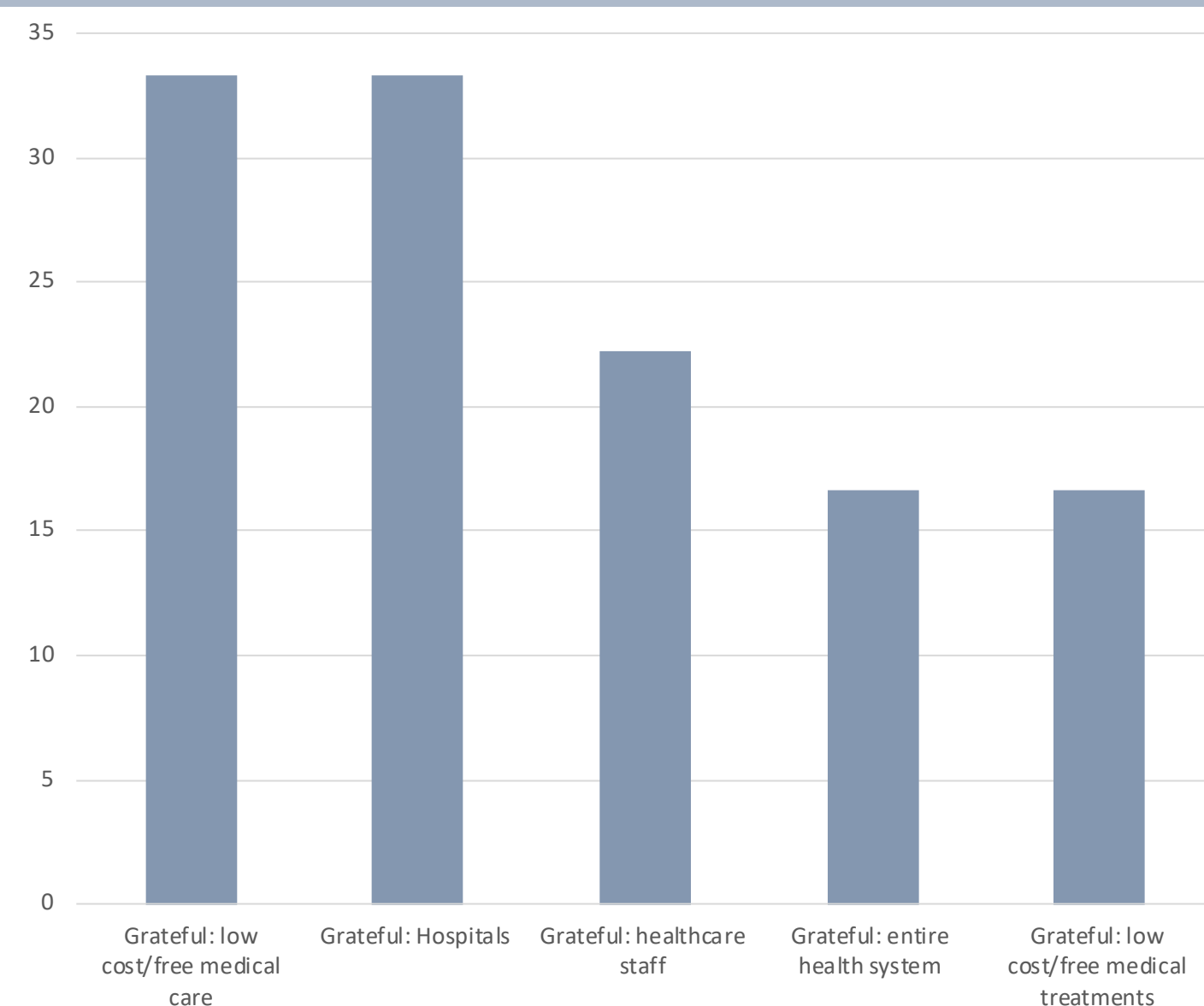
It would be nice to have a specialist that does even just research or something that you can talk to or whatever. They can say yay or nay. Participant NMO_013

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

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



Section 9



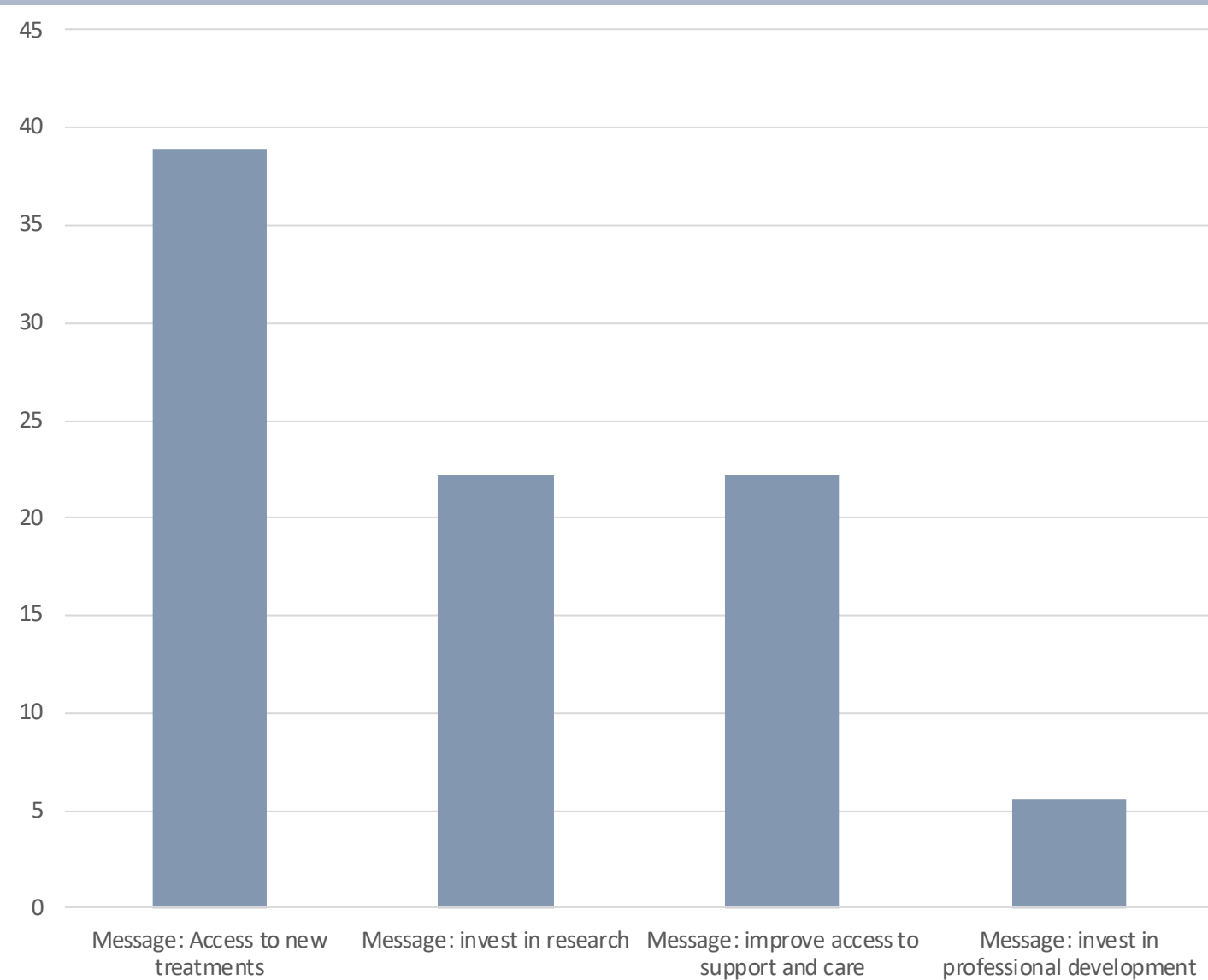
Totally. Everything that I've had has been amazing. As in, within the hospital system and the infusions, they've been able to pay for the whole. I really can't complain with that. Participant NMO_008

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

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



Section 9



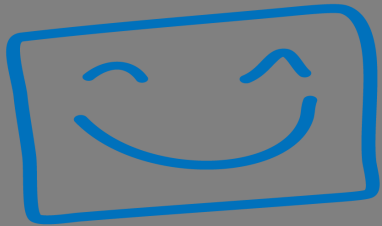
That there's not enough in Australia for NMO specific conditions. There needs to be more treatment options, better funding and more support, I think. Participant NMO_001

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

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



Section 10

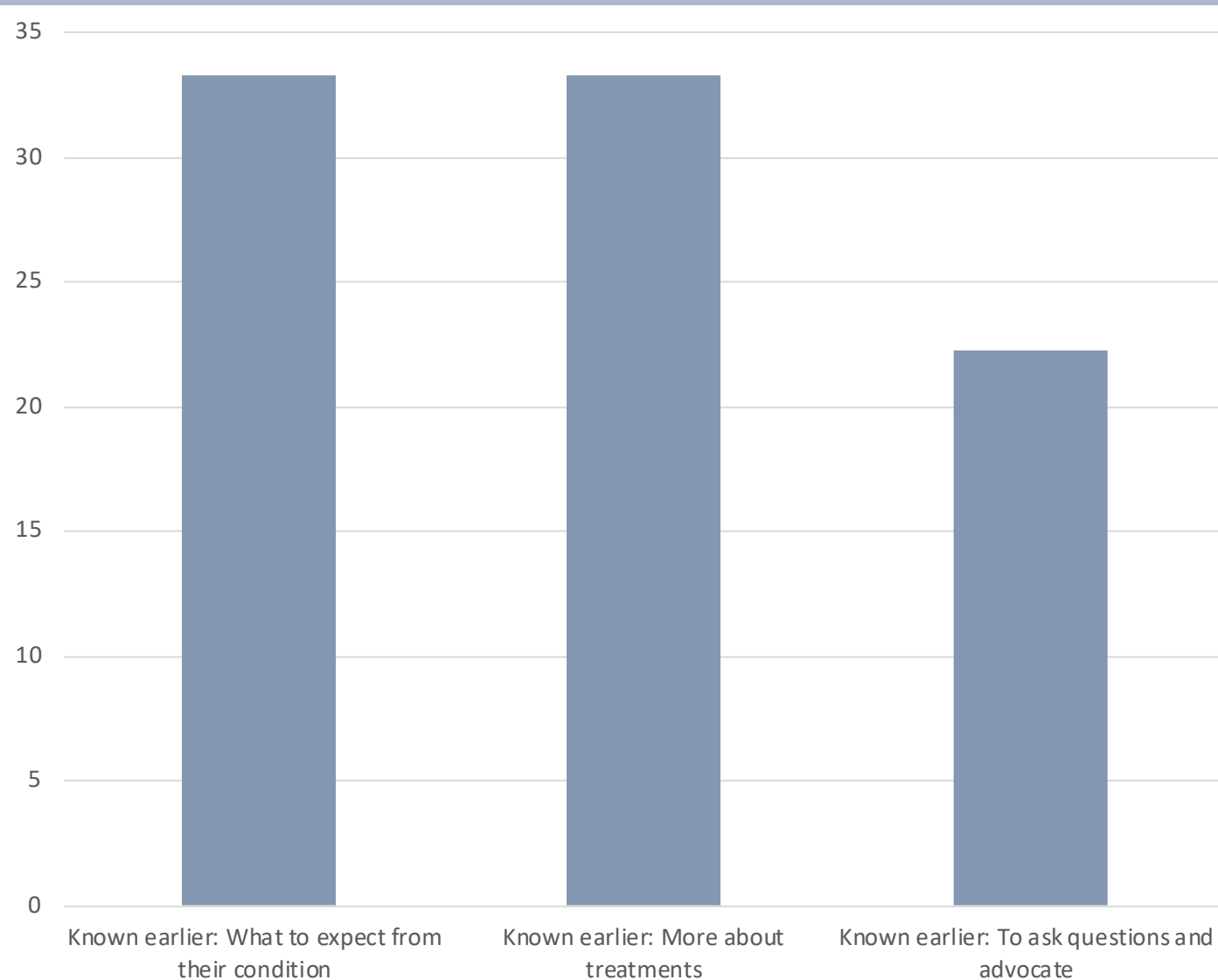


Advice from current patients
to
patients in the future

In this section we present the response to the question 'what is your advice to other people who are diagnosed in the future?' This gives participants the chance to impart knowledge and for patients to feel connected with others in the community.



Section 10



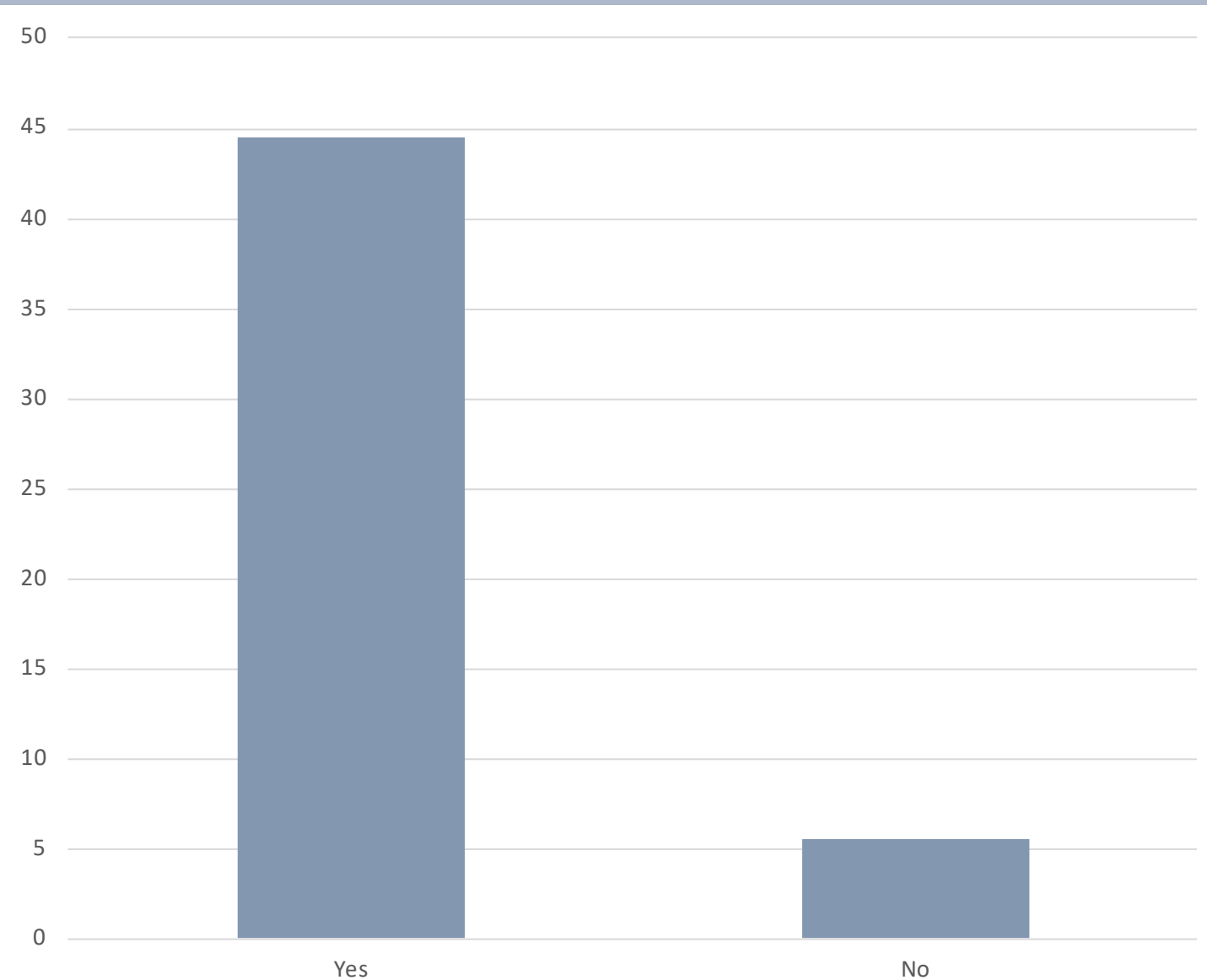
Yes, it was pretty grim. When I was diagnosed, they really didn't know very much. The statistics were really bad. The prognosis was particularly bad. In a way, I just thought, "Well, things are going to turn to shit in the next few years. Maybe don't bother doing-- It's just not going to be good," but that wasn't the case at all. I'm doing really well. Probably if I had a realistic picture from the beginning, it would have been better. Participant NMO_010

Probably to take IVIG the first go. Participant NMOCA_005

100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness, I think. Participant NMO_005



Section 10



100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness. Participant NMO_005

Yes, if I had have known about-- not that if I hadn't have known about rehab because I knew rehab was there but what things would have made it easier in the beginning to avoid the weight gain and things like that. Participant NMO_014

I don't think so. Because I was focused so much on MS because I thought that's what I had, it wasn't really that much of a change in, I guess, my physical outlook for the rest of my life. I kind of already knew that I'm going to go downhill, and I kind of knew that I'll degrade. I already knew all those things, so I don't think so. Participant NMO_003



Section 11

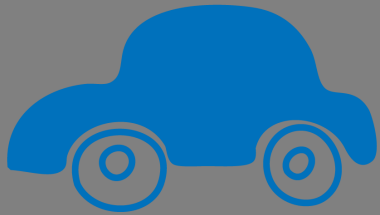


Discussion

The discussion is a review of the current landscape across all of the PEEK domains and commentary on how the PEEK cohort's experience compares to the literature.



Section 12



Where to from here?

The final section summarises three key things that would make life better for people with the condition or disease. There is also a matrix of key findings so that when we repeat the project in the future with a new cohort, we can see whether their experience has improved.



Section 12

1. 1. Information: Throughout the study, participants noted the difficulties in finding local, disease-specific information. This patient population would benefit from an Australian website with transparent and forthcoming information about what NMOSD is, as well as current and emerging treatments. This may be complemented by an annual or biennial conference updating the community on current research and treatments.
2. 2. Health system navigation: Once diagnosed with NMOSD, there is complex health system that needs to be navigated to ensure patients are accessing allied health and supportive care. This patient population would benefit from the development of a 'Health System Navigation' kit, so that they can anticipate the services that they may need in the future and how to access them.
3. 3. Symptom tracking and monitoring: A recurring theme within the study was the importance of avoiding relapse and maintaining current health and independence. This patient population would benefit from the development of bespoke symptom tracking tools so that they can monitor their ability to function over time and recognise changes so that they can access timely or early medical or therapeutic interventions.

