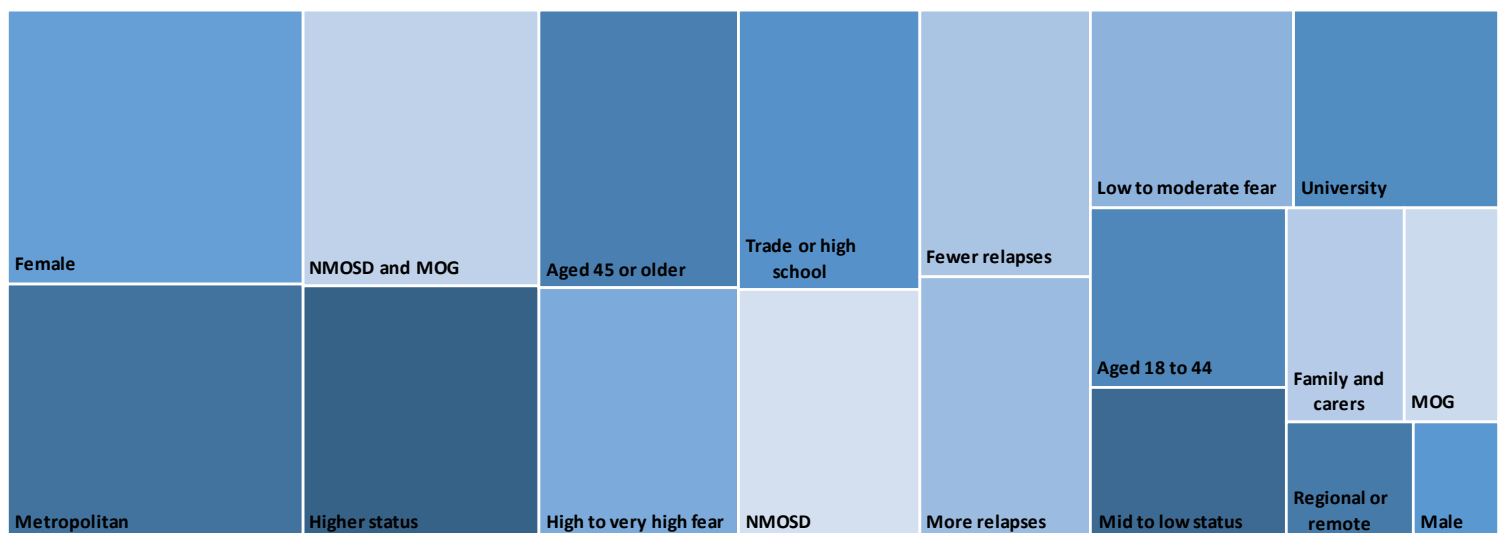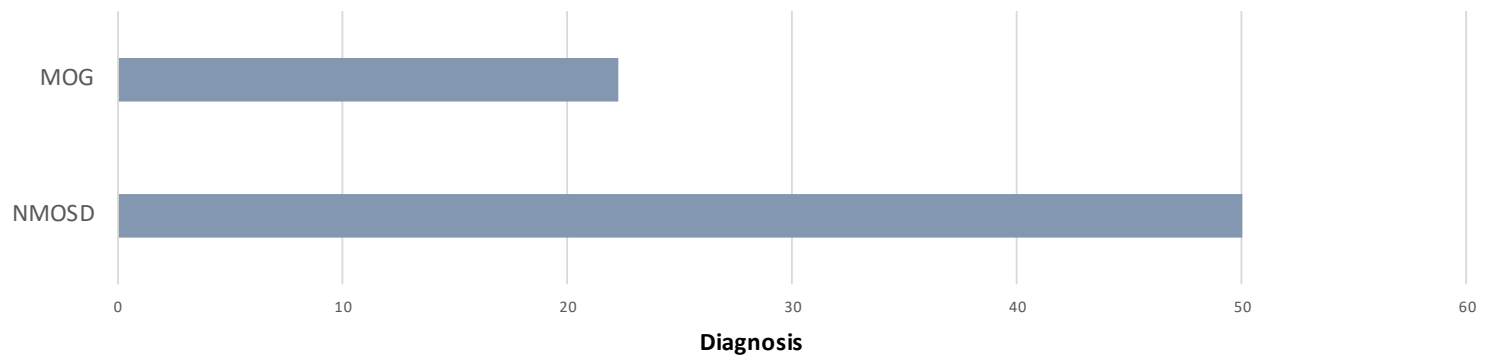PEEK
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36 participants

Female   Male

Gender

Age

NSW

QLD

ACT

VIC   WA

- Major Cities of Australia
- Inner Regional Australia
- Outer Regional Australia/Remote

Location

Lower to medium   33.33

Higher   66.66

Socioeconomic status

MOG

NMOSD

0	10	20	30	40	50	60

Diagnosis

Female

NMOSD and MOG

Aged 45 or older

Trade or high school

Fewer relapses

Low to moderate fear   University

Aged 18 to 44   Family and carers   MOG

Metropolitan   Higher status   High to very high fear   NMOSD   More relapses   Mid to low status   Regional or remote   Male

Sub-groups for analysis

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PERSONAL EXPERIENCE EXPECTATIONS KNOWLEDGE

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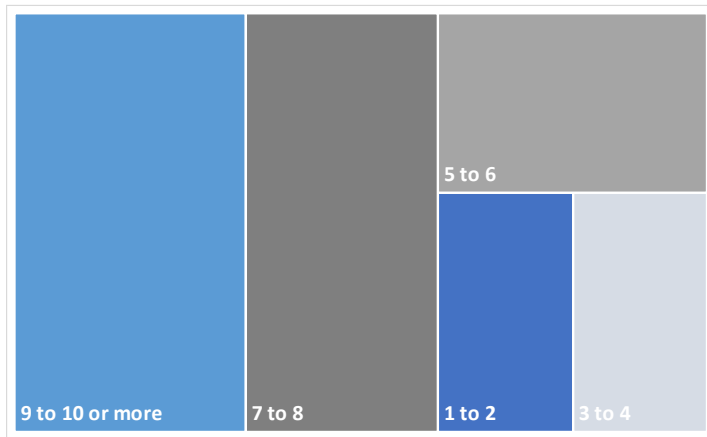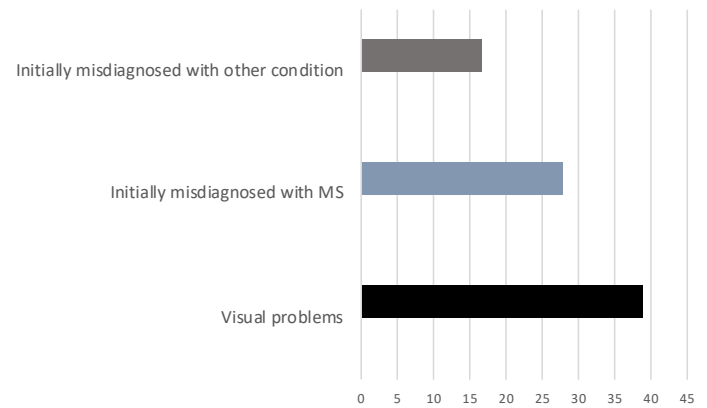AUSTRALIAN STUDY 2020

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Number of symptoms before diagnosis

9 to 10 or more | 7 to 8 | 5 to 6 | 1 to 2 | 3 to 4

Most common symptoms before diagnosis

Initially misdiagnosed with other condition

Initially misdiagnosed with MS

Visual problems

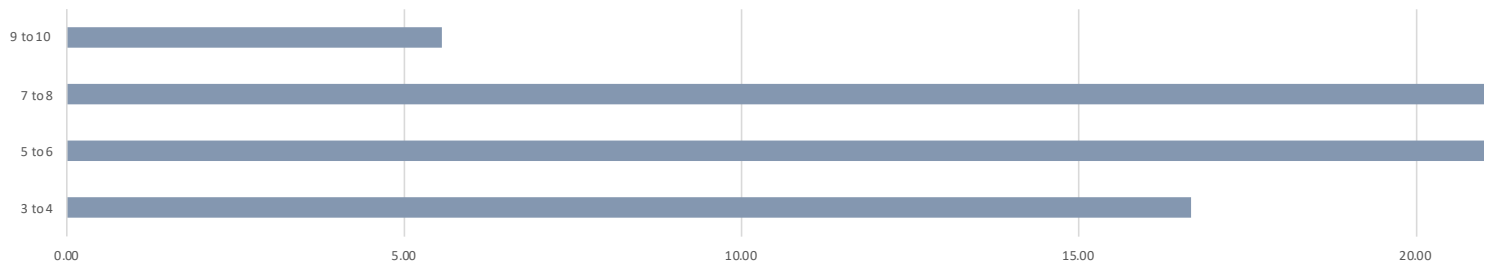0 5 10 15 20 25 30 35 40 45

% of people that had enough information at diagnosis

5.56

% of people who had an understanding   of disease at diagnosis

38.89

9 to 10

7 to 8

5 to 6

3 to 4

0.00   5.00   10.00   15.00   20.00

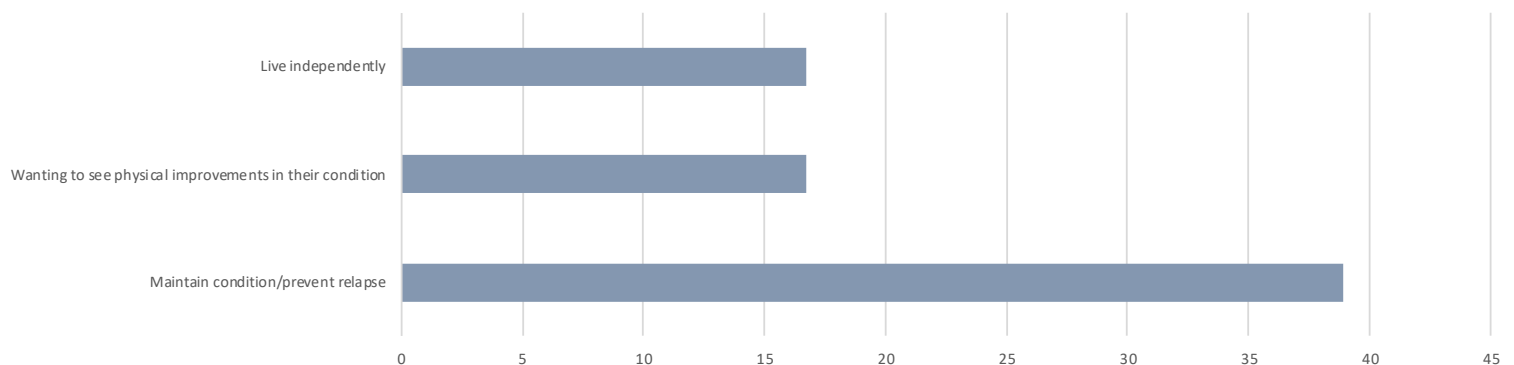**Number of diagnostic tests at diagnosis**

"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."

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Multiple treatments discussed | One treatment discussed
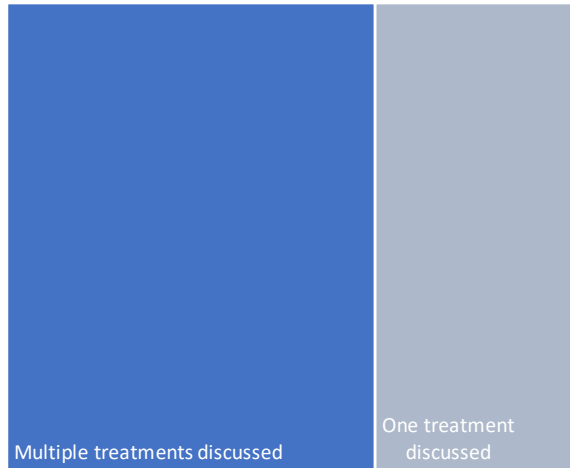
Discussions about treatment

Rituximab | Steroids | Plasma exchange
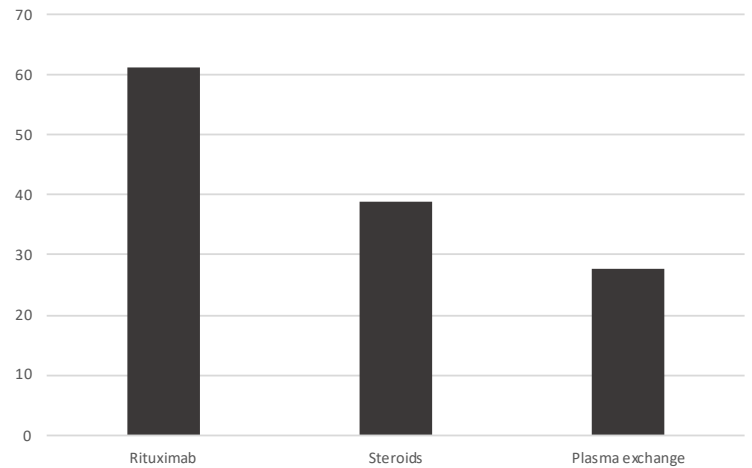
Most common treatments discussed (that patients recalled)

Does not change
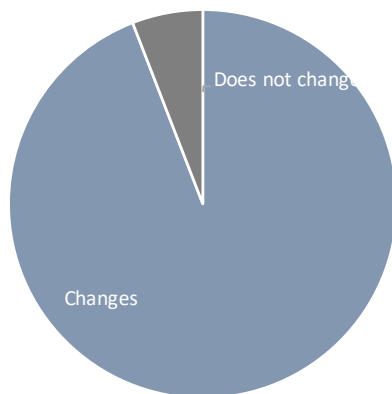
Changes

Does decision-making change over time?

Participants are more informed and/or more assertive

Main reason why decision-making changes

Live independently

Wanting to see physical improvements in their condition

Maintain condition/prevent relapse

0   5   10   15   20   25   30   35   40   45

Top 3 treatment goals

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No

Yes, with the exceptions

Yes
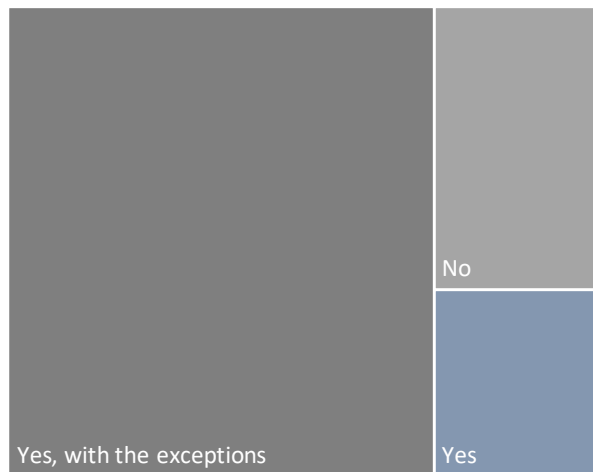
Were patients treated respectfully?

Neurologist — 100.00

Main provider of ongoing treatment

Tocilizumab
Methotrexate
Azathioprine
Mycophenolate mofetil
Plasma exchange
Prednisone
Rituximab
IV high dose steroid
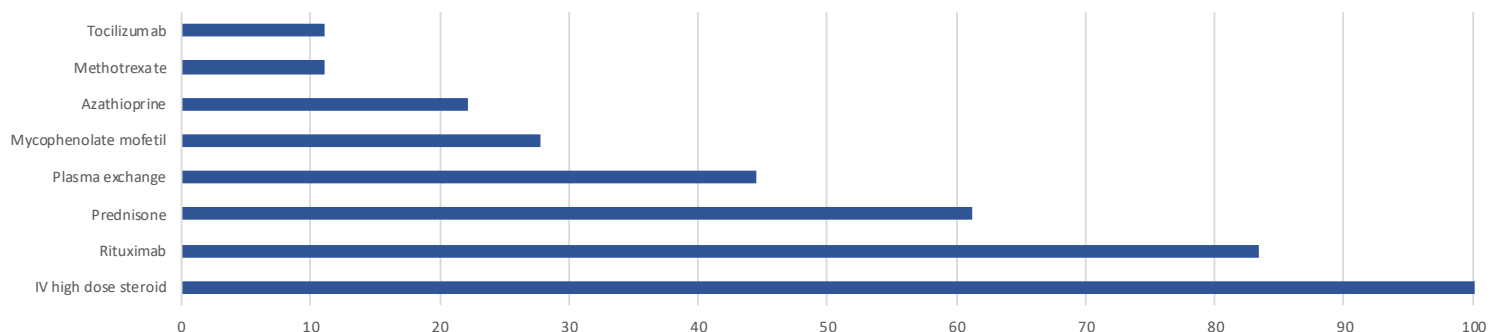
Medications taken

61.11

**% people with
private insurance**

88.89

% people who never missed filling prescription due to cost

16.67

**% people who
paid for extra carers**

61.11

**% asked if about
preference for public
or private treatment**

66.67

% people who never cancelled appointments due to cost

50.01

**% people who paid
$250+ monthly for
out-of-pocket expenses**

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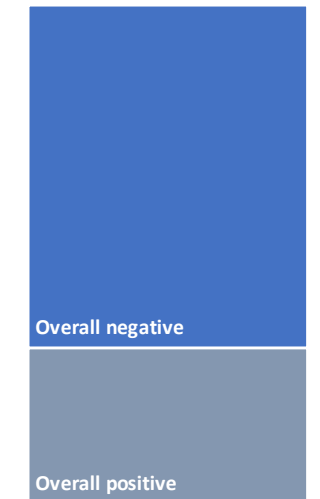
NEUROMYELITIS OPTICA
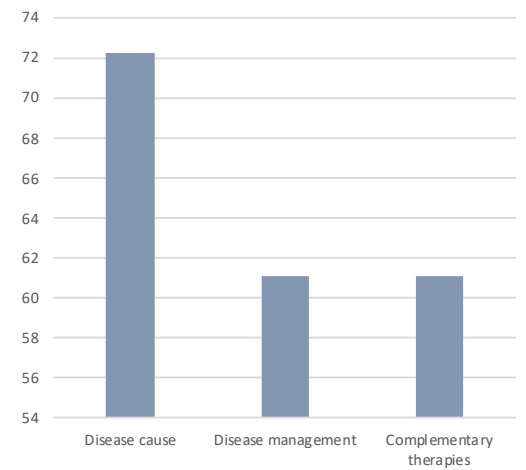AUSTRALIAN STUDY 2020

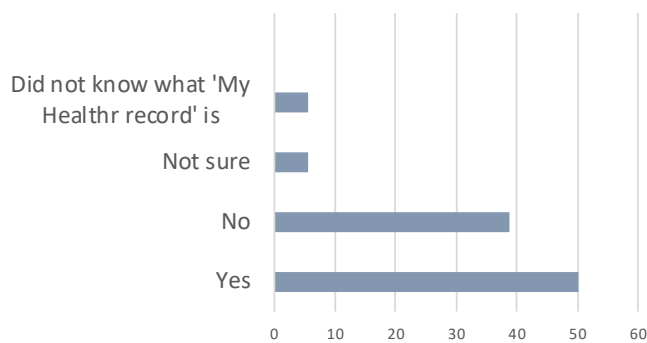CENTRE FOR COMMUNITY-DRIVEN RESEARCH
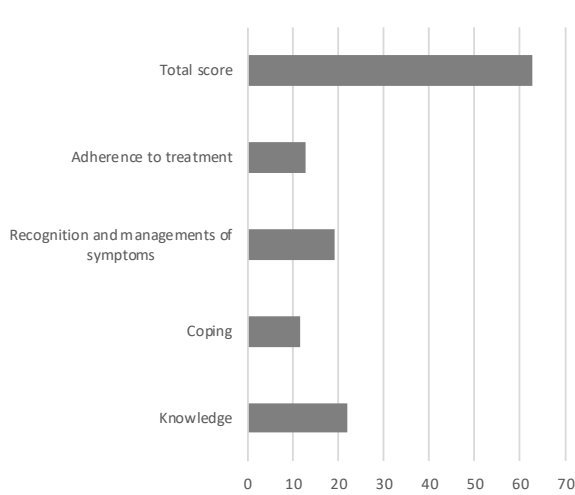
Partners in Health Scores

Experience of communication

Biggest gaps in information
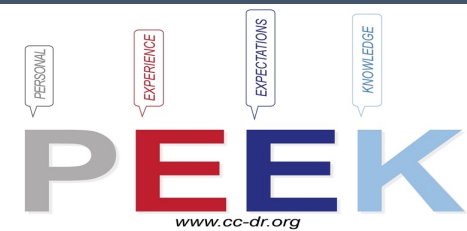

Access to My Health Record

Usefulness of My Health Record

Internet + Facebook

Main souce of information

Online + talking to someone

Most common preference: method of information

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Top three suppliers of care & support

Domestic services | Transport | Hospital or clinical setting

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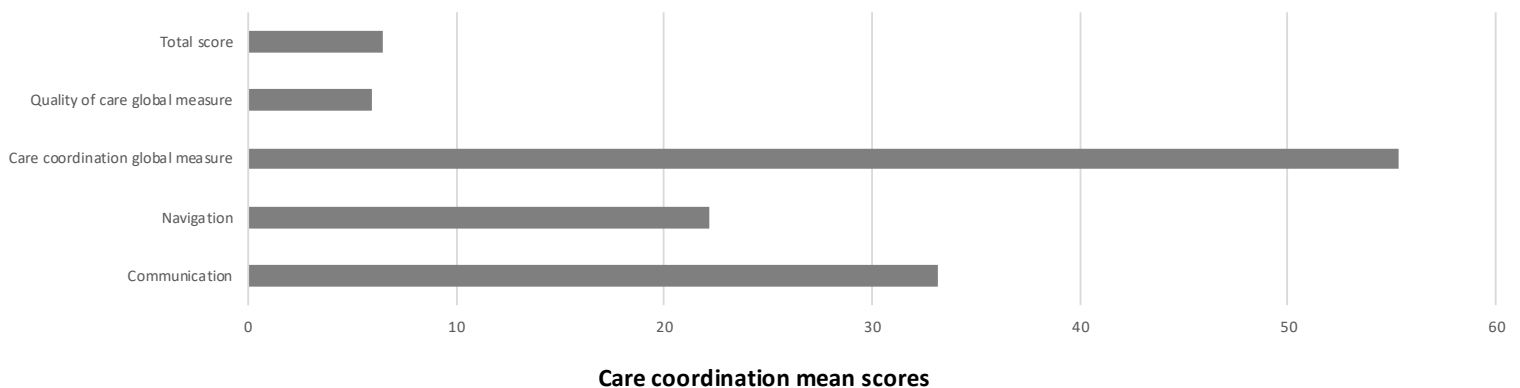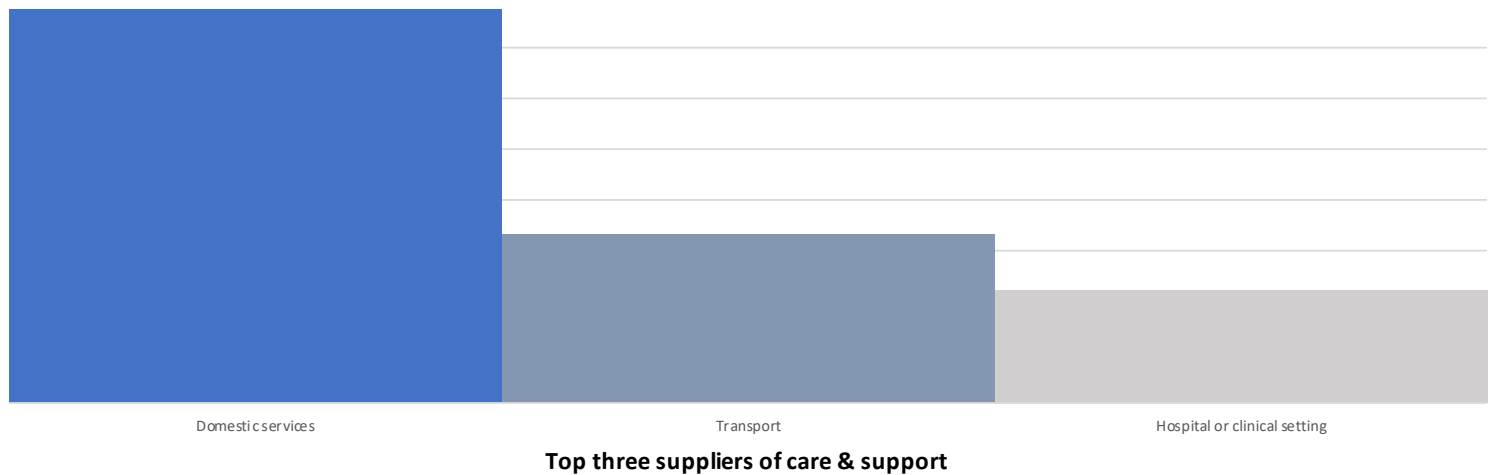
"They have been quite good, but seeing that we've had COVID, I only had one to two weeks of going out shopping and feeling like I was normal again, and then COVID hit. I haven't really been able to get out and about, but they have been taking me to my hospital appointments and doctors' appointments.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

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| Emotional strain on family and/or a change in the dynamics of relationships | Reduced capacity for physical activity | Reduced social interaction |

Reasons for negative impact on quality of life

88.89

% of people that described a negative impact on quality of life

Overall impact on quality of life (Likert scale)

77.78

% of participants that felt there was overall some cost burden

Needing to take time off work

Most common reason for cost burden

83.33

% of participants that felt there was some impact on their mental health

41.50

Fear of Progression median score

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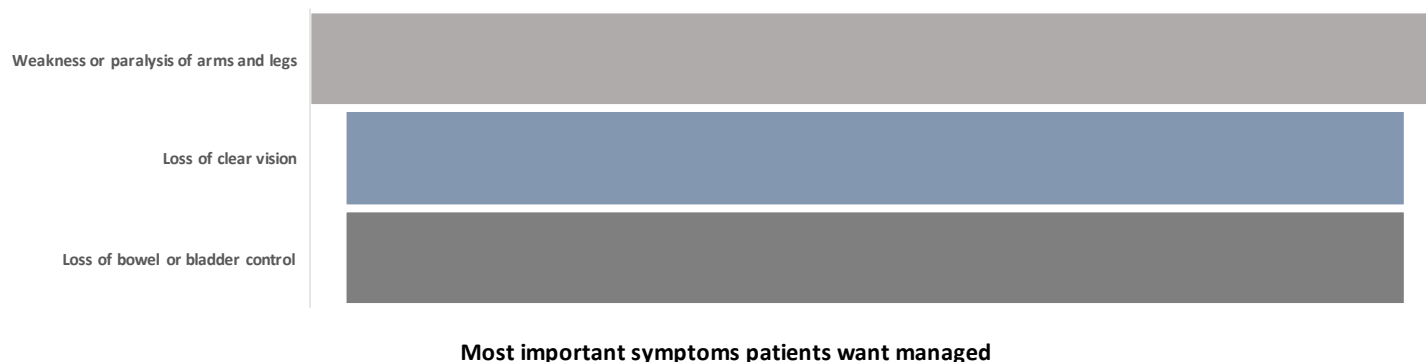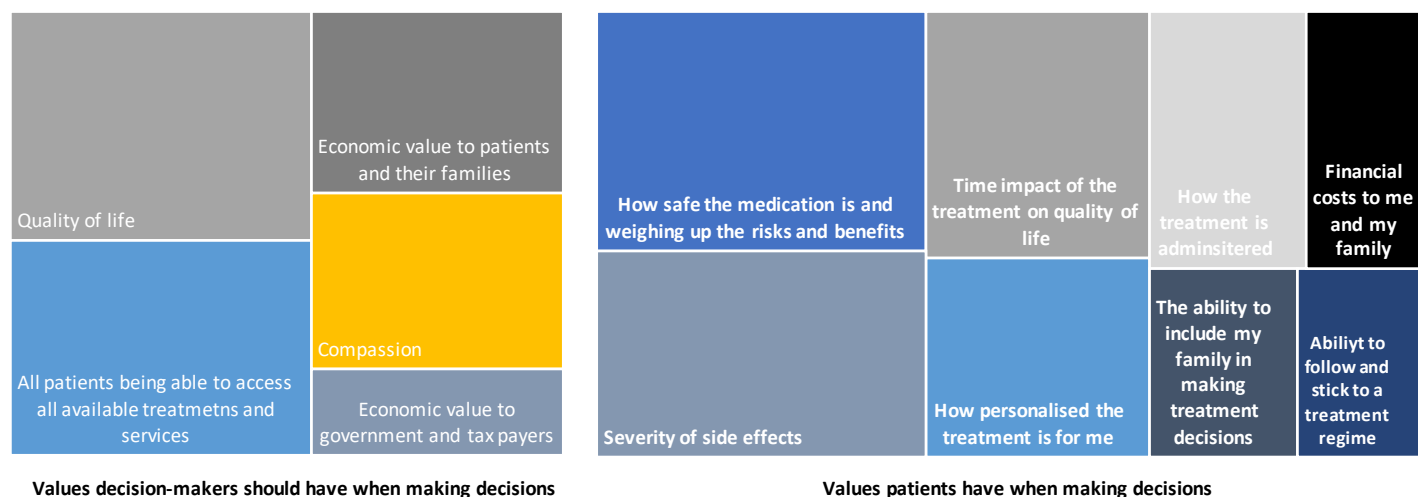NEUROMYELITIS OPTICA
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Quality of life

Economic value to patients and their families

All patients being able to access all available treatmetns and services

Compassion

Economic value to government and tax payers

Values decision-makers should have when making decisions

How safe the medication is and weighing up the risks and benefits

Time impact of the treatment on quality of life

How the treatment is adminsitered

Financial costs to me and my family

Severity of side effects

How personalised the treatment is for me

The ability to include my family in making treatment decisions

Abiliyt to follow and stick to a treatment regime

Values patients have when making decisions

Weakness or paralysis of arms and legs

Loss of clear vision

Loss of bowel or bladder control

Most important symptoms patients want managed

Fewer or less intense side effects

Most common expectation of future treatment

More specific to their condition

Most common expectation of future information

More transparent & forthcoming

Most common expectation of future commnuication

Specialist clinic or services

Most common expectation of future support

Low cost/freee medical care through the government

Healthcare staff

Top three things patients are most grateful for in the health system

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What to expect from their condition	33.33
More about treatments that were available and/or what treatments ...	33.33
Ask more questions and advocate for themselves	22.22

Main things participants wish they'd know earlier (top 3)

Better communication and/or continuity of care

What to expect from their condition (e.g. symptoms, side effects of medication)

What participants would change about their care with hindsight

What participants wish they knew earlier

"If there was somewhere or some information he could have sent me to, instead of me having to go through the minefield of everything in the world... Just so that there was a basic grounding of NMO rather than it being this humongous thing that some people do die of, and some people get vomiting, and some people get choking, and you're like, "What?" Just a basic information would have been good when you first get told NMO"