

Supplement S1: Survey Instrument

SCREENING ITEMS

0.a Select the language you would like to take the survey in.
Seleccione el idioma en el que desea realizar la encuesta.

- English / Inglés
- Spanish / Español

1.1 In what country is your main residence?

- United States
- Canada
- Neither the United States nor Canada

Section 1: Background

1.1a In what state/province is your main residence?

[If US] Specify State: [PULLDOWN MENU LIST US STATES]

Alabama	Maine	Pennsylvania
Alaska	Maryland	Rhode Island
Arizona	Massachusetts	South Carolina
Arkansas	Michigan	South Dakota
California	Minnesota	Tennessee
Colorado	Mississippi	Texas
Connecticut	Missouri	Utah
Delaware	Montana	Vermont
District of Columbia	Nebraska	Virginia
Florida	Nevada	Washington
Georgia	New Hampshire	West Virginia
Hawaii	New Jersey	Wisconsin
Idaho	New Mexico	Wyoming
Illinois	New York	
Indiana	North Carolina	
Iowa	North Dakota	
Kansas	Ohio	
Kentucky	Oklahoma	
Louisiana	Oregon	

[If Canada] Specify Province: [PULLDOWN MENU LIST CANDIAN PROVINCES]

Alberta	Nova Scotia	Quebec
British Columbia	Nunavut	Saskatchewan
Manitoba	Northwest Territories	Yukon
New Brunswick	Ontario	
Newfoundland and Labrador	Prince Edward Island	

[ASK ALL] [DROPDOWN]

9.2 Date of birth:

Month: _____ **[RANGE: January – December]**

Day: _____ **[RANGE: 1 - 31]**

Year: _____ **[RANGE: 1910 - 2017]**

[IF RESPONDENT AGE LESS THAN 18, TERMINATE SURVEY AND REDIRECT TO TERMINATION SCREEN 1]

[ASK ALL] [SINGLE CODE]

1.2 Are you diagnosed with NMO or NMO spectrum disorder (NMO/SD)?

- NMO
- NMO/SD
- I am not diagnosed with NMO or NMO spectrum disorder (NMO/SD). **[TERMINATE SURVEY AND REDIRECT TO TERMINATION SCREEN 1]**

[ASK ALL] [SINGLE CODE]

1.3 Which of the following options best describes your diagnosis?

- Seropositive or tested positive for aquaporin 4
- Seronegative or tested negative for aquaporin 4
- I don't know

[TERMINATION SCREEN 1, DISPLAY IF PARTICIPANT HAS CHOSEN OPTION THAT DISQUALIFIES THEM]

Section 2: Physical and Mental Health

[DISPLAY ON OWN SCREEN]

The following questions will ask about your general physical and mental health.

[ASK ALL] [SINGLE CODE]

2.1 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?

[COLUMNS]

Yes

No

Prefer not to answer

[ROWS]

2.1a Cut down on the amount of time you could spend on work or other activities

2.1b Accomplished less than you would like

2.1c Were limited in the kind of work or other activities

2.1d Had difficulty performing the work or other activities (for example, it took extra effort)

[ASK ALL] [SINGLE CODE]

2.2 During the past 4 weeks, have you had any of the following problems with your work or regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?

[COLUMNS]

Yes

No

Prefer not to answer

[ROWS]

2.2a Cut down the amount of time you spend on work or other activities.

2.2b Accomplished less than you would like.

2.2c Didn't do work or other activities as carefully as usual.

[ASK ALL] [SINGLE CODE]

2.3 How much bodily pain have you had during the past four weeks?

1	2	3	4	5	6
None	Very Mild	Mild	Moderate	Severe	Very Severe

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

2.4 During the past four weeks, how much did pain interfere with your normal work including both work outside the home and housework?

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

2.5 During the past 4 weeks, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family, friends, neighbors, or groups?

1	2	3	4	5
Not at all	Slightly	Moderately	Quite a bit	Extremely

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

2.6 Overall, how satisfied were you with your sexual function during the past 4 weeks?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

2.7 The following questions address the current status of your vision. During the past 4 weeks, how difficult did you find it to...

[COLUMNS]

Not at all difficult

Somewhat difficult

Extremely difficult

Could not do due to visual problems

Prefer not to answer

[ROWS]

2.7a read or access personal letters or notes?

2.7b read or access printed materials, such as books, magazines, newspapers, etc.?

2.7c read or access dials, such as on stoves, thermostats, etc.?

2.7d watch television or identify faces from a distance?

2.7e identify house numbers, street signs, etc?

2.7f read digital text, such as text on computer or smartphone screens?

2.7g view digital pictures, such as pictures on computer or smartphone screens?

Section 3: Effects of NMO/SD on Daily Life

[DISPLAY ON OWN SCREEN]

Now, think specifically how *NMO/SD* has affected your life.

The following questions will address the various ways that NMO may affect daily life. The term NMO/SD includes all forms of NMO/SD, including seropositive & seronegative antibody status, and is inclusive of differing signs & symptoms (e.g. some patients have optic neuritis, loss of bowel / bladder function, or pain — while others do not).

[ASK ALL] [SINGLE CODE]

3.1 Overall, to what extent do you feel your quality of life has been affected by NMO/SD?

1	2	3	4	5	6
Not at all affected by NMO/SD					Greatly affected by NMO/SD

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

3.2 Are you currently employed?

- Yes
- No
- Prefer not to answer

[ASK IF Q3.2 = “Yes”] [SINGLE CODE]

3.3 How many hours per week do you typically work?

- 1-10 hours
- 11-20 hours
- 21-30 hours
- 31-40 hours

- more than 40 hours
- Prefer not to answer

[ASK IF Q 3.2 = “No”] [MULTICODE]

3.4 If you are not currently employed, what is your current status? (Please select all that apply)

- Seeking employment
- Not seeking employment **[FIRST TWO CODES ARE EXCLUSIVE OF EACH OTHER]**
- Full-time homemaker or caregiver
- Student
- Disabled
- Retired
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer **[should be exclusive option]**

[ASK IF Q3.2 = “Yes”] [SINGLE CODE]

3.5 Have NMO/SD symptoms caused you to miss work in the past six months?

- Yes
- No
- Prefer not to answer

[ASK IF Q3.5 = “Yes”] [SINGLE CODE]

3.6 How many work days did you miss due to NMO/SD in the past 6 months?

- 1-7 days
- 2 to 4 weeks
- 1-2 months
- 3-4 months
- 5-6 months

Prefer not to answer

[ASK IF Q3.2 = "Yes"] [SINGLE CODE]

3.7 To what degree do you feel like NMO/SD affected your ability to work, such as a reduction in work hours, loss of productivity, or a change from full-time to part-time status?

1	2	3	4	5	6
Not at all affected by NMO/SD					Greatly affected by NMO/SD

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK IF Q3.2 = "Yes"] [SINGLE CODE]

3.8 To what extent do you feel NMO/SD has hurt your career?

1	2	3	4	5	6
Not hurt at all					Hurt a great deal

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

3.9 To what extent do you feel your social life has been affected by NMO/SD?

1	2	3	4	5	6	7	8	9	10
Strongly Negatively Affected									Strongly Positively Affected

Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

3.10 To what extent do you feel your personal and family relationships have been affected by NMO/SD?

[ASK IF Q3.12="Yes"] [SINGLE CODE]

3.14 Did any pregnancy have complications due to NMO/SD?

- Yes
- No
- Prefer not to answer

[ASK IF Q3.14="Yes"] [SPECIFY]

3.15 Please specify about your pregnancy complication due to NMO/SD:

[SPECIFY] _____ [Mutual Exclusive, Single Punch]_____ Prefer not to share.

[ASK ALL] [SINGLE CODE]

3.16 Please rate the extent to which you agree or disagree with the following statement:

My NMO/SD diagnosis makes me uncertain about my future.

1	2	3	4	5
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

Section 4: NMO Diagnosis

[DISPLAY ON OWN SCREEN]

The following questions will ask about your NMO diagnosis.

[ASK ALL] [DROPDOWN]

4.1 What is the date of your initial NMO diagnosis?

Month: _____ **[RANGE: January – December, with additional “Don’t know month” answer at the top]**

Year: _____ **[RANGE: 1910-2017, with additional “Don’t know year” answer at the top]**

- Don’t know/don’t remember month or year of initial diagnosis **[Single Punch][Mutually Exclusive Option]**
- Prefer not to answer **[Single Punch][Mutually Exclusive Option]**

[ASK ALL] [MULTI CODE]

4.2 Which symptoms led you to initially report to your doctor? (Please select all that apply)

- Difficulty walking
- Vision problems
- Numbness/tingling
- Paralysis
- Pain
- Fatigue
- Depression
- Bladder control problems
- Bowel control problems
- Spasticity (sudden involuntary contraction of a muscle)
- Prolonged hiccups
- Prolonged vomiting
- Insomnia
- Cognitive problems (such as memory, mood, mental effectiveness)

- Sexual dysfunction
- Emotional symptoms
- Excessive daytime sleepiness
- Other (please specify) **[SPECIFY]**_____
- Prefer not to answer **[should be exclusive option]**

[ASK ALL] [SINGLE CODE]

4.3 Before your NMO/SD diagnosis, were you diagnosed with a different condition for your NMO/SD symptoms?

- Yes
- No
- Prefer not to answer

[ASK IF Q4.3="Yes"] [MULTICODE]

4.4 What other condition(s), if any, were you diagnosed with before the diagnosis was changed to NMO/SD? Select all that apply.

- None **[should be exclusive option]**
- Acute disseminated encephalomyelitis (ADEM)
- Arteriovenous fistula
- Stroke
- Lupus
- Cancer
- Depression
- Multiple sclerosis (MS)
- Optic neuritis
- Post-infectious syndrome
- Progressive multifocal leukoencephalopathy (PML)
- Transverse myelitis

- Sarcoidosis
- Subacute combined degeneration
- Vasculitis
- I don't know **[should be exclusive option]**
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer **[should be exclusive option]**

[ASK ALL]

4.5 How much time elapsed between your first symptoms and your NMO/SD diagnosis?

- Years Please specify: _____ **[RANGE: 0-100]**
- Months Please specify: _____ **[RANGE: 0-12]**
- Weeks Please specify: _____ **[RANGE: 0-52]**
- Prefer not to answer **[Mutual Exclusive, Single Punch]**

[ASK ALL]

4.6 How much time elapsed between your diagnosis and your first NMO/SD treatment?

- Years Please specify: _____ **[RANGE: 0-100]**
- Months Please specify: _____ **[RANGE: 0-12]**
- Weeks Please specify: _____ **[RANGE: 0-52]**
- Prefer not to answer **[Mutual Exclusive, Single Punch]**

Section 5: NMO Treatment

[DISPLAY ON OWN SCREEN]

The following set of questions will ask about your NMO treatments.

[ASK ALL][MULTIPUNCH]

5.1 What NMO/SD treatments are you currently receiving (please select all that apply):

- 5.1a Prednisone / corticosteroid
- 5.1b Azathioprine (Imuran)
- 5.1c Mycophenolate mofetil (CellCept)
- 5.1d Rituximab (Rituxan or MabThera)
- 5.1e Cyclophosphamide (Cytoxan)
- 5.1f Tocilizumab (Actemra)
- 5.1g Mitoxantrone
- 5.1g1 Plasma exchange (PLEX)
- 5.1g2 Investigational drug/clinical trial
- 5.1h Other (specify) **[SPECIFY]**
- 5.1i Other (specify) **[SPECIFY]**
- 5.1j Prefer not to answer

[ASK IF Q5.1 = ANY RESPONSE EXCEPT 'Prefer not to answer'][DROPDOWN]

[HAVE THIS QUESTION LOOP FOR EVERY TREATMENT SELECTED IN Q5.1]

5.1.a For the treatments you are currently receiving, when did you start this treatment, and when was your most recent treatment?

[Show treatment selected in 5.1]

- 5.1a Prednisone / corticosteroid
- 5.1b Azathioprine (Imuran)
- 5.1c Mycophenolate mofetil (CellCept)
- 5.1d Rituximab (Rituxan or MabThera)
- 5.1e Cyclophosphamide (Cytoxan)
- 5.1f Tocilizumab (Actemra)
- 5.1g Mitoxantrone
- 5.1g1 Plasma exchange (PLEX)
- 5.1g2 Investigational drug/clinical trial
- 5.1h text pipe in from Other specify

5.1i text pipe in from Other specify

[Response Options]

Date begun – month [RANGE: January - December, with additional “Don’t know month” answer at the top]

Date begun – year [RANGE: 1910-2017, with additional “Don’t know year” answer at the top]

Most recent – month [RANGE: January - December, with additional “Don’t know month” answer at the top]

Most recent – year [RANGE: 1910-2017, with additional “Don’t know year” answer at the top]

Not applicable [Mutually Exclusive, Single Punch]

Don’t remember when I started this treatment nor when my most recent treatment was [Mutually Exclusive, Single Punch]

Prefer not to answer [Mutually Exclusive, Single Punch]

[ERROR MESSAGE: Answer choices ‘Not applicable’, ‘Don’t remember’, and ‘Prefer not to answer’ cannot be selected if a date range is provided for a treatment.]

[ASK ALL] [SINGLE CODE]

5.2 Please rate how well your current NMO/SD treatment works for you.

1 2 3 4 5 6 7 8 9 10
Not well at all Very well

Prefer not to answer [MUTUALLY EXCLUSIVE, SINGLE PUNCH]

[ASK ALL] [SINGLE CODE]

5.3 Do you have concerns regarding your current NMO/SD treatment?

Yes

No

Prefer not to answer

[ASK IF Q5.3=”Yes”] [MULTICODE]

5.4 If unsatisfied with your current treatment, describe why (please select all that apply):

- I am still having relapses
- I still have significant disability
- Side effects
- Concern about the future effectiveness of the treatment
- Discomfort during treatment administration
- Inconvenience
- Impact on pregnancy decisions
- Other (please specify): **[SPECIFY]** ____
- Prefer not to answer **[should be exclusive option]**

[ASK IF Q5.3="Yes"] [MULTICODE]

5.5 Please specify your greatest concern(s) (please select all that apply):

- Short-term side effects
- Long-term side effects
- The treatment doesn't work well for relapses
- The treatment doesn't work well for the pain and/or fatigue associated with NMO/SD
- The treatment is uncomfortable
- Inconvenience
- Other (please specify): **[SPECIFY]**_____
- Prefer not to answer **[should be exclusive option]**

[ASK ALL] [SINGLE CODE]

5.6 Have the medications prescribed for your NMO/SD been changed over the course of your treatment?

- Yes
- No
- Prefer not to answer

[ASK IF Q5.6= "Yes"] [MULITCODE]

5.7 Please specify the reason(s) why the medications prescribed for your NMO/SD have been changed over the course of your treatment. (Please select all that apply)

- Side effects
- The medication didn't work well
- Pregnancy
- Cost, including lack of insurance or insufficient coverage
- Participation in clinical trial
- I don't know **[should be exclusive option]**
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer **[should be exclusive option]**

[ASK IF Q5.6="Yes"] [MULTIPUNCH]

5.8 What NMO/SD treatments did you receive previously (please select all that apply):

[ROWS]

- 5.8a Prednisone / corticosteroid
- 5.8b Azathioprine (Imuran)
- 5.8c Mycophenolate mofetil (CellCept)
- 5.8d Rituximab (Rituxan or MabThera)
- 5.8e Cyclophosphamide (Cytoxan)
- 5.8f Tocilizumab (Actemra)
- 5.8g Mitoxantrone
- 5.8g1 Plasma exchange (PLEX)
- 5.8g2 Investigational drug/clinical trial
- 5.8h Other (specify) **[SPECIFY]**
- 5.8i Other (specify) **[SPECIFY]**
- 5.8j Prefer not to answer **[should be exclusive option]**

[ASK IF Q5.8=ANY RESPONSE EXCEPT "Prefer not to answer"] [DROPDOWN]

[HAVE THIS QUESTION LOOP FOR EVERY TREATMENT SELECTED IN Q5.8]

5.8a. For the treatments you received previously, when did you start this treatment, and when was your most recent treatment?

[Show treatment selected in 5.8]

- 5.8aa Prednisone / corticosteroid
- 5.8bb Azathioprine (Imuran)
- 5.8cc Mycophenolate mofetil (CellCept)
- 5.8dd Rituximab (Rituxan or MabThera)
- 5.8ee Cyclophosphamide (Cytosan)
- 5.8ff Tocilizumab (Actemra)
- 5.8gg Mitoxantrone
- 5.8gg1 Plasma exchange (PLEX)
- 5.8gg2 Investigational drug/clinical trial
- 5.8hh text pipe in from Other specify
- 5.8ii text pipe in from Other specify

[Response Options]

Date begun – month **[RANGE: January - December, with additional “Don’t know month” answer at the top]**

Date begun – year **[RANGE: 1910-2017, with additional “Don’t know year” answer at the top]**

Date discontinued – month **[RANGE: January - December, with additional “Don’t know month” answer at the top]**

Date discontinued – year **[RANGE: 1910-2017, with additional “Don’t know year” answer at the top]**

Not applicable **[Mutually Exclusive, Single Punch]**

Don’t remember when I started this treatment nor when my most recent treatment was **[Mutually Exclusive, Single Punch]**

Prefer not to answer **[Mutually Exclusive, Single Punch]**

[ERROR MESSAGE: Answer choices ‘Not applicable’, ‘Don’t remember’, and ‘Prefer not to answer’ cannot be selected if a date range is provided for a treatment.]

[ASK IF Q5.3 = “Yes”] [SINGLE CODE]

5.9 What is your outlook on future treatments?

- Not satisfied with current treatment options but believe it is the best that can be achieved
- Not satisfied with current treatment options and believe that more can be done to remedy
- I am satisfied with my current treatment
- Other (please specify): **[SPECIFY]**_____
- Prefer not to answer

Section 6: Experience with Relapses

[DISPLAY ON OWN SCREEN]

The following questions will ask about relapses.

[ASK ALL] [SINGLE CODE]

6.1 How many clinically confirmed relapses have you *ever* experienced?

- 0
- 1
- 2
- 3-5
- 6 or more
- Prefer not to answer

[ASK IF ANYTHING BUT “0” OR “Prefer not to answer” WAS SELECTED IN Q6.1] [SINGLE CODE]

6.2 In total, how many clinically confirmed relapses required inpatient hospitalization?

- 0
- 1
- 2
- 3-5
- 6 or more
- Prefer not to answer

[ASK IF ANYTHING BUT “0” OR “Prefer not to answer” WAS SELECTED IN Q6.1] [SINGLE CODE]

6.3 How many clinically confirmed relapses have you experienced *in the past year*?

- 0
- 1
- 2
- 3-5
- 6 or more
- Prefer not to answer

[ASK IF ANYTHING BUT “0” OR “Prefer not to answer” WAS SELECTED IN Q6.3] [SINGLE CODE]

6.4 In total, how many of these clinically confirmed relapses *in the past year* required inpatient hospitalization?

- 0
- 1
- 2
- 3-5
- 6 or more
- Prefer not to answer

[ASK IF ANYTHING BUT “0” OR “Prefer not to answer” WAS SELECTED IN Q6.3] [MULTIPUNCH]

6.7 In the past year, did you receive the following treatments to treat relapses?

6.7a Intravenous immunoglobulin (IVIg)

6.7b Plasma exchange (PLEX)

6.7b1 Oral steroids/Prednisone

6.7b2 IV steroids

6.7 c other (specify):

6.7d other (specify):

6.7e I did not receive treatments for relapses in the past year **[MUTUALLY EXCLUSIVE]**

6.7f Prefer not to answer **[MUTUALLY EXCLUSIVE]**

[ASK IF 6.7 does not equal 6.7e or 6.7f] [NUMERIC]

[HAVE THIS QUESTION LOOP FOR EVERY TREATMENT SELECTED IN Q6.7]

6.7.a. How many times did you receive these treatments to treat relapses in the past year?

[Show treatments selected in 6.7]

6.7aa Intravenous immunoglobulin (IVIg)

6.7bb Plasma exchange (PLEX)

6.7bb1 Oral steroids/Prednisone

6.7bb2 IV steroids

6.7cc text pipe in from Other specify

6.7dd text pipe in from Other specify

[Response Options]

Number of times **[RANGE: 0-999]**

Not applicable [**Mutually Exclusive, Single Punch**]

Don't remember [**Mutually Exclusive, Single Punch**]

Prefer not to answer [**Mutually Exclusive, Single Punch**]

[ERROR MESSAGE: Answer choices 'Not applicable', 'Don't remember', and 'Prefer not to answer' cannot be selected if a number is provided for a treatment.]

[ASK IF ANYTHING BUT "0" OR "Prefer not to answer" WAS SELECTED IN Q6.1] [SINGLE CODE]

6.5 On average, how long do your relapses last?

- 1-7 days
- 1-2 weeks
- 2 to 4 weeks
- 1-2 months
- 3-4 months
- 5-6 months
- More than 6 months
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

6.6 How many times have you visited an emergency room, urgent care center, or casualty department due to your NMO/SD in the past year?

- 0
- 1
- 2
- 3-5
- 6 or more
- Prefer not to answer

[ASK ALL] [MULTIPUNCH]

Section 7: Doctors/HCPs

[DISPLAY ON OWN SCREEN]

The following questions will ask about the doctors and healthcare providers that have treated you.

[ASK ALL] [SINGLE CODE]

7.1 Which type of health care provider did you first see to discuss your NMO/SD symptoms?

- Primary care physician
- Emergency room physician
- Ophthalmologist /eye physician
- Neurologist (NMO specialist)
- Neurologist (not an NMO specialist)
- Orthopedist
- Gastroenterologist
- Rheumatologist
- I don't know
- Other type of physician (please specify): [SPECIFY] _____
- Prefer not to answer

[ASK ALL] [MULTI-PUNCH]

7.2 After your initial evaluation, were you referred to a specialist physician (select all that apply)?

- Referred to ophthalmologist /eye physician
- Referred to neurologist (NMO specialist)
- Referred to neurologist (not an NMO specialist)
- Referred to neuro-ophthamologist
- Referred to gastroenterologist
- Referred to rheumatologist
- Referred to other type of physician (please specify): [SPECIFY] _____

- Not referred to a specialist physician **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**
- I don't know **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [MULTI-PUNCH]

7.3 What type of physician diagnosed you as having NMO/SD (select all that apply)?

- Ophthalmologist /eye physician
- Neurologist (NMO specialist)
- Neurologist (not an NMO specialist)
- Neuro-ophthamologist
- Gastroenterologist
- Rheumatologist
- I don't know **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**
- Other type of physician (please specify): **[SPECIFY]** _____
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [MULTICODE]

7.4 Which physician(s) currently prescribe your NMO/SD medicine(s)? (Please select all that apply)

- Primary care physician
- Ophthalmologist
- Neurologist
- Neuro-ophthamologist
- Orthopedist
- Rheumatologist
- Hematologist
- Psychiatrist
- I don't know **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**
- Other (please specify): **[SPECIFY]** _____

- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

7.5 How did you find the doctor who currently treats your NMO/SD?

- Referral from another doctor or Emergency Room
- Internet search
- Another NMO/SD patient
- Friend or relative
- Co-worker
- Foundation or advocacy group
- Health insurance
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

7.6 Approximately how often are you examined by your NMO/SD doctor?

- Every month
- Every 3 months
- Every 6 months
- Every year
- Only at time of relapse
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

7.7 Do you feel that your doctor(s?) should be more concerned about any of your symptoms than he or she is now?

- No
- Yes
- Prefer not to answer

[ASK IF Q7.7="Yes"] [MULTICODE]

7.8 Which symptoms do you feel this way about?

- Disability
- Pain
- Fatigue
- Depression
- Bladder control
- Cramping/muscle spasms
- Frequency of relapses
- Memory or cognitive deficits
- Side effects of medication (please specify): **[SPECIFY]**_____
- Other (please specify): **[SPECIFY]**_____
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

Section 8: Financial Implications of NMO

[DISPLAY ON OWN SCREEN]

The following questions will ask about your financial NMO / SD experience.

[ASK ALL] [SINGLE CODE]

8.1 Over an average 6-month period, how much time *in total* do you spend traveling to and from your NMO/SD doctors' offices?

- 30 minutes or less
- 1-2 hours
- 3-6 hours
- More than 6 hours
- Prefer not to answer

[ASK ALL] [MULTICODE]

**8.2 What method of transportation do you usually use to get to and from your medical appointments?
(Please select all that apply)**

- My household car
- A friend's or relative's car
- Public bus or subway
- Taxi (including Uber, Lyft, etc.)
- Transport provided by healthcare institution
- Specialized public transportation
- Train
- Airplane
- Other (please specify): [SPECIFY] _____
- Prefer not to answer [MUTUALLY EXCLUSIVE, SINGLE PUNCH]

[ASK ALL] [SINGLE CODE]

8.3 Does a professional caregiver currently provide service to your home?

- Yes
- No
- I live in an assisted living facility.
- Prefer not to answer

[ASK IF Q8.3="Yes"] [MULTICODE]

8.4 What support do you receive from this service? (Please select all that apply)

- Personal care / hygiene
- Mobility assistance
- Food preparation
- Housekeeping
- Transportation
- Childcare
- Other (please specify): [SPECIFY]_____
- Prefer not to answer [MUTUALLY EXCLUSIVE, SINGLE PUNCH]

[ASK IF Q8.3="Yes"] [SINGLE CODE]

8.5 Approximately how much did you pay out-of-pocket for this care in the past year?

- Less than 10% of my household income
- 10-24% of my household income
- 25-50% of my household income
- More than 50% of my household income
- Prefer not to answer

[ASK IF Q8.3="Yes"] [SINGLE CODE]

8.6 How much do you currently use of this service?

- Less than 2 hours per day
- 2-3 hours per day
- 4-5 hours per day
- 6-11 hours per day
- 12-23 hours per day
- 24 hours per day
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

8.7 Do you currently receive any financial support for your NMO/SD treatment?

- Yes
- No
- I have received support in the past, but I do not currently
- Prefer not to answer

[ASK IF Q8.7="Yes"] [MULTICODE]

8.8 Which sources provide you financial support for NMO/SD treatment? (Please select all that apply)

- Government (e.g. disability benefits)
- Employer
- Disability insurance
- Patient organization
- Clinical trial participation
- Family, friends, or other personal relationships
- Other (please specify): **[SPECIFY]**_____
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

8.9 Has your health insurance sufficiently covered medicines prescribed to treat your NMO/SD?

- Yes

- No
- Prefer not to answer

[ASK IF Q8.9="No"] [MULTICODE]

8.10 If no, why is the coverage insufficient? (Please select all that apply)

- Denied access to medication
- Denied insurance coverage
- Co-payment is too expensive
- Entire payment is too expensive
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [MULTICODE]

8.11 On average, how much do you pay annually out of pocket due to NMO/SD for the following:

[COLUMNS]

Annual Cost (\$) [0-999,999,999]

Prefer not to answer

[ROWS]

- 8.11a Prescription medicine(s)
- 8.11b Emergency / urgent care costs
- 8.11c Hospitalization
- 8.11d Travel cost for clinical exams or treatment
- 8.11e Caregiver or support services
 - 8.11e1 Medical supplies
 - 8.11e2 Support groups
- 8.11f Other costs (please specify): **[SPECIFY]**

[ASK ALL] [SINGLE CODE]

8.12 What accounts for your largest portion of medical costs due to NMO/SD?

- Prescription medicine(s)
- Emergency / urgent care costs
- Hospitalization
- Travel cost for clinical exams or treatment
- Caregiver or support services
- 8.11e1 Medical supplies
- 8.11e2 Support groups
- Other costs (please specify): **[SPECIFY]** _____

[ASK ALL] [SINGLE CODE]

8.13 How do you describe your out of pocket expense due to NMO/SD each month?

1	2	3	4	5	6	7	8	9	10
No Burden									Significant Burden

- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

Section 9: Demographics

[DISPLAY ON OWN SCREEN]

These final set of questions will ask about your demographic information.

[ASK ALL] [SINGLE CODE]

9.1 What is your gender?

- Female
- Male
- Specify: **[SPECIFY]** _____
- Prefer not to answer

[ASK ALL] [MULTICODE]

9.3 How do you identify your racial /ethnic background? (Please select all that apply)

- African American / Black
- Asian
- Caucasian / White
- Hispanic, Latino, or Spanish American
- Indian
- Japanese
- Native American
- Pacific Islander
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer

[ASK ALL] [MULTICODE]

9.4 With whom do you currently live? (Please select all that apply)

- Alone **[MUTUALLY EXCLUSIVE]**
- Spouse/Partner
- Children
- Parent(s)
- Sibling(s)
- Other relative(s)
- Friend(s)/companion(s)
- Domestic help
- Institutional domicile / care facility / assisted living center
- Other (please specify): **[SPECIFY]** _____
- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

9.5 To what degree is where you live by choice or by necessity, because of NMO/SD?

1	2	3	4	5	6	7	8	9	10
Choice									Necessity

- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

9.6 To what degree is with whom you live by choice or by necessity, because of NMO/SD?

1	2	3	4	5	6	7	8	9	10
Choice									Necessity

- Prefer not to answer **[MUTUALLY EXCLUSIVE, SINGLE PUNCH]**

[ASK ALL] [SINGLE CODE]

9.7 Do you have children?

- Yes
- No

- Prefer not to answer

[ASK ALL] [SINGLE CODE]

9.8 What is the average annual income of your household?

- Less than \$10,000
- \$10,000-\$24,999
- \$25,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000 or more
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

9.9 What is the highest level of education you have completed?

- Primary education / High school / GED
- Associate or Technical degree
- Bachelor degree
- Post-graduate education (Masters, Doctorate)
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

9.10 Did you receive help from another person when filling out this survey, or did you fill it out alone?

- I received help filling out this survey
- I did not receive help; I completed this survey alone
- Prefer not to answer

[ASK ALL] [SINGLE CODE]

9.11 Would you consider participating in patient-reported outcomes studies that assess NMO/SD disease disability, severity or other measures?

- Yes
- No
- Prefer not to answer

[DISPLAY ON OWN SCREEN]

You have now completed the research study. Thank you for your participation! Your answers provide useful insight into the life experiences of individuals with NMO/SD.

I want to emphasize that your responses are completely confidential. Although the questions we asked you to answer are not likely to have an effect on your emotional state, people can experience a variety of thoughts and feelings after thinking about a personal topic. If you are experiencing any negative feelings - regarding this study or otherwise - I encourage you to contact the principle investigator listed below.

If you have any questions about medications used to treat NMO/SD, please consult a health care professional, or contact the Guthy-Jackson Charitable Foundation at: (858) 638-7638 or email info@guthyjacksonfoundation.org.

If you have any questions about the research or for information about the study procedures, contact:

Principal Investigator

Aysha Keisler, PhD
Ipsos Public Affairs
2020 K Street NW, Suite 410
Washington, DC 20006
Phone: 202.831.5363
Email: nmo.research@ipsos.com

Please proceed to the next page to provide information to receive your compensation.

[REDIRECT TO SECOND SURVEY]

[DISPLAY ON OWN SCREEN]

We will be sending your compensation to you by email.

Please provide your email address below. Please note that this information will remain confidential and will not be linked with your responses in any way.

If you do not wish to receive an incentive, please select the box that reads "I am not interested in receiving an incentive."

[RESPONDENTS MUST ANSWER BOTH 1) “In what country is your main residence?” question and provide an email address in both fields 2) OR check off “I am not interested in receiving an incentive”.]

[PN: Add custom error message. If the respondent provides email addresses that match, but did not answer the country question, please display ‘Please provide an answer to the country of main residence question’]

[ASK ALL][SINGLE PUNCH]

In what country is your main residence?

- United States
- Canada

[ASK ALL] [VERBATIM]

[RESPONSES TO BOTH SPECIFIES BELOW MUST MATCH]

Email address: _____ **[SPECIFY]**

Confirm email address: _____ **[SPECIFY]**

I am not interested in receiving an incentive. **[SINGLE PUNCH][MUTUALLY EXCLUSIVE]**

[DISPLAY ON OWN SCREEN]

Thank you! If you have elected to receive compensation for your participation in this survey, you should expect a gift card to be provided to you electronically **within a week**. If you have any questions or issues related to your gift card please reach out to nmo.research@ipsos.com