

Health Survey

Thank you for agreeing to take this survey. Before we begin, we would like to ask a few questions to determine whether you are eligible to participate.

S1. What is your age (in years)?

[Dropdown list; Must be 18 years or older]

S2. Are you a resident of the United States?

☐ Yes [Eligible, must answer to continue]

☐ No [Ineligible]

S3. What gender identity best describes you?

☐ Female

☐ Male

☐ Gender fluid

☐ Non-binary

☐ A gender identity not listed here

☐ Prefer not to answer

S4. What race(s) do you consider yourself to be? *(Please select all that apply.)*

- ☐ American Indian or Alaskan Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Prefer not to answer [\[Exclusive\]](#)

S5. Which of the following ethnicity categories best describes you?

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ Prefer not to answer

- S6. Using the five racial categories listed below, to the best of your knowledge, please provide the approximate percentage of each race that best describes you. For example, if you are 25% Cherokee and 75% African American, then you would enter 25% for the American Indian or Alaskan Native category and 75% for the Black or African American category.

Your selections should total to 100%.

American Indian or Alaskan Native: _____
Asian: _____
Black or African American: _____
Native Hawaiian or other Pacific Islander: _____
White: _____
Other: _____
Unknown: _____
Total: _____

[Please ensure that the total does not exceed 100%]

- S7. Using the sliding scale below, please describe your skin tone using a scale from 1 to 10 where 1 is light and 10 is dark.

Light	1	2	3	4	5	6	7	8	9	10	Dark
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[Please program a sliding scale]

S8. Have you been told by a healthcare provider that you have neuromyelitis optica spectrum disorder (NMOSD)?

☐ Yes [\[Eligible, must select to continue\]](#)

☐ No [\[Ineligible, end survey\]](#)

S9. Most people who have been diagnosed with NMOSD have certain types of antibodies that attack their immune system. Knowing what type of antibodies you have can help your healthcare provider determine what type of treatments may work better for you. To your knowledge, has your healthcare provider ever told you what type of antibodies you have?

☐ Yes, I am aquaporin-4 (AQP4) positive [\[Eligible, must select to continue\]](#)

☐ Yes, I am aquaporin-4 (AQP4) negative [\[Ineligible, end survey\]](#)

☐ No, I have not discussed my antibody status with my healthcare provider [\[Ineligible, end survey\]](#)

☐ Don't know or not sure [\[Ineligible, end survey\]](#)

S10. Which of the following medications or treatments have you ever taken to prevent or suppress a relapse in your NMOSD symptoms? *A relapse in your NMOSD is when your symptoms suddenly get worse or more severe, or you suddenly experience new neurological symptoms that you have never experienced before.* Please select only those medications that you have taken to treat your NMOSD and not medications for other conditions that you may have. *(Please select all that apply.)*

- ☐ Azathioprine [Imuran, Azasan]
- ☐ Cyclosporine [Gengraf, Norel, Sandimmune]
- ☐ Eculizumab [Soliris]
- ☐ Immune globulin intravenous (IVIg) [Carimune, Gamunex, Gammagard, Octagam]
- ☐ Inebilizumab [Uplizna]
- ☐ Methotrexate [Trexall]
- ☐ Methylprednisolone (intravenous) [Medrol, Medlone]
- ☐ Mycophenolate mofetil [CellCept]
- ☐ Plasmapheresis (Plasma Exchange [PLEX])
- ☐ Prednisone [Flo-Pred, Millipred, Orapred, Pediapred, Veripred]
- ☐ Rituximab [Rituxan]
- ☐ Satralizumab [Enspryng]
- ☐ Other prescription medicine to prevent or suppress a relapse in your NMOSD symptoms
- ☐ None of the above [Exclusive response; Ineligible, end survey]

[Must select at least one of the above. If "Other" is selected, then must select at least one other response option]

S11. [\[Display only those selected in S10\]](#) Which of the following medications or treatments are you currently taking to prevent or suppress a relapse in your NMOSD symptoms? Please select only those medications that you are taking to treat your NMOSD and not medications for other conditions that you may have. *(Please select all that apply.)*

- ☐ Azathioprine [Imuran, Azasan]
- ☐ Cyclosporine [Gengraf, Norel, Sandimmune]
- ☐ Eculizumab [Soliris]
- ☐ Immune globulin intravenous (IVIg) [Carimune, Gamunex, Gammagard, Octagam]
- ☐ Inebilizumab [Uplizna]
- ☐ Methotrexate [Trexall]
- ☐ Methylprednisolone (intravenous) [Medrol, Medlone]
- ☐ Mycophenolate mofetil [CellCept]
- ☐ Plasmapheresis (Plasma Exchange [PLEX])
- ☐ Prednisone [Flo-Pred, Millipred, Orapred, Pediapred, Veripred]
- ☐ Rituximab [Rituxan]
- ☐ Satralizumab [Enspryng]
- ☐ Other medicine to prevent or suppress a relapse in your NMOSD symptoms
- ☐ None of the above [\[Exclusive response\]](#)

[Respondent is eligible if:

- Aged at least 18 years (S1), and
- Yes to S2, and
- Yes to S58, and
- Yes, I am aquaporin-4 (AQP4) positive in S99, and
- Does not select None of the above in S1010, OR if selected "Other," must have selected at least one other response option
- Note: S1, S3, S4, S5, S6 and S7 will be used to track diversity in the sample]

Your Experience With Neuromyelitis Optica Spectrum Disorder

Thank you for your interest in this survey. We appreciate your time. To begin, we will start with a few questions to help us understand your experience with NMOSD.

1. In what year did a healthcare provider first tell you that you had NMOSD?

[\[Dropdown list\]](#)

2. On a scale from 1 to 5, where 1 is "Not affected at all" and a 5 is "Significantly affected," please review the table and tell us how your NMOSD has affected each of the functions listed in the table below. When answering the question, please think about your NMOSD over the past 7 days.

	Not affected at all	Somewhat affected	Affected	Very affected	Significantly affected
Function	1	2	3	4	5
Mobility/walking	☐	☐	☐	☐	☐
Hand coordination	☐	☐	☐	☐	☐
Bladder/bowel control	☐	☐	☐	☐	☐
Vision	☐	☐	☐	☐	☐
Memory and thinking	☐	☐	☐	☐	☐
Fatigue/tiredness	☐	☐	☐	☐	☐
Pain	☐	☐	☐	☐	☐

3. On a scale from 1 to 5, where 1 is "Poor" and 5 is "Excellent," thinking about your NMOSD and all the ways it affects you, how would you rate your overall health in the past 7 days?

Poor	1	2	3	4	5	Excellent
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Your Experience With Relapse in Your NMOSD

4. A relapse in your NMOSD is when your symptoms suddenly get worse or more severe, or you suddenly experience new neurological symptoms that you have never experienced before. Approximately how many times have you experienced a relapse in your NMOSD since your NMOSD diagnosis?

[Drop down list with numbers from 0 to 100]

☐ Don't know or not sure [Exclusive]

5. [Display only if Q4 > 0] Approximately how many times have you experienced a relapse in your NMOSD in the past 12 months?

[Drop down list with numbers from 0 to 100]

☐ Don't know or not sure [Exclusive]

6. [Display only if Q4 > 0] When was the last time you experienced a relapse in your NMOSD?

Month _____ Year _____ [Dropdown list for month and year]

7. [Display only if Q4 > 0] Did you fully recover after your most recent relapse? By fully recover, we mean that your symptoms went away or went back to what they were before your relapse.

☐ Yes

☐ No

8. [If "Yes" to Q7] Since your last relapse, which of the following statements apply to you? (Please select all that apply.)

- ☐ I have experienced a new symptom that I did not have before
- ☐ I have experienced multiple new symptoms that I did not have before
- ☐ I have experienced a worsening in some of my existing symptoms
- ☐ I have experienced a worsening in all of my existing symptoms
- ☐ None of the above [Exclusive]

9. [If selected "I have experienced a worsening of some of my existing symptoms" OR "I have experienced a worsening in all of my existing symptoms" in Q0] Using the scale below, how much worse have your existing symptoms gotten since your last NMOSD relapse?

Not much worse	1	2	3	4	5	Much worse
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10. [Display only if Q4 > 0] Using the scale below, please tell us how much you agree with the following statement: "I feel that I am able to do most of the things that I want to do since my last NMOSD relapse."

Completely disagree	1	2	3	4	5	Completely agree
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11. [Display only if Q4 > 0] During your last relapse, did you require assistance from a friend, family member, or care partner/care giver to help you with your daily or personal activities?

- ☐ Yes
- ☐ No

12. Have you ever been hospitalized because of a relapse in your NMOSD? By hospitalized, we mean that you were formally admitted to a hospital or clinic and received in-patient care because of your NMOSD.

☐ Yes

☐ No

Thinking About Treatments for NMOSD

Now we would like you to suppose that your healthcare provider tells you about new treatments for NMOSD. These treatments can be taken in different ways and on different schedules and cause different side effects. In this survey, we will ask you to think about the following features of treatments for NMOSD:

- Chance that you will have a relapse within the first year of treatment
- What is required before starting treatment
- What activities are required to stay on treatment
- How you take the treatment
- How often you have to take the treatment
- Whether the treatment has an increased risk of meningococcal infection and requires a meningococcal vaccine
- Whether the treatment has an increased risk of liver injury
- Whether the treatment has an increased risk of a serious infection (other than a meningococcal infection)

Treatment Feature: Chance That You Will Have a Relapse Within the First Year of Treatment

One of the primary goals of the treatment for NMOSD is to prevent you from having a relapse while on treatment. A relapse in your NMOSD can cause a permanent worsening of your symptoms or disability that does not get better after the relapse is over.

Medical studies have shown that some treatments for NMOSD work better than others to prevent relapses while on treatment.

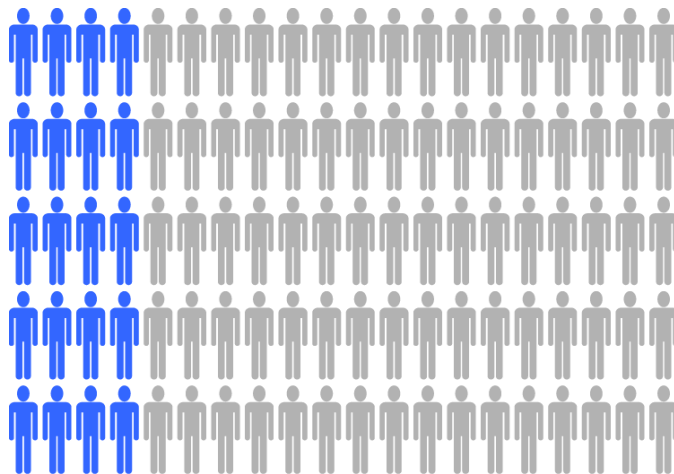
In this survey, we will show you treatments for NMOSD that are different in terms of the chance of a relapse within the first year of treatment.

Thinking About the Chance That You Will Have a Relapse Within the First Year of Treatment

We will use the following graphic to help you think about the chance that you will have a relapse within the first year of taking the NMOSD treatment.

- The picture below has 100 figures.
- Each figure is 1 person who takes an NMOSD treatment to prevent a relapse.
- In this graphic, the figures shown in color indicate people who will have a relapse within the first year of treatment.
- The figures in gray show the number of people who will not have a relapse within the first year of treatment.

Nobody can say for sure who will have a relapse within the first year of treatment. The more figures shown in color, the higher your chance of having a relapse within the first year of treatment.

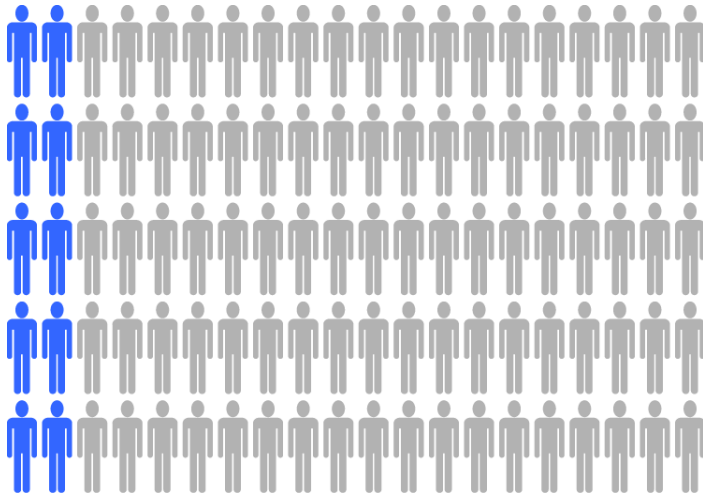


In this example:

There are 20 figures in blue. This means that 20 people out of 100 (20%) who take an NMOSD treatment will have a relapse in the first year of treatment. In other words, there is a 20% chance of having a relapse while on treatment.

80 of the figures are gray. This means that 80 people out of 100 (80%) who take an NMOSD treatment will not have a relapse in the first year of treatment. In other words, there is an 80% chance of not having a relapse in the first year of treatment.

Please look at the graphic below:

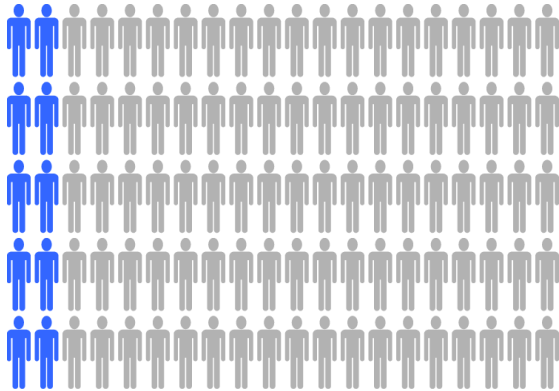


Remember that the figures shown in color represent the number of people who will have a relapse within the first year of treatment.

13. If each figure in the graphic is 1 person who is taking an NMOSD treatment, how many people will have a relapse within the first year of treatment?

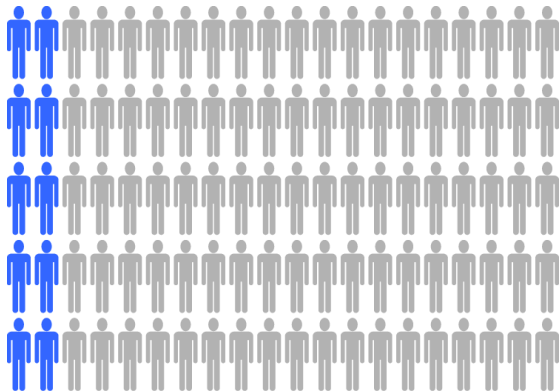
- ☐ 10 out of 100 (10%)
- ☐ 30 out of 100 (30%)
- ☐ 90 out of 100 (90%)
- ☐ 1 out of 100 (1%)
- ☐ Don't know or not sure

[If Q13 = 10%]



You are correct. There are 100 figures in the picture, and 10 of these figures appear in blue. These 10 figures in color indicate that 10 people taking an NMOSD treatment will have a relapse within the first year. Therefore, 10 out of 100 people (10%) is the correct answer.

[If Q13 $\neq$ 10%]



Based on your response, we want to remind you that each figure in the picture represents someone who is taking an NMOSD treatment.

- There are 100 figures in the picture.
- 10 of these figures appear in blue. These 10 figures in color indicate that 10 people out of 100 who are taking an NMOSD treatment will have a relapse within the first year of treatment.
- Therefore, 10 out of 100 people (10%) is the correct answer.

Treatment Feature: What is Required Before Starting Treatment

For some NMOSD treatments, it is necessary to have routine bloodwork to make sure you don't have any conditions such as hepatitis B or tuberculosis. For other NMOSD treatments, routine bloodwork is not required to start treatment. These options are described in the table below.

What is Required Before Starting Treatment	
Routine bloodwork	• Routine bloodwork is required to make sure that you don't have any conditions, such as hepatitis B or tuberculosis. • People with these conditions cannot safely take these NMOSD treatments. If the treatment requires routine bloodwork, you will have to go to your doctor's office or local lab to have your blood drawn and tested. • The test results will tell your doctor whether you can take the treatment or not.
No bloodwork required	• Routine bloodwork is not required before starting treatment.

14. Using the scale below, how concerned are you about having to get routine bloodwork to be able to take an NMOSD treatment?

Not at all concerned _____ Extremely concerned
1 2 3 4 5

Treatment Feature: What Activities Are Required to Stay on Treatment

For some NMOSD treatments, you will need to do 1 or more of the following to continue treatment:

- Have regular routine bloodwork in the first year of treatment to make sure that you do not have abnormally high levels of certain enzymes and proteins in your blood
- Take certain medications each time that you receive the treatment for as long as you are on the treatment
- Have both regular routine bloodwork in the first year of treatment and medication before each treatment

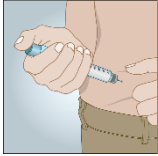
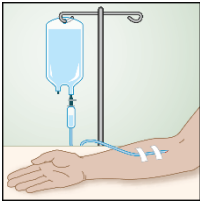
For other NMOSD treatments, no activities are required to stay on treatment. Please review the descriptions in the table below.

What Activities Are Required to Stay on Treatment	
Routine bloodwork	• If the NMOSD treatment requires routine bloodwork after starting treatment, you would have to go once a month for the first 3 months of treatment and then every 3 months after that, for a total of 6 times in the first year of treatment. • Then, your doctor will decide how often you will need the bloodwork after that. • If the bloodwork shows that you have high levels of enzymes and proteins in your blood, then you would have to stop taking the treatment.
Medication before each treatment	• If the NMOSD treatment requires you to take medications each time you receive the treatment, you will need to take a dose of steroids, known as corticosteroids, by intravenous infusion at least 30 minutes prior to taking the NMOSD treatment. • You will also need to take an oral antihistamine such as Benadryl and an oral pain reliever such as Tylenol at least 30 to 60 minutes before taking the NMOSD treatment. • You will have to do this each time you receive the treatment for as long as you get the treatment.
Both routine bloodwork and medication before each treatment	• Both routine bloodwork and medication before each treatment are required.

No activities required	• Neither routine bloodwork nor medication are required to stay on treatment
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Treatment Feature: How You Take the Treatment

The possible treatments that we will ask you to think about are taken in different ways. Please review the descriptions in the table below.

How you take the treatment	
 Self-administered injection with a prefilled syringe or pen	• The injection will come ready to use as a prefilled syringe or a “pen” (an autoinjector). • You (or a family member or friend) will inject the needle under your skin, usually in the abdomen, thigh, or back of the arm. • It will take you approximately less than 1 minute to inject yourself. • You will need to monitor yourself for any side effects such as pain, swelling, and/or rash.
 Intravenous infusion administered by a healthcare professional	• You will need to go to your doctor’s office, hospital, or clinic, or a nurse or other healthcare professional will come to your home. • If you do not have a port, a nurse will insert a needle into a vein in your arm. If you have a port, a nurse will insert a needle into the port. The needle is attached to a bag filled with liquid medicine. • It will take about 1 hour for you to get the infusion. • After the infusion is complete, nurses or your doctor will monitor you for side effects such as pain, swelling and/or rash for up to 1 hour.

15. Please read the following statements and select the statement that applies to you. By regular, we mean on a schedule, as part of a treatment plan, and not a 1-time event. You may select more than one statement if it applies to you.

- ☐ I have received regular injections for my NMOSD or another health condition.
- ☐ I have received regular IV infusions for my NMOSD or another health condition.
- ☐ I have received neither regular injections nor regular infusions. [Exclusive]

16. Using the scale below, how interested are you in starting a new treatment for NMOSD?

Not at all interested	1	2	3	4	5	Extremely interested
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17. Using the scale below, how satisfied are you with your current NMOSD treatment(s)?

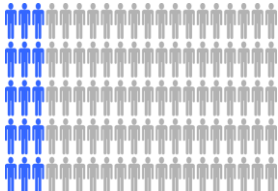
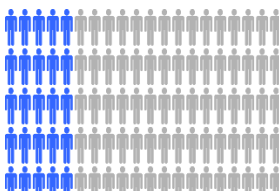
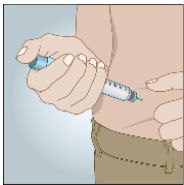
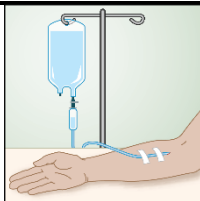
Not at all satisfied	1	2	3	4	5	Extremely satisfied
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Thinking About NMOSD Treatments

[If selected anything other than "None of the above" in S0] Suppose that you go to your doctor for a checkup, and your doctor tells you about other treatments you can take to prevent you from having a relapse of your NMOSD.

[If selected "None of the above" in S0] Suppose that you go to your doctor for a checkup, and your doctor recommends that you start taking a treatment to prevent you from having a relapse of your NMOSD.

Your doctor recommends that you start a new treatment and that there are 2 treatments that you could take: Treatment A and Treatment B. In the table below, each column describes a treatment. Which treatment would you choose?

Treatment Feature	Treatment A	Treatment B
Chance that you will have a relapse within the first year of treatment	 15 out of 100 people (15%)	 25 out of 100 people (25%)
What is required before starting treatment	No bloodwork required	Routine bloodwork
What activities are required to stay on treatment	Medication before each treatment	No activities required
How you take the treatment	 Self-administered injection with a prefilled pen or autoinjector	 Intravenous infusion administered by a healthcare professional
Which would you choose?	☐	☐

Treatment Feature: How Often You Have to Take the Treatment

The NMOSD treatments we will ask you to think about in this survey are taken on different schedules.

Please assume that you will remain on the treatment until you and your doctor decide you should stop taking the treatment. The table below provides the information about the different dosing schedules.

How Often You Have to Take the Treatment	
 (2 times per month)	You will take the treatment on a schedule <u>once every 2 weeks (2 times per month)</u>.
 (Once per month)	You will take the treatment on a schedule <u>once every 4 weeks (Once per month)</u>.
 (Once every 2 months)	You will take the treatment on a schedule <u>once every 8 weeks (Once every 2 months)</u>.
 (Once every 6 months)	You will take the treatment on a schedule <u>once every 24 weeks (Once every 6 months)</u>.

19. Using the scale below, how important is it for you to reduce the frequency of your NMOSD treatment(s)?

Not at all important

1	2	3	4	5
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Extremely important

Treatment Feature: Treatment Has an Increased Risk of Meningococcal Infection and Requires a Meningococcal Vaccine

Some treatments for NMOSD have an increased risk of meningococcal infection and some of the treatments will not. The most common type of a meningococcal infection is meningitis, a serious infection that affects the brain and nervous system.

Most of the time these infections can be treated with medicines. However, a meningococcal infection may result in an extended hospital stay, may cause significant disability, or may even lead to death. If the treatment has an increased risk of meningococcal infection, you will be required to start the process of getting vaccinated against meningococcal disease at least 2 weeks before you can begin treatment. If you have not been vaccinated against meningococcal disease, you will need a total of 4-5 shots to be fully vaccinated. If you are already fully vaccinated, you may still need a booster shot before starting treatment.

If a treatment has an increased risk of meningococcal infection, it will be very low, occurring in approximately 1 out of every 100 people treated (1%).

20. Have you ever had a meningococcal infection as described above?

- ☐ Yes
- ☐ No
- ☐ Don't know or not sure

21. Using the scale below, how concerned would you be about getting a meningococcal infection (as described above) because of an NMOSD treatment?

Not at all concerned	1	2	3	4	5	Extremely concerned
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22. Using the scale below, how concerned are you about getting vaccinated against meningococcal disease to be able to take an NMOSD treatment?

Not at all concerned	1	2	3	4	5	Extremely concerned
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Treatment Feature: Treatment Has an Increased Risk of Liver Injury

Some treatments for NMOSD have an increased risk of injury to your liver and some of the treatments will not. Most people who have a liver injury do not experience any symptoms. Some people may experience symptoms such as stomach pain, fatigue, dark or discolored urine, jaundice (yellowing of the skin), or nausea and vomiting.

In most cases, if you experience a liver injury because of an NMOSD treatment it will go away within a few weeks. If your liver injury does not go away, then your doctor may need to perform additional tests and will determine how severe the problem is and whether you can continue taking the treatment.

If a treatment has an increased risk of a liver injury, it will be low, occurring in approximately 7 of every 100 people treated (7%).

23. Using the scale below, how concerned would you be about getting a liver injury (as described above) because of an NMOSD treatment?

Not at all concerned

1	2	3	4	5
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Extremely concerned

Treatment Feature: Treatment Has an Increased Risk of a Serious Infection (Other Than Meningococcal Infection)

Some treatments for NMOSD have an increased risk of serious infection other than a meningococcal infection, and some of the treatments will not. Some of the most common types of these serious infections in patients who take these medicines include tuberculosis (TB), shingles, and other infections caused by bacteria, fungi, or viruses that can spread throughout the body.

Most of the time these infections can be treated with medicines. However, these infections may result in an extended hospital stay, may cause significant disability, or may even lead to death.

If a treatment has an increased risk of these serious infections, it will be low, occurring in approximately 9 of every 100 people treated (9%).

24. Have you ever had a serious infection as described above?

- ☐ Yes
- ☐ No
- ☐ Don't know or not sure

25. Using the scale below, how concerned would you be about getting a serious infection (as described above) because of an NMOSD treatment?

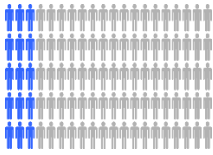
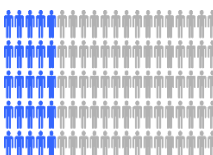
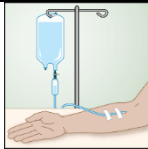
Not at all concerned	1	2	3	4	5	Extremely concerned
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Thinking About Treatments for NMOSD

26. Please look at the table below. Which treatment has a higher chance that you will have a relapse within the first year of treatment?

☐ Treatment A

☐ Treatment B

Treatment Feature	Treatment A	Treatment B
Chance that you will have a relapse within the first year of treatment	 15 out of 100 people (15%)	 25 out of 100 people (25%)
What is required before starting treatment	No bloodwork required	Routine bloodwork
What activities are required to stay on treatment	Medication before each treatment	No activities required
How you take the treatment	 Self-administered injection with a prefilled pen or autoinjector	 Intravenous infusion administered by a healthcare professional
How often you have to take the treatment	 (Once every 2 months)	 (Once every 2 months)
Treatment has an increased risk of meningococcal infection and requires a meningococcal vaccine	Yes	No
Treatment has an increased risk of liver injury	No	Yes
Treatment has an increased risk of a serious infection	Yes	No

(other than meningococcal infection)		
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[If Q266 Treatment A] Based on your response, we want to remind you that the figures in the top row show the number of people taking an NMOSD treatment who will have a chance of relapsing within the first year of treatment.

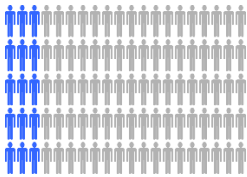
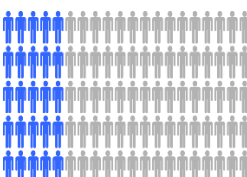
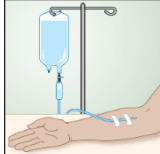
- For Treatment A, there are 15 figures in color. This means that 15 of 100 people (15%) will have a relapse within the first year of treatment.
- For Treatment B, there are 25 figures in color. This means that 25 of 100 people (25%) will have a relapse within the first year of treatment.
- Therefore, Treatment B has a higher chance of relapse within the first year of treatment.

[If Q266 is Treatment B] You are correct. For Treatment A, there are 15 figures in color. This means that 15 of 100 patients (15%) will have a relapse within the first year of treatment. For Treatment B, there are 25 figures in color. This means that 25 of 100 people (25%) will relapse within the first year of treatment. Therefore, Treatment B has a higher chance of relapse within the first year of treatment.

27. This is the same table again. Which treatment would you choose?

☐ Treatment A

☐ Treatment B

Treatment Feature	Treatment A	Treatment B
Chance that you will have a relapse within the first year of treatment	 15 out of 100 people (15%)	 25 out of 100 people (25%)
What is required before starting treatment	No bloodwork required	Routine bloodwork
What activities are required to stay on treatment	Medication before each treatment	No activities required
How you take the treatment	 Self-administered injection with a prefilled pen or autoinjector	 Intravenous infusion administered by a healthcare professional
How often you have to take the treatment	 Once every 2 months	 Once every 2 months
Treatment has an increased risk of meningococcal infection and requires a meningococcal vaccine	Yes	No
Treatment has an increased risk of liver injury	No	Yes
Treatment has an increased risk of a serious infection (other than meningococcal infection)	Yes	No

Your Opinions About Treatments for NMOSD

[If selected anything other than "None of the above" in S0] As before, suppose that you go to your doctor for a checkup, and your doctor tells you about other treatments you can take to prevent having a relapse of your NMOSD. Your doctor recommends that you start a new treatment.

[If selected "None of the above" in S0] As before, suppose that you go to your doctor for a checkup, and your doctor recommends that you start taking a treatment to prevent having a relapse of your NMOSD.

Your doctor tells you that there are 2 options that you could choose from: Treatment A and Treatment B. Each of the next 8 questions will show you a different pair of hypothetical treatments (Treatment A or Treatment B). For each pair of treatments, please tell us which treatment you would prefer (Treatment A or Treatment B).

Suppose that all the treatments would cost the same.

[Display if S0 ≠ "None of the above"] The treatment you choose would replace any other NMOSD treatment you might be taking now.

Please consider the treatments as they are described, even if they are different from treatments you have considered or taken in the past.

When deciding which treatment to choose, please choose the treatment that you prefer the most and not what you think is best for other people. There are no right or wrong answers.

If you need to see the description for any treatment feature, feel free to move the mouse over that feature to see the description again. [NOTE: this depends on how it is programmed online... please check that the sentence is accurate]

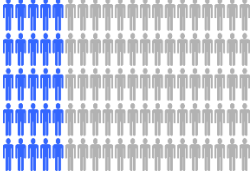
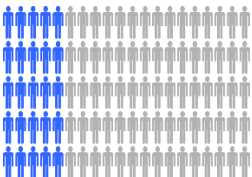
[NOTE: Insert the set of discrete-choice experiment (DCE) questions here. There are 6 different sets of DCE questions defined in the experimental design. RTI-HS has prepared the final experimental design and sent it in a separate Excel file. There are 6 sets of DCE questions, each with 8 questions each. One set should be randomly assigned to each respondent and the questions in that set should be presented to the respondent in randomized order).

The following page includes an example DCE task. It is a placeholder and should not actually be shown to respondents.

Each respondent will be presented with 8 experimentally designed DCE tasks in random order.

Each DCE task will also include programming that will allow respondents to hover their mouse over the medicine feature to review an abbreviated description of the feature. The text for each medicine feature is on the Tool tip tab in the DCE experimental design spreadsheet]

Example Choice Question

Treatment Feature	Treatment A	Treatment B
Chance that you will have a relapse within the first year of treatment	 25 out of 100 people (25%)	 25 out of 100 people (25%)
What is required before starting treatment	No bloodwork required	Routine bloodwork
What activities are required to stay on treatment	No activities required	No activities required
How you take the treatment	 Self-administered injection with a prefilled pen or autoinjector	 Intravenous infusion administered by a healthcare professional
How often you have to take the treatment	 2 times per month	 2 times per month
Treatment has an increased risk of meningococcal infection and requires a meningococcal vaccine	Yes	No
Treatment has an increased risk of liver injury	No	Yes
Treatment has an increased risk of a serious infection (other than meningococcal infection)	No	No

Which one would you choose?	☐	☐
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Other Questions About You

28. Do you have a regular care partner or caregiver that helps you with your day-to-day activities?

☐ Yes

☐ No

29. [\[If "Yes" to Q288\]](#) From the list below, please select the person who is your primary care partner or caregiver. (Select only 1 answer).

☐ Close friend

☐ Spouse/partner

☐ Sibling

☐ Child(ren)

☐ Grandparent(s)

☐ Parent(s)/Parent(s)-in-law

☐ Home healthcare aid or other healthcare professional

☐ Other

30. Using the table below, please tell us how often you require the assistance of a friend, family member, or caregiver to help you with the following activities because of your NMOSD:

Activity	Never	Rarely	Sometimes	Often	Always	Does Not Apply to Me
Performing moderate physical activities (such as shopping, vacuuming, ironing, cleaning the bathroom)	☐	☐	☐	☐	☐	☐
Running errands outside the home	☐	☐	☐	☐	☐	☐
Caring for family members (such as children, siblings, parents, pets)	☐	☐	☐	☐	☐	☐
Performing light physical activities (such as cooking, opening jars, daily hygiene)	☐	☐	☐	☐	☐	☐
Participating in leisure or social activities outside the house	☐	☐	☐	☐	☐	☐
Managing personal finances	☐	☐	☐	☐	☐	☐
Going to medical appointments	☐	☐	☐	☐	☐	☐

31. From the list below, please select all of the ways in which you have modified or adjusted your day-to-day life to help manage your NMOSD. (*Please select all that apply.*)

- ☐ Using an assistive device, such as a cane, walker, wheelchair, or scooter
- ☐ Getting help from a care partner/caregiver
- ☐ Physical therapy (at home or outside the home)
- ☐ Using stress-reducing activities (such as yoga, exercise, meditation)
- ☐ Using special products or adaptive devices around the home (such as reachers, handlebars, shower seats)
- ☐ Using technology to aid in communication (such as computer screen readers, magnification software, voice-activated software or writing programs)
- ☐ Adapting your home to make it easier to move around (such as a stair lift or permanent ramp to your front door, countertops that raise and/or lower)
- ☐ Eating a special diet or having dietary restrictions
- ☐ Taking vitamins or other dietary supplements
- ☐ Other
- ☐ None of the above [\[Exclusive\]](#)

32. Which form of transportation do you use to get from your home to the location (such as a healthcare provider's office or infusion center) where you receive your NMOSD treatment? *(Please select all that apply.)*

- ☐ A car that I own and I drive myself
- ☐ A car that is driven by someone else (such as a friend, family member, or caregiver)
- ☐ A shuttle service
- ☐ Public transportation (such as a bus, train, subway, metro)
- ☐ Ridesharing (such as Uber, Lyft)
- ☐ Taxi
- ☐ Other

33. On average, how long does it take you to get from your home to the location (such as a healthcare provider's office, infusion center) where you receive your NMOSD treatment?

_____ hours and _____ minutes

[Drop down lists for 0 to 9 hours and 0 to 59 minutes]

34. Have you ever been diagnosed with any of the following medical conditions? *(Please select all that apply.)*

- ☐ Arthritis
- ☐ Asthma or allergies
- ☐ Atopic dermatitis (eczema)
- ☐ Diabetes
- ☐ Depression
- ☐ Emphysema
- ☐ Epilepsy
- ☐ Heart disease
- ☐ High blood pressure
- ☐ High cholesterol
- ☐ Kidney disease
- ☐ Migraines
- ☐ Multiple sclerosis
- ☐ Osteoporosis
- ☐ Psoriasis
- ☐ Rheumatoid arthritis
- ☐ Seizures
- ☐ Stomach or digestive problems
- ☐ Stroke
- ☐ Swelling or edema
- ☐ Systemic lupus erythematosus (SLE)
- ☐ Thyroid problems (low or high thyroid levels)
- ☐ None of the above [\[Exclusive\]](#)

35. Which of the following best describes the geographic area in which you live?

☐ Urban

☐ Suburban

☐ Rural

36. What is your marital status?

☐ Single/never married

☐ Married/living as married/civil partnership

☐ Divorced or separated

☐ Widowed/surviving partner

☐ Other

☐ Prefer not to say

37. What is the highest level of education you have completed? (*Select only one answer.*)

- ☐ Less than high school
- ☐ Some high school
- ☐ High school or equivalent (such as a GED)
- ☐ Some college but no degree
- ☐ Technical school
- ☐ Associate's degree (2-year college degree)
- ☐ 4-year college degree (such as a BA, BS)
- ☐ Some graduate school but no degree
- ☐ Graduate or professional degree (such as an MBA, MS, MD, PhD)
- ☐ Prefer not to say

38. Which of the following best describes your current employment status? (*Select only one answer.*)

- ☐ Employed full time
- ☐ Employed part time
- ☐ Self-employed
- ☐ Homemaker
- ☐ Student
- ☐ Retired
- ☐ Disabled/unable to work
- ☐ Unemployed but looking for work
- ☐ Unemployed and not looking for work
- ☐ Prefer not to say

39. What type of health insurance do you have? *(Please select all that apply.)*
- ☐ I do not have health insurance
 - ☐ Private insurance that I pay for myself
 - ☐ Private insurance that my employer or my spouse's employer pays all or part of
 - ☐ Medicaid
 - ☐ Medicare
 - ☐ Veteran's Health Insurance
 - ☐ Other
 - ☐ Don't know or not sure
40. Do you have difficulty accessing healthcare related to the treatment of your NMOSD?
- ☐ Yes
 - ☐ No
 - ☐ Don't know or not sure
41. *[If "Yes" to Q40]* From the list below, please select the reasons you have had difficulty accessing healthcare related to the treatment of your NMOSD? *(Please select all that apply.)*
- ☐ My co-pay/deductible is too expensive
 - ☐ Transportation or difficulty getting to healthcare provider's office, clinic, or hospital
 - ☐ My insurance wouldn't cover my treatment
 - ☐ My symptoms prevented me from leaving the house
 - ☐ Healthcare provider's office, clinic, or hospital is too far away
 - ☐ Don't know or not sure

42. Have you ever needed financial assistance to help cover your out-of-pocket expenses associated with your NMOSD treatment?

- ☐ Yes
- ☐ No
- ☐ Don't know or not sure

43. [\[If Yes to Q422\]](#) Which of the following types of financial assistance have you ever used or received to help cover the cost of your NMOSD treatment? *(Please select all that apply.)*

- ☐ NORD Financial Assistance Program
- ☐ The Assistance Fund
- ☐ Patient Access Network Foundation
- ☐ Assistance from a pharmaceutical company
- ☐ Discounts through the hospital where I receive my care
- ☐ Medicare supplemental programs
- ☐ Local funding through my community
- ☐ Other