



## Attitudes and Practices Regarding COVID-19 in People with Multiple Sclerosis (MS)

---

**Instructions:** Please complete the following survey about your MS and your view on COVID-19. Do your best to answer all the questions on this survey. Take as much time as you need to finish. If you need help filling out this survey, a friend or care-partner may fill it out with or for you.

---

**Survey Date:** \_\_\_\_\_

**Please tell us a little about your MS:**

1. Have you been diagnosed with MS?
  - Yes
  - No
  - Unsure

If you answered **“No”** or **“Unsure”** to the question above, STOP HERE!

2. How many years ago were you diagnosed with MS?

- < 1 year ago
- 1 -2 years ago
- 3-5 years ago
- 5-10 years ago
- > 10 years ago

3. How many years ago did you first experience MS symptoms?

- < 1 year ago
- 1 -2 years ago
- 3-5 years ago
- 5-10 years ago
- > 10 years ago

4. What type of MS do you currently have?

- Relapsing-Remitting
- Primary Progressive
- Secondary Progressive
- Not Sure

5. From the choices below, mark the circle that best fits your condition:

**None/Minimal:**

I have no or minimal MS-related symptoms, no limitations in walking ability, and no limitations on daily activities.

**Mild:**

I have noticeable MS-related symptoms but no limitations in my walking ability and no limitations on daily activities

**Moderate:**

I have many MS-related symptoms that affect my daily activities but can walk at least 1 block without support.

**Some support needed for walking:**

I have significant MS-related symptoms that limit physically demanding activities. I need support (e.g. cane, touching a wall, leaning on someone's arm) to walk ½ - 1 block.

**Walker/two-handed crutch:**

I have significant MS-related symptoms that limit daily activities. I can walk only short distances with a walker or two-handed crutches.

**Wheelchair-bound:**

I have many severe MS-related symptoms and am restricted to a wheelchair.

**Bed-bound:**

I have many severe MS-related symptoms and am bed-bound for most of the day.

6. Would you be willing to get vaccinated against COVID-19 if it were recommended by your physician?
- Yes**, I would be willing to get vaccinated against COVID-19
  - No**, I would not be willing to get vaccinated against COVID-19.
  - I am **unsure** if I would be willing to get vaccinated against COVID-19.
7. If “Yes” to Question 6: What are the *most important* reasons for getting vaccinated against COVID-19 (maximum of 3)?
- To protect myself from getting COVID-19
  - To decrease the chance of getting seriously ill from COVID-19
  - To protect my loved ones from getting COVID-19
  - To protect others who are unable to get the vaccine because of health conditions
  - To prevent any MS complications related to COVID-19
  - Because my MS medication makes me vulnerable to COVID-19
  - Other
8. If “Other” was selected in Question 7: Please specify your most important reason for getting vaccinated: \_\_\_\_\_
9. If “Other” is selected for Question 9: Please specify the most important reason you would not get COVID-19 vaccine as soon as it comes available for you: \_\_\_\_\_
10. If you answered you would NOT be willing to be vaccinated (“No” to Question 6), please answer the following question: What are the main reasons you would *not* be willing to be vaccinated against COVID-19? (select a maximum of 3)
- I’m concerned about potential side effects
  - I’m concerned about interaction between the vaccine and my MS medications
  - I’m concerned that the vaccine will worsen my MS disease and/or symptoms
  - I’ve had an allergic reaction to a component of vaccines in the past
  - I am against vaccination in general
  - I’m concerned that the vaccine was developed too rapidly
  - It’s best to let nature take its course
  - I don’t think that COVID-19 is dangerous to my health
  - I’m afraid of injections
  - I believe natural or traditional remedies are superior to vaccines

- I believe that vaccines contain poisons/toxins/contaminants
- I believe vaccination policies are motivated by profit
- I believe information about vaccine side effects are withheld from the public
- Religious reasons
- I think that people without MS should get the vaccine before people with MS.
- I think the vaccine may have been rushed and would like more evidence to prove it is safe.
- I'm concerned about exposure to a public space (e.g. healthcare office) in order to receive the vaccine.
- I have previously tested positive for COVID and am likely immune.
- Other
- 
- Other (specify):

11.If "Other" was selected in Question 11: Please specify the reason(s) why you would not be willing to be vaccinated: \_\_\_\_\_

12. If "unsure" was selected: What are the main reasons you would not get the COVID-19 vaccine as soon as it becomes available for you? (select a maximum of 3)

- I think that people without MS should get the vaccine before people with MS due to concerns about safety for people with MS.
- I think political pressure rushed the vaccine trials and it should be tested more thoroughly to prove it is safe
- I would like it to be proven safe on a large-scale, population level to prove it is safe before I take it.
- I'm concerned about exposure to a public space (e.g. healthcare office) in order to receive the vaccine.
- Even if my doctor recommends it, I would like to assess the data that shows it is safe/effective prior to taking the vaccine.
- Other

13. If you answered you were UNSURE if you would be willing to be vaccinated ("Unsure" to Question 6), please select which scenario below you would be willing to get the vaccine.

<b>Would you be willing to get the vaccine if</b>	<b>Yes</b>	<b>No</b>
<b>At least 25%</b> of people who gets the vaccine would be protected from getting COVID-19 for at least 1 year	<input type="radio"/>	<input type="radio"/>
<b>At least 50%</b> of people who gets the vaccine would be protected from getting COVID-19 for at least 1 year	<input type="radio"/>	<input type="radio"/>
<b>At least 75%</b> of people who gets the vaccine would be protected from getting COVID-19 for at least 1 year	<input type="radio"/>	<input type="radio"/>
<b>Almost 100%</b> of people who gets the vaccine would be protected from getting COVID-19 for at least 1 year	<input type="radio"/>	<input type="radio"/>

14. Have you been recommended a vaccine as an adult but declined?

- Yes
- No

15. If “Yes” to Question 14 was selected: What was the vaccine you declined (check all that apply)?

- Pneumonia vaccine (PSV13 or Prevnar, PSV23 or Pneumovax)
- Shingles vaccine (Zostavax, Shingrix)
- Human papilloma virus (HPV) vaccine (Gardasil)
- Influenza vaccine/Flu shot
- I don’t know or I don’t remember
- Other

16. If “Other” to Question 15 was selected: Please specify which vaccine(s) you were recommended but declined: \_\_\_\_\_

17.If “Yes” to Question 14 was selected: What are the main reasons you declined the recommended vaccine(s)? (maximum of 3)

- I’m concerned about potential side effects of vaccines
- I’m concerned about interaction between the vaccine and my MS medications
- I’m concerned that the vaccine will worsen my MS disease and/or symptoms
- I am against vaccination in general
- The best way is to let nature take its course
- In general, I do not get sick and don’t think I need a vaccination
- I am concerned about the price of the vaccinations
- I am concerned that vaccinations are not effective.
- I’m afraid of injections
- I believe natural or traditional remedies are superior to vaccines
- I believe that vaccines contain poisons/toxins/contaminants
- I believe vaccination policies are motivated by profit
- I believe information about vaccine side effects are withheld from the public
- Religious reasons
- Other

18.If “Other” to Question 17 was selected: Please specify the main reason why you declined the recommended vaccine(s). \_\_\_\_\_

19. Which of the following describes your experience with the influenza (flu) vaccine?

- I get the influenza vaccine every year
- I get the influenza vaccine some years, but not all
- I do not get the influenza vaccine

20.How often do you see your primary care provider?

- At least twice per year
- Once per year
- Every few years
- I do not have an established primary care provider right now.

21. Do you plan to ask your MS provider/neurologist about the COVID-19 vaccine?

- Yes, I have already discussed the COVID-19 vaccine with my MS provider/neurologist
- Yes, I plan to discuss the COVID-19 vaccine with my MS provider/neurologist
- No, I do not plan to discuss the COVID-19 vaccine with my MS provider/neurologist

22. In general, have your vaccine practices/beliefs changed because of COVID-19?
- Yes**, I am now **more likely** to receive a vaccine than before COVID-19
  - Yes**, I am now **less likely** to receive a vaccine than before COVID-19
  - No**, my vaccine practices/beliefs have NOT changed
23. How concerned are you that you will personally get COVID-19?
- Not at all concerned
  - Slightly concerned
  - Somewhat concerned
  - Moderately concerned
  - Extremely concerned
24. How concerned are you that you will require hospitalization, have severe complications, or die if you contract COVID-19?
- Not at all concerned
  - Slightly concerned
  - Somewhat concerned
  - Moderately concerned
  - Extremely concerned
25. How does your MS affect your concerns about COVID-19?
- I'm **a lot more worried** about COVID-19 because of my MS
  - I'm **a little more worried** about COVID-19 because of my MS
  - My worries about COVID-19 are **not affected** by my MS
  - I'm **a little less worried** about COVID-19 because of my MS
  - I'm **a lot less worried** about COVID-19 because of my MS
26. Have you ever personally tested positive or has a physician suspected you were positive for COVID-19?
- Yes, I was tested and had a confirmed positive COVID-19 test
  - Yes, I had suspected COVID-19 but did not receive a test
  - Yes, I had suspected COVID-19 but testing was negative
  - No
27. If any of the choices that began with "Yes" in Question 25 was selected: - Did you require hospitalization for COVID-19?

- Yes – required intensive care unit
- Yes – did not require intensive care unit
- No

28. Do you personally know anyone who has tested positive or was suspected to be positive for COVID-19?

- Yes
- No

29. Do you personally know anyone who has been hospitalized for confirmed or suspected COVID-19?

- Yes
- No

30. Do you personally know anyone who passed away from confirmed or suspected COVID-19?

- Yes
- No

31. Which of the following best describes your current social behavior? (Here, we consider “family/friends” as people who do not live in your home):

- I am not going to public places and only socialize virtually with family or friends.
- I am not going to public places, but I am socializing with family or friends in my, or their, home
- I am only socializing in public places if I can maintain a distance of 6-feet from other people.
- I am continuing to socialize in public places, but less than before
- I am continuing to socialize in public places

32. How likely are you to wear a mask the next time you enter the following locations:

Location	Extremely unlikely	Unlikely	Likely	Extremely likely	No plans to go
Grocery store	○	○	○	○	○



Restaurant (indoor waiting area or when away from table)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public park or beach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gym	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socializing with friends who live outside my home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socializing with family who live outside my home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**33. Disease-Modifying Therapies:** From the following list of disease-modifying drugs, please indicate which ones you are **currently taking for your MS**.

<b>Disease-modifying drugs for MS</b>	
Alemtuzumab (Lemtrada)	<input type="radio"/>
Cladribine (Mavenclad)	<input type="radio"/>
Daclizumab (Zinbryta)	<input type="radio"/>
Dimethyl Fumarate (Tecfidera) or Diroximel fumarate (Vumerity)	<input type="radio"/>
Fingolimod (Gilenya) or Spinonimod (Mayzent) or Ozanimod (Zeposia)	<input type="radio"/>
Interferons (Avonex, Betaseron, Plegridy, Rebif, Extavia)	<input type="radio"/>
Glatiramer acetate (Copaxone, Glatopa)	<input type="radio"/>
Mitoxantrone	<input type="radio"/>
Natalizumab (Tysabri)	<input type="radio"/>

Ocrelizumab (Ocrevus) or Rituximab (Rituxan)	<input type="radio"/>
Teriflunomide (Aubagio)	<input type="radio"/>
Other:	<input type="radio"/>

34.If “Other” was selected for Question 32: Please specify which disease-modifying drug you are currently taking for your MS. \_\_\_\_\_

35. Have your disease-modifying drugs for your MS changed since February 2020?

- Yes, **because** of COVID-19
- Yes, but **not because** of COVID -19
- No

36.If either answer that began with “Yes” to Question 35 was selected: -Please indicate which disease-modifying drug you were taking prior to switching to your current regimen.

<b>Disease-modifying drugs for MS</b>	
---	--

Alemtuzumab (Lemtrada)	<input type="radio"/>
Cladribine (Mavenclad)	<input type="radio"/>
Daclizumab (Zinbryta)	<input type="radio"/>
Dimethyl Fumarate (Tecfidera) or Diroximel fumarate (Vumerity)	<input type="radio"/>
Fingolimod (Gilenya) or Spinonimod (Mayzent) or Ozanimod (Zeposia)	<input type="radio"/>
Interferons (Avonex, Betaseron, Plegridy, Rebif, Extavia)	<input type="radio"/>
Glatiramer acetate (Copaxone, Glatopa)	<input type="radio"/>
Mitoxantrone	<input type="radio"/>
Natalizumab (Tysabri)	<input type="radio"/>
Ocrelizumab (Ocrevus) or Rituximab (Rituxan)	<input type="radio"/>
Teriflunomide (Aubagio)	<input type="radio"/>
Other (specify):	<input type="radio"/>

37.If "Other" was selected for Question 36: Please specify which disease-modifying drug you were taking prior to switching to your current regimen. \_\_\_\_\_

38. **Other Conditions:** Has a doctor diagnosed you and/or do you take a medication to treat any of the following conditions? For each condition please mark NO or YES.

<b>Medical Condition</b>	<b>Yes</b>	<b>No</b>
High blood pressure (hypertenstion)	<input type="radio"/>	<input type="radio"/>
Diabetes	<input type="radio"/>	<input type="radio"/>
Pre-diabetes	<input type="radio"/>	<input type="radio"/>
Heart disease (coronary artery disease)	<input type="radio"/>	<input type="radio"/>
Heart failure	<input type="radio"/>	<input type="radio"/>
Stroke	<input type="radio"/>	<input type="radio"/>
Asthma	<input type="radio"/>	<input type="radio"/>
COPD (emphysema)	<input type="radio"/>	<input type="radio"/>
Pulmonary fibrosis	<input type="radio"/>	<input type="radio"/>
Chronic kidney disease	<input type="radio"/>	<input type="radio"/>
Liver disease	<input type="radio"/>	<input type="radio"/>
Cancer	<input type="radio"/>	<input type="radio"/>
HIV/AIDS	<input type="radio"/>	<input type="radio"/>
Obesity (BMI $\geq 30$ )	<input type="radio"/>	<input type="radio"/>
Sickle cell disease	<input type="radio"/>	<input type="radio"/>
Solid organ transplant	<input type="radio"/>	<input type="radio"/>
Blood or bone marrow transplant	<input type="radio"/>	<input type="radio"/>
Immune deficiencies	<input type="radio"/>	<input type="radio"/>
Cystic fibrosis	<input type="radio"/>	<input type="radio"/>
Thalassemia (a type of blood disorder)	<input type="radio"/>	<input type="radio"/>
<b>Other (specify):</b>	<input type="radio"/>	<input type="radio"/>

39. If “Other” was selected to Question 38: Please specify what other conditions you have been diagnosed with. \_\_\_\_\_

40. Which of the following best matches your current **tobacco** smoking situation? For this question, please consider smoking to be the use of cigarettes, e-cigarettes, or cigars.

- I am a current smoker
- I smoked in the past, but not currently

- I never smoked

**Please tell us a little about yourself:**

41. Biological sex at birth:

- Female
- Male
- Other

42. Are you currently pregnant?

- Yes
- No

43. Your age (in years): \_\_\_\_\_

44. Choose one category that most closely reflects your racial and ethnic background:

a. Race:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- More than one race
- Unknown or would prefer not to say

b. Ethnicity:

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown or would prefer not to say

45. What is your highest educational level:

- Less than high school
- Some high school
- High school diploma or GED
- Some college
- Bachelor's degree
- Some graduate school
- Master's degree or higher

46. Are you currently working?

- Yes
- No

47. If “Yes” to Question 46 was selected: Are you currently working:

- Inside the home (or teleworking) all the time
- Inside the home (or teleworking) most of the time
- Half of the time inside the home and half outside the home
- Outside the home most of the time
- Outside the home all the time

48. If either answers that begin with “Outside the home” or if “Half of the time inside the home and half outside the home” to Question 47 was selected: If you are working outside the home, are you a(n):

- Active health care worker (e.g. nurse, technician, physician, hospital worker)
- Active law enforcement, public safety, and other first line responder (e.g. police, firefighter, paramedic)
- Active essential worker in food and agriculture (e.g. grocery store, restaurant, farm)
- Active essential worker in transportation (e.g. bus driver)
- Active worker in shelter, prison
- Other essential worker
- None of the above, but I’m working in person

49. What is your total annual household income:

- Less than \$25,000
- \$25,000 - \$34,999
- \$35,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 or more

50. How many people age 65 years or older do you currently live with?

- 0
- 1-2

- 3 or more

51. How many children under age 18 years do you currently live with?

- 0
- 1-2
- 3 or more

52. What is your zip code: \_\_\_\_\_

53. What type of health insurance do you currently have? (**Mark all that apply**)

- None
- Medicare
- Medicaid
- Dept. of Veterans Affairs
- Commercial plan
- I have an insurance that's not represented here

54. At any time in the past year, have you been without health insurance?

- Yes, for less than 3 months
- Yes, for greater than 3 months
- No

55. How would you rate the **state/local** government response to COVID-19?

- I feel like the state/local government has done a **good job** responding to COVID-19.
- I feel like the state/local government has done a **fair job** responding to COVID-19.
- I feel like the state/local government has done a **poor job** responding to COVID-19.

56. How would you rate the **federal** government response to COVID-19?

- I feel like the federal government has done a **good job** responding to COVID-19.
- I feel like the federal government has done a **fair job** responding to COVID-19.
- I feel like the federal government has done a **poor job** responding to COVID-19.

57. Please select the **top THREE** information sources that you use to provide **medical information about vaccines in general (Please select THREE choices)?**

- Primary care physician
- Neurologist/Multiple Sclerosis Specialist
- Centers for Disease Control and Prevention (CDC)
- National MS Society (NMSS) website
- Other multiple sclerosis websites
- The Executive Branch of the federal government (The White House/President)
- Members of the Senate/House of Representatives
- State governor
- State Health Department
- Social Media (e.g.. Facebook, Twitter)
- YouTube
- Cable News/ Local TV news
- Public radio
- National newspaper/Internet sites affiliated with national news
- Local newspaper/ Internet sites affiliated with local news
- Other

58.If “Cable News” or “national newspaper” or “local newspaper” to Question 56 was ranked: Please specify the name(s) of your primary news outlet). \_\_\_\_\_

59.If “Other” to Question 56 was ranked: You selected “Other” as one of the top three information sources that you use. Please specify the information source. \_\_\_\_\_

60.Please select the **top THREE** information sources that you use to provide **treatment and vaccine information about COVID-19 (Please select THREE choices)?**

- Primary care physician
- Neurologist/Multiple Sclerosis Specialist
- Centers for Disease Control and Prevention (CDC)
- National MS Society (NMSS) website
- Other multiple sclerosis websites
- The Executive Branch of the federal government (The White House/President)
- Members of the Senate/House of Representatives
- State governor
- State Health Department
- Social Media (e.g.. Facebook, Twitter)
- YouTube
- Cable News/ Local TV news
- Public radio



- National newspaper/ Internet sites affiliated with national news
- Local newspaper/Internet sites affiliated with local news
- Other

61.If “Cable News” or “national newspaper” or “local newspaper” to Question 59 was selected: Please specify the name(s) of your primary news outlet . \_\_\_\_\_

62.If “Other” to Question 59 was ranked: You selected “Other” as one of the top three information sources that you use. Please specify the information source. \_\_\_\_\_

63. Is there anything else you would like us to know about?

---

---

---

---

---

---

---

---

---

---

64.[OPTIONAL] If you would like to be entered into a drawing for a \$50 Amazon gift card, please submit your e-mail address or phone number here.

**THANK YOU**  
Thank you for completing this survey. Your contribution to MS research is greatly appreciated!