

## LISTENING TO PEOPLE AFFECTED BY MS 2.0 INITIATIVE

*Our Mission: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.*

Dear Survey Participant:

Thank you in advance for sharing your voice. Results of this important survey will help inform the strategic plan of the MS Society of Canada and our programs, services, research and government relations work.

**Please answer the survey if any of the following apply to you:**

- I have a diagnosis of multiple sclerosis (MS) or Clinically Isolated Syndrome (CIS).
- I have an allied disease such as NMO, TM, ADEM
- I have a close relationship with someone with MS or CIS (family member, spouse or partner, friend).
- I am waiting for a diagnosis with respect to MS.
- I am an unpaid caregiver of someone with MS or CIS (family member, spouse, partner or friend, who provides care some of the time or all of the time).
- I am currently or in the past have been a member of the MS Society of Canada.

The survey will take you approximately 20 minutes to complete.

Doing the survey is voluntary.

All your answers will be kept completely private.

We will not ask you to provide your name, address or phone number but will ask for your province / region of Canada at the end of this survey.

We will not contact you after you have finished the survey.

If you need assistance to complete the survey, please call us at 1-844-859-6789 or go to [www.mssociety.ca](http://www.mssociety.ca) to print out a paper copy.

Results will be posted to the website by early 2019.

Stay tuned to our website for more information on what people affected by MS have to say about their day to day lives with MS.

## **MS SOCIETY OF CANADA SURVEY**

Please answer all the questions in the survey from your own point of view. For example, if you are a caregiver for someone with MS, answer the questions from your experience as a caregiver. Do not answer the questions from the point of view of the person you care for.

Please note that at the end of the survey, you will have an opportunity to provide any additional feedback that you feel we may have missed. Your time and participation are greatly valued.

**1. Which ONE of the following categories BEST describes you?**

- I have a diagnosis of Multiple Sclerosis (MS) or Clinically Isolated Syndrome (CIS).
- I live with an allied disease (NMO, TM, ADEM)
- I have a close relationship with someone with MS or CIS (family member, spouse or partner, friend)
- I am waiting for a diagnosis with respect to MS
- I am an unpaid caregiver of someone with MS or CIS or allied disease (family member, spouse, partner or friend, who provides care some of the time or all of the time)
- I am currently or in the past have been a member of the MS Society of Canada (only select this option if none of the above apply)
- None of the above

**2. Please indicate which, if any, of the following ways you have interacted with the MS Society in the past year? Please check all that apply.**

- I am a current member of the MS Society
- I used to have a membership with the MS Society, but did not renew it
- I received information in print form or from the MS Society's website
- I receive an e-newsletter from the MS Society in my region
- I called the MS Society to ask for information or support and spoke with an MS staff person
- I received in person information or support from the MS Society in my community
- I received financial help or equipment (on loan or purchased) from the MS Society.
- I went to MS Society presentations, workshops, or conferences (in person, online or on the phone).
- I was part of an MS Society wellness program
- I was part of an MS Society education program
- I was part of an MS Society social program
- I was part of an MS Society support, self-help or peer support group
- I have participated in the research review process as a community representative
- I was part of a Friendly Visiting Program
- I follow MS Society research through...
  - Dr. Karen Lee blog
  - Newsletter
  - Participation in research studies
- I was a participant of MS Walk
- I was a participant of MS Bike
- I was involved in other MS Society fundraising events
- I volunteered for the MS Society at a fundraising event
- I volunteered for the MS Society in a non-fundraising capacity
- I donated to the MS Society

- Other (please specify)

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- I have not interacted or dealt with the MS Society in the past year
- Do not know / Prefer not to answer

**3. If you have NOT been in touch with the MS Society in the past year, please explain why:**

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- I have interacted or dealt with the MS Society in the past year
- Do not know / Prefer not to answer

**4. How many years have you been diagnosed with Multiple Sclerosis, CIS or allied diseases?**

- 1 to 5 years
- 6 to 10 years
- 11 to 20 years
- More than 20 years
- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases
- Do not know / Prefer not to answer

**5. What type of MS do you have at this time?**

- Clinically Isolated Syndrome (CIS)
- Allied conditions such as NMO, TM, ADEM
- Relapsing-remitting
- Secondary progressive
- Primary progressive
- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases
- Do not know / Prefer not to answer

**6. What is your current living arrangement?**

- I live by myself at home
- I live with others (spouse or partner, friends or family) at home
- I live in supportive housing that provides some health care as well as services like meals or housekeeping
- I live in a long-term care facility
- Other (please describe)

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- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases / or waiting for a diagnosis
- Do not know / Prefer not to answer

**7. Information about MS is available from many places. Where do you get YOUR information about MS? Please choose your top 3 sources.**

- Health professionals (such as doctors, nurses, or pharmacists, physiotherapists, occupational therapists)
- MS Clinics
- Other registered health professionals (such as naturopaths or chiropractors)
- Exercise professionals or exercise therapists
- Friends or family
- Face-to-face or online support groups for people with MS
- Product, health or disease websites
- MS Society of Canada staff and volunteers
- MS Society of Canada website
- MS Society of Canada print resources
- MS Society regional newsletter
- MS Society of Canada Facebook page
- MS Society of Canada Twitter feed
- MS Society Instagram
- MS Society research information
  - Dr. Karen Lee blog
  - MS research newsletters
  - MS research portal
- Online news stories or print
- Other (please specify)

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- None
- Do not know / Prefer not to answer

**8. There are a number of factors that impact the quality of life of people affected by multiple sclerosis. As someone affected by MS, please rate how important these factors have been in your day-to-day life in the past year? Use the scale from 1 to 10 where 1 is not important at all and 10 is extremely important.**

	1 Not important at all	2	3	4	5	6	7	8	9	10 Extremely important	Don't know/prefer not to answer
Feeling empowered to participate in decisions about treatment and care that affect my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having access to comprehensive and effective treatments and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having the support of a network of family, friends, loved ones and unpaid caregivers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having access to work, volunteering, education and leisure and wellness opportunities that are accessible and flexible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having access to public and private spaces, technology and transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having access to age appropriate assisted housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having the financial resources to meet the changing needs and costs of living with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling and being supported by positive attitudes, beliefs and practises that promote equality and challenge stigma and discrimination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. In general, would you say that YOUR quality of life in the past year was....**

- 1. Excellent
- 2. Very good
- 3. Good
- 4. Fair
- 5. Poor
- 6. Do not know / Prefer not to answer

**10. Reflecting on your current situation as a person affected by MS, identify up to *three urgent needs and/or problems you faced or that you needed help with* in the past 12 months from the list below:**

- I was not included in decisions affecting my care and treatment
- Health professionals did not listen to me about my needs
- I had difficulty contacting a doctor
- I had difficulty getting an appointment
- I was unable to access information I needed
- I lacked the money for needed supports or services
- I lacked the financial resources needed for treatment
- I am living in a long-term care facility with people that are not close in age to me
- I was unable to access financial supports from government
- A support or service I needed was not available at the time
- A support or service I needed was not available in my community
- I had a lack of support from family and friends
- Those that support and care for me were unable to cope
- I was unable to access personal care services
- I lacked the support to work or continue working
- I was unable to access the educational opportunities that were important to me
- I had problems accessing the Internet or other technology I needed
- I had problems accessing supports for emotional/psychological issues
- I did not know where to go for help
- I had problems moving around (such as transportation challenges or needing mobility aids)
- I was faced with negative and/or discriminatory attitudes towards me and my MS
- Other (please describe)

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- Other (please describe)

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- Other (please describe)

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- I had no urgent issues
- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases / or waiting for a diagnosis
- Do not know / Prefer not to answer

[FOR EACH PROBLEM IDENTIFIED IN Q10 ANSWER EACH OF THE QUESTIONS BELOW]

NEED/PROBLEM #1:

- a. Did you contact the MS Society to address your needs and the problem facing you?
  - Yes
  - No
  - Do not know / Prefer not to answer
- b. Did you contact another source of support outside of the MS Society?
  - Yes: who did you contact? (describe)

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- No
- Do not know / Prefer not to answer
- c. Were you successful in resolving the need/problem (yes/no partially)
  - Yes
  - Partially
  - No
  - Do not know / Prefer not to answer

- d. What the barrier was to meeting your needs and/or resolving the issue? What got in the way?

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- Do not know / Prefer not to answer
- Not applicable

NEED/PROBLEM #2:

a. Did you contact the MS Society to address your needs and the problem facing you?

- Yes
- No
- Do not know / Prefer not to answer

b. Did you contact another source of support outside of the MS Society?

- Yes: who did you contact? (describe)

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- No
- Do not know / Prefer not to answer

c. Were you successful in resolving the need/problem (yes/no partially)

- Yes
- Partially
- No
- Do not know / Prefer not to answer

d. What the barrier was to meeting your needs and/or resolving the issue? What got in the way?

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- Do not know / Prefer not to answer
- Not applicable

NEED/PROBLEM #3:

a. Did you contact the MS Society to address your needs and the problem facing you?

- Yes
- No
- Do not know / Prefer not to answer

b. Did you contact another source of support outside of the MS Society?

- Yes: who did you contact? (describe)

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- No
- Do not know / Prefer not to answer

c. Were you successful in resolving the need/problem (yes/no partially)

- Yes
- Partially
- No
- Do not know / Prefer not to answer

d. What the barrier was to meeting your needs and/or resolving the issue? What got in the way?

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- Do not know / Prefer not to answer
- Not applicable

**11. How often have the following statements been true for YOU within the past year:**

	All the time	Most of the time	Some of the time	Never	Not sure	Does not apply to me	I am not diagnosed with MS, CIS or allied diseases / or waiting for a diagnosis	Do not know / prefer not to answer
I am involved in decisions on medical treatments and other aspects of living with MS that affect my life.	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to programs and services in my community	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to rehabilitative services in my community.	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to disease modifying treatments or medicine to manage symptoms	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to rehabilitation services (such as physiotherapy).	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to equipment and technology that I can afford and that helps me maintain my independence (such as mobility aids and changes to my car or home).	<input type="checkbox"/>	<input type="checkbox"/>						
I feel that my healthcare team cares about my wellbeing and does not just focus on treating my disease.	<input type="checkbox"/>	<input type="checkbox"/>						
I have had the opportunity to participate in clinical trials or research	<input type="checkbox"/>	<input type="checkbox"/>						
My family doctor is knowledgeable about MS.	<input type="checkbox"/>	<input type="checkbox"/>						
The people who are paid to care for me are	<input type="checkbox"/>	<input type="checkbox"/>						

knowledgeable about MS.								
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	All the time	Most of the time	Some of the time	Never	Not sure	Does not apply to me	I am not diagnosed with MS, CIS or allied diseases / or waiting for a diagnosis	Do not know / prefer not to answer
Transportation services where I live allow me to get around.	<input type="checkbox"/>	<input type="checkbox"/>						
My workplace makes changes so that I can still work despite my MS.	<input type="checkbox"/>	<input type="checkbox"/>						
My disability benefits (public or private) allow me to maintain a good standard of living	<input type="checkbox"/>	<input type="checkbox"/>						
My health care provider(s) provides me with routine medical care, like flu shots, blood tests, or other tests that are not related to my MS.	<input type="checkbox"/>	<input type="checkbox"/>						
My school accommodates my MS so I can continue my education.	<input type="checkbox"/>	<input type="checkbox"/>						
I am able to be part of community life as much as I want to.	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to a broad range of information and advice about MS.	<input type="checkbox"/>	<input type="checkbox"/>						
I have access to information and advice about exercise, nutrition, and ways to manage stress.	<input type="checkbox"/>	<input type="checkbox"/>						
I feel that I have the support I need to stay in my home as long as possible.	<input type="checkbox"/>	<input type="checkbox"/>						
Community buildings such as government offices, hospitals, clinics,	<input type="checkbox"/>	<input type="checkbox"/>						

and schools (at all levels) are accessible.								
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	All the time	Most of the time	Some of the time	Never	Not sure	Does not apply to me	I am not diagnosed with MS, CIS or allied diseases / or waiting for a diagnosis	Do not know / prefer not to answer
I am retired from work but I feel fulfilled by volunteer work, hobbies or domestic life.	<input type="checkbox"/>	<input type="checkbox"/>						
My/our children (under the age of 18) have caregiving responsibilities.	<input type="checkbox"/>	<input type="checkbox"/>						
I find it difficult to get financial assistance for MS related issues.	<input type="checkbox"/>	<input type="checkbox"/>						
I have felt supported and have experienced positive attitudes towards me and my MS.	<input type="checkbox"/>	<input type="checkbox"/>						

	All the time	Most of the time	Some of the time	Never	Not sure	Does not apply to me	I am not diagnosed with MS, CIS or allied diseases / or waiting for a diagnosis	Do not know / prefer not to answer

**12. Please indicate whether the statements below are true for you: Were you referred to the MS Society at the time of your diagnosis?**

- Yes – upon my diagnosis
- Yes – for support following my diagnosis
- I was referred to the MS Society before my diagnosis
- No – I was not referred to the MS Society
- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases / or waiting for a diagnosis

**13. Who referred you to the MS Society?**

- Neurologist
- General practitioner/family doctor
- Other (specify)

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- Do not know / Prefer not to answer
- Not applicable
- I am not diagnosed with Multiple Sclerosis, CIS or allied diseases / or waiting for a diagnosis

**14. MS impacts the lives not just of those who might have or do have a confirmed diagnosis of MS but also the friends, families and caregivers of people with MS. What worries YOU most as a caregiver?**

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- Do not know / Prefer not to answer
- I am not a caregiver

**15. How often have the following statements been true for YOU within the past year:**

	All the time	Most of the time	Some of the time	Never	Not sure	Does not apply to me	I am not a caregiver	Do not know / prefer not to answer
I can find the support I need as a caregiver or family member.	<input type="checkbox"/>							
I have access to respite services that allow me to take breaks from caregiving.	<input type="checkbox"/>							
As a caregiver, I have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving.	<input type="checkbox"/>							
I feel that I have someone to talk to when I am feeling tired or when negative feelings arise.	<input type="checkbox"/>							
My employer gives me time off, as needed, so I can care for the person with MS in my life.	<input type="checkbox"/>							

**IMPACT** (of the activities of the MS Society of Canada)

**16. To what extent do you agree with the following statements regarding the MS Society of Canada’s activities and how they impact the lives of people affected by MS**

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	Not applicable	Do not know / prefer not to answer
Interacting with the MS Society has improved my quality of life	<input type="checkbox"/>							
The programs and services offered by the MS Society of Canada have met my needs	<input type="checkbox"/>							
By contacting the MS Society I have been able to get the answers I need	<input type="checkbox"/>							
Receiving a quality of life equipment grant has improved my independence	<input type="checkbox"/>							
I believe that the MS Society’s advocacy efforts on behalf of people with MS to all levels of government are making a difference in the lives of people living with MS	<input type="checkbox"/>							
Attending MS Society educational events has helped me better understand issues related to MS	<input type="checkbox"/>							
I believe the MS Society of Canada investments in world-leading research will lead to a cure	<input type="checkbox"/>							
MS Society research communications have improved my knowledge and understanding of current and new research initiatives underway	<input type="checkbox"/>							
I have had the opportunity to interact with MS researchers	<input type="checkbox"/>							

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	Not applicable	Do not know / prefer not to answer
I have had the opportunity to participate in MS related research studies	<input type="checkbox"/>							
Recent MS research advancements have enabled people affected by MS to make informed choices in health care and well being	<input type="checkbox"/>							

17. Are there other benefits to your having interacted with the MS Society that were not mentioned?

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18. What is the most important way the MS Society positively impacts in the lives of people affected by MS? Is there something else we should be doing?

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19. As a person affected by MS, to what degree do you agree that the MS Society achieves the following for people in your age group affected by MS...

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	Not applicable	Do not know / prefer not to answer
Supports our needs	<input type="checkbox"/>							
Has a positive impact in our lives	<input type="checkbox"/>							
Addresses the relevant issues affecting us	<input type="checkbox"/>							
Provides meaningful opportunities to engage us	<input type="checkbox"/>							

**20.** What could the MS Society do to be more relevant to your age group?

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**RELEVANCE (IMPORTANCE)**

**21. To what extent do you agree with the following statements about the MS Society and its importance as an organization today:**

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	Not applicable	Do not know / prefer not to answer
Programs and services provided by the MS Society of Canada are relevant to me.	<input type="checkbox"/>							
The MS Society of Canada is an effective voice on behalf of those affected by MS.	<input type="checkbox"/>							
The MS Society is a strong advocate to all levels of government on behalf of people living with MS.	<input type="checkbox"/>							
The MS Society is a strong advocate for research.	<input type="checkbox"/>							
The MS Society is a vital supporter/funder of ground breaking research.	<input type="checkbox"/>							
The MS Society is funding research that aligns with the needs of and has the potential to impact people affected by MS.	<input type="checkbox"/>							
The MS Society is the main source of information about important matters associated with MS.	<input type="checkbox"/>							
The MS Society of Canada is a vital partner to those affected by MS as they manage daily issues associated with MS.	<input type="checkbox"/>							
The MS Society provides information to me in the language I prefer.	<input type="checkbox"/>							
People affected by MS feel connected to the MS Society.	<input type="checkbox"/>							

The MS Society of Canada provides meaningful support for people affected by MS.	<input type="checkbox"/>							
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**ENGAGEMENT/Interaction with the MS Society of Canada**

22. The MS Society strives to engage people affected by MS and the broader community to support our mission (donate, fundrais, volunteer, advocate, participate in events, engage in research, become member, etc.). How important were the following in your decision to engage with the MS Society?

	Very important	Moderately important	Somewhat important	Not important	I have not interacted with the MS Society within the past year	Do not know / prefer not to answer
Efficient use of funds raised	<input type="checkbox"/>	<input type="checkbox"/>				
Provides relevant supports and services for people affected by MS	<input type="checkbox"/>	<input type="checkbox"/>				
A strong voice and advocate on behalf of people living with MS	<input type="checkbox"/>	<input type="checkbox"/>				
Invests in world class MS research	<input type="checkbox"/>	<input type="checkbox"/>				
Opportunity to participate in research	<input type="checkbox"/>	<input type="checkbox"/>				
Open and transparent reporting of financial status and the use of funds raised	<input type="checkbox"/>	<input type="checkbox"/>				
Awareness of the work of the organization	<input type="checkbox"/>	<input type="checkbox"/>				
Reputation of the organization in the community	<input type="checkbox"/>	<input type="checkbox"/>				
Demonstrating the positive impact of the work that the organization does in the lives of people affected by MS	<input type="checkbox"/>	<input type="checkbox"/>				
Knowing someone who has benefitted from the work of the organization	<input type="checkbox"/>	<input type="checkbox"/>				
The MS Society demonstrates the value and impact of research	<input type="checkbox"/>	<input type="checkbox"/>				
Belief that the MS Society can achieve its mission of improving quality of life and finding a cure for MS	<input type="checkbox"/>	<input type="checkbox"/>				

	Very important	Moderately important	Somewhat important	Not important	I have not interacted with the MS Society within the past year	Do not know / prefer not to answer
Being part of the MS community	<input type="checkbox"/>	<input type="checkbox"/>				
Show support to the MS cause	<input type="checkbox"/>	<input type="checkbox"/>				
Stay informed about the activities of the MS Society	<input type="checkbox"/>	<input type="checkbox"/>				
Stay informed about the impact of the MS Society	<input type="checkbox"/>	<input type="checkbox"/>				

Is there anything else that was important in your decision to engage with the MS Society?  
(please specify)

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**23. The MS Society strives to engage people affected by MS and the broader community to support our mission (donate, fundraiser, volunteer, participate, become member, other).** You indicated you have MS or are a caregiver, close friend or family but currently do not interact or engage with the MS Society of Canada. Which of the following would be most likely to encourage you to interact with us as a person affected by MS or as a new member? Please rate degree of importance.

	Very important	Moderately important	Somewhat important	Not important	Do not know / prefer not to answer
Efficient use of funds raised	<input type="checkbox"/>				
Providing supports and services for people affected by MS	<input type="checkbox"/>				
Offering programs relevant to me	<input type="checkbox"/>				
A strong voice and advocate on behalf of people affected by MS	<input type="checkbox"/>				
Opportunity to participate in research	<input type="checkbox"/>				
Open and transparent reporting of financial status and the use of funds raised (trust)	<input type="checkbox"/>				
Having awareness of the work of the organization	<input type="checkbox"/>				
Reputation of the organization in the community	<input type="checkbox"/>				
Awareness of the positive impact of the work that the organization does in the lives of people affected by MS	<input type="checkbox"/>				
Knowing someone who has benefitted from the work of the organization	<input type="checkbox"/>				
Seeing the value and impact of research	<input type="checkbox"/>				
The MS Society engages individuals affected by MS sufficiently when making decisions about research programs/initiatives	<input type="checkbox"/>				
The MS Society provides opportunities (research engagement sessions, conferences, programs, events) to interact with various groups within the MS Community (individuals impacted by MS, Researchers, Trainees, MS Society Staff, Clinicians)	<input type="checkbox"/>				

	Very important	Moderately important	Somewhat important	Not important	Do not know / prefer not to answer
Believe the MS Society can achieve its mission of improving quality of life and finding a cure for MS	<input type="checkbox"/>				
Being part of the MS community	<input type="checkbox"/>				
Opportunity to participate in research	<input type="checkbox"/>				
Show my support to the MS cause	<input type="checkbox"/>				
Stay informed about the activities of the MS Society	<input type="checkbox"/>				
Stay informed about the impact of the MS Society	<input type="checkbox"/>				

Is there anything else that would encourage you to interact with us? (please specify)

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[NON-MEMBERS ONLY]

**24. You indicated you are not a member of the MS Society or you have let your membership lapse. How important were the following factors in your decision to not obtain a membership or to not renew your membership with the MS Society of Canada?**

	Very important	Moderately important	Somewhat important	Not important	Do not know / prefer not to answer
Inefficient use of funds raised	<input type="checkbox"/>				
Membership offers me no benefit	<input type="checkbox"/>				
Lack of relevant supports and services for people affected by MS	<input type="checkbox"/>				
Not a strong voice and advocate on behalf of people living with MS.	<input type="checkbox"/>				
Lack of opportunities to participate in research	<input type="checkbox"/>				
Lack of transparency in reporting of financial status and the use of funds raised (trust)	<input type="checkbox"/>				
Lack of awareness of the work of the organization	<input type="checkbox"/>				
Reputation of the organization in the community	<input type="checkbox"/>				
Lack of awareness of the impact of the work that the organization does in the lives of people affected by MS	<input type="checkbox"/>				
Do not know anyone who has benefitted from the work of the organization	<input type="checkbox"/>				
Do not see the value and impact of research	<input type="checkbox"/>				
Do not believe the MS Society can achieve its mission of improving quality of life and finding a cure for MS	<input type="checkbox"/>				
Lack of engagement in the MS community	<input type="checkbox"/>				
Have no reason to support to the MS cause	<input type="checkbox"/>				
Not informed about the activities of the MS Society	<input type="checkbox"/>				
Not informed about the impact of the MS Society	<input type="checkbox"/>				

I did not receive a renewal notice	<input type="checkbox"/>				
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Is there anything else that was important in your decision to not obtain or renew a membership with the MS Society?

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[ALL RESPONDENTS]

**25. How do you prefer to interact with the MS Society of Canada and stay informed about the work that it does? SELECT ALL THAT APPLY.**

- Facebook
- Instagram
- Twitter
- E-newsletter
- MS Society website
- MS Society blog
- Dr. Karen Lee blog
- Am not interested in learning about the MS Society of Canada nor what it does
- Other (specify)

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- Do not know / Prefer not to answer

**26. How would you prefer the MS Society of Canada contact you? Select One Only**

- Email
- Letter mail
- Social Media
- Website
- Phone
- Newsletter
- Other (specify)

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- There is no need to contact me
- Do not know / Prefer not to answer

**WHERE SHOULD WE BE GOING AS AN ORGANIZATION?**

**27. What are the top 3 priorities you think the MS Society should focus on over the next 3 years?**

1. Top priority

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Don't know

2. 2<sup>nd</sup> priority

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Don't know

3. 3<sup>rd</sup> priority

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Don't know

**28. When you hear of the MS Society, a number of things may come to mind. Please indicate your level of agreement with the following statements. The MS Society is...**

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	Do not know / prefer not to answer
A worthy cause	<input type="checkbox"/>						
An organization that helps people affected by MS	<input type="checkbox"/>						
An organization that supports research that aligns with the needs of people affected by MS	<input type="checkbox"/>						
An organization that is a strong advocate for people affected by MS	<input type="checkbox"/>						
An organization that helps people affected by MS find the help they need and solve their day to day issues	<input type="checkbox"/>						
An organization that	<input type="checkbox"/>						

keeps me up to date on all the latest in research progress for people living with MS							
An organization that is open and transparent about how it operates and reports on the monies it raises	<input type="checkbox"/>						
An organization that runs excellent and exciting events	<input type="checkbox"/>						
A champion of research	<input type="checkbox"/>						
An organization that is positively portrayed in the media	<input type="checkbox"/>						
An organization that appreciates and honours its volunteers	<input type="checkbox"/>						
An organization I'm proud to support	<input type="checkbox"/>						
A good steward of its resources	<input type="checkbox"/>						

Other (please explain):

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**29. If the MS Society did not exist, what would that mean to you as a person affected by MS?  
Please indicate your level of agreement with the following statements.**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Somewhat agree</b>	<b>Somewhat disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Do not know / prefer not to answer</b>
People with MS would not have access to the services and supports they need.	<input type="checkbox"/>						
Research in MS would not occur or progress	<input type="checkbox"/>						
People with MS would lose their most important advocate	<input type="checkbox"/>						
People would lose an important opportunity to volunteer	<input type="checkbox"/>						
It would mean nothing to me	<input type="checkbox"/>						

Other (please explain):

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## DEMOGRAPHICS

To conclude this survey, we have a few demographic questions for classification purposes only.

### 30. What province or territory do you live in?

- British Columbia
- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- New Brunswick
- Nova Scotia
- Prince Edward Island
- Newfoundland and Labrador
- Yukon Territory
- Northwest Territories
- Nunavut
- Prefer not to answer

### 31. Which of the following best describes where you live? Is it a...

- Urban centre
- Rural community
- Do not know / Prefer not to answer

### 32. I am...

- Male
- Female
- Non-binary/ third gender
- Prefer to self-describe \_\_\_\_\_
- Prefer not to answer

### 33. Please select your age range:

- 19 and under
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80+

