LISTENING TO PEOPLE AFFECTED BY MS

Findings Report: Online Survey Results
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The advisory group met 11 times from April 2012 to July 2013. The group provided sound input on the evaluation methodology for the initiative, input on reach, the type of questions to ask for the poll, survey and focus groups, identification of key stakeholder groups and sound feedback on the analysis of the various components.

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SUMMARY OF FINDINGS

Listening to People Affected by MS Initiative is a multi-pronged evaluation conducted by MS Society of Canada (MSSOC) between 2012 and 2013. The Initiative aims to hear from Canadians affected by multiple sclerosis (MS) about their quality of life (QOL) short- and long-term priorities, their MS-related needs, and about barriers to having their needs met. The MS Society hopes this information will better inform decisions that relate to programs, services and advocacy. The Initiative consisted of a poll, a web-based survey, an environmental scan and a series of focus groups.

This document reports on the findings of the web-based survey that was made available to people with MS, people waiting for a diagnosis of MS, caregivers, and close friends or family members of a person with MS. The survey was open from November 2012 to January 2013. Respondents with no computer or Internet access were able to fill in paper copies of the survey or to call the MS Society to have their responses recorded. Response to the survey was self-selected. No incentives were provided to survey respondents.

1. Respondents’ profile

A total of 5,497 surveys were analysed for this report. Over three quarters of respondents are female. The average age of respondents is 50 years old. Sixty-three percent of respondents are over 44 years old. Eighty-five percent of respondents live in an urban area. The majority of respondents are from Ontario (one third) and from Québec (one fifth). Almost two thirds of respondents report a very good or good quality of life. Over half of respondents work either full-time or part-time; one quarter receives long-term disability benefits and sixteen percent are retired.

The majority of survey respondents (under three quarters) have a confirmed diagnosis of MS or Clinically Isolated Syndrome (CIS) followed by respondents who have a close relationship with a person with MS (less than one quarter). Caregivers (3.7%) and those waiting for a diagnosis with respect to MS (2%) are represented in a small proportion. Of those with MS, over half have relapsing-remitting MS (RRMS) while one third have a progressive form of MS. On average, an equal number of respondents have lived with MS for up to 5 years, 6 to 10 years, or more than 20 years. The largest number of respondents (almost one third) has lived with MS for 11 to 20 years. Almost all respondents live in a private residence either alone or with family; a minority live in long term care or in supportive housing.

The most common MS symptoms that impact the day to day life of respondents with MS or waiting for a diagnosis (3299 respondents) over the last year are: fatigue (75%) and problems with walking, balance and coordination (55%). Other symptoms include feeling numb or tingling (37%), bladder problems (35%), pain (31%), not thinking clearly (cognitive problems) (29%). Respondents who report substantial use of MSSOC client services\(^1\) are more likely to have a progressive form of MS and to report problems with balance, walking and coordination (67%), bladder problems (43%), and spasticity (33%).

The majority of respondents with MS or waiting for a diagnosis of MS (3315 respondents) indicate they never require supports to remain mobile. Responses range from 52% of respondents who never require help from another person to remain mobile to 81% who never need to use a scooter. Over one third of

\(^1\) Definitions of different levels of use of MS Society client services are described on page 12
respondents (35%, 1103) require help some of the time from another person to remain mobile while 22% (676) need to use a cane some of the time. Men are more likely than women to require the use of a wheelchair or a scooter. The type of MS influences the need for mobility supports: more respondents with progressive forms of MS require mobility supports than respondents with relapsing-remitting MS.

2. Respondents’ relationship with the MS Society

Respondents were asked to select from a list all ways in which ways they have been engaged in the past year with the MS Society, from using different types of client services, to volunteering, fundraising, donating or not having been in touch with the organization. Responses were grouped into 5 levels of usage of MS Society client services (CS): substantial use, considerable use, moderate use, some use and no use.

One third of respondents report some use of CS. An equal number of respondents (one quarter) report either considerable use or no use of CS. Eleven percent respondents report moderate use of CS while eight percent report substantial use of CS. The respondents’ profile varies by use of client services: the higher the use of services, the more likely it is respondents are older, have MS or CIS, report a lower quality of life, are on long- or short-term disability or are retired. The higher the use of CS, the more likely those with MS are to have a progressive form of MS, have lived with the diagnosis for a longer period of time, receive care or need care from a paid/unpaid caregiver, live at home by themselves (although the majority live with others). Those reporting moderate or no use of client services are more likely to need more care from a paid or unpaid caregiver than they currently receive (compared with some and considerable use of client services).

Respondents who indicate they have not been in touch with MSSOC in the past year were asked for the reasons for not connecting with our organization. Most respondents say they did not need support during that time. Only a small number of respondents (about 50, but second most frequent cited reason) reference the Society’s attitude in relation to and respondents’ perceived lack of support for CCSVI by the MS Society. An even smaller numbers of respondents (under 50 for each) reference a lack of relevant services; the program time and or location not being suitable; lack of awareness of services available; poor quality of services received or cuts in funding for programs; lack of trust in the MSSOC. Few respondents note they are not ready to reach out for help to Society; they do not have time or have health issues that get in the way.

MS information sources

Respondents were asked where they get information about MS. Two thirds of respondents note they get information from health care professionals. Under half (45%) indicate they get information from the MS Society. MS Clinics and online and printed news stories are referenced by one third of respondents.

With respect to the role of the MSSOC in providing support, a large number of respondents indicate they did not use MSSOC supports (two thirds did not reach out to MSSOC staff and volunteers, and almost one half did not use MSSOC online or print resources). Of those who used these MSSOC resources, one third rated them “very useful” and half or under “somewhat helpful”.

2 Definitions of these groups can be found on page 12
Overall survey findings suggest that people with MS reach out and use the Society’s services is dependent on their disease progression. In the early stages of the disease respondents are less likely to need support or information from the MS Society of Canada. At this stage they are more likely to report that MSSOC online and print resources are one of the most important sources of information and support. As the disease progresses so do their needs and they actively reach out for support to the MS Society of Canada. At this stage they are more likely to report that MSSOC staff and volunteers are one of the most important sources of information and support.

3. Respondents’ priorities

Long-term priorities

When asked what worries them most about having MS in their lives, respondents speak about the impact of the disease on their family; the unpredictability, uncertainty of the future and the unknown of the disease; about increased levels of disability (loss of mobility and vision); about the decrease of the overall quality of life of the person with MS; and about the loss of independence for the person with MS. Responses are consistent among geography, category of clients, use of client services, and genders.

Respondents were also asked to select the three most important factors that help improve the quality of life of people affected by multiple sclerosis. Listed in decreasing order of their importance, the 5,064 respondents prioritize the QOL factors as follows:

1. **Medical care**: People with MS have access to medical care, treatments, and therapies appropriate to their needs (a priority for 68% of respondents)
2. **Support for family members**: Family members and caregivers receive information and support to mitigate the effects of MS (a priority for 54% of respondents)
3. **Health promotion and disease prevention**: People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle (a priority for 50% of respondents)
4. **Independence and empowerment**: People with MS are empowered as full participants in their communities and in decision making about the management and treatment of the disease (a priority for 49% of respondents)
5. **Continuing (long-term or social) care**: People with MS have access to a wide range of age-appropriate care services that enable them to function as independently as possible (a priority for 46% of respondents)
6. **Housing and accessibility of buildings in the community**: Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS (a priority for 36% of respondents)
7. **Disability benefits and cash assistance**: Disability entitlements and services are available to those in need, provide an adequate standard of living and have flexibility to allow for disease variability that is characteristic of MS (a priority for 35% of respondents)

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3 Clients of the MS Society of Canada are defined as individuals: (1) living with MS or Clinically Isolated Syndrome (CIS); (2) Awaiting a diagnosis with respect to MS or CIS; (3) A caregiver of person with MS or CIS; (4) A close friend or family member of a person with MS or CIS.
8. **Transportation:** People with MS have access to their communities through accessible public transportation and assistive technology for personal automobiles (a priority for 28% of respondents)

9. **Employment and volunteer activities:** Support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work (a priority for 20% of respondents)

10. **Education:** MS does not inhibit the education of people with MS, their families or careers (a priority for 11% of respondents)

When comparing the top five priorities of the four categories of primary clients, respondents with MS or waiting for a diagnosis place more emphasis on health promotion and disease prevention while caregivers and friends and family of a person with MS place more emphasis on housing and accessibility. Priorities also vary by type of MS, and, to a lesser extent, by geography.

**Short-term priorities**

When asked what would help improve their quality of life today, the majority of respondents speak about the need to find a cure, to repair the damage of the disease and reverse its effects, as well as about treatment of MS and symptom management. Other short-term priorities identified by respondents are: financial support; information and education about MS; advocacy for research and treatment of CCSVI; support and services for the person with MS; community access; and access to and quality health care.

These findings are supported by respondents’ perspective on the best investment for the Society’s resources. When asked to imagine they donate $100 to the MS Society and to tell how they would spend the money between two categories (1) research and (2) programs, services and government relations, respondents allocate on average $60 to research and $40 to programs, services and government relations. More specifically, half of respondents allocate more than $51 to research, one third allocate the funds equally between research and services, programs and government relations and 13% allocate over $51 to services, programs and government relations. Respondents who report considerable use of CS are more likely to invest more in services, programs and government relations, or to favor equal spending between the two categories.

4. **Respondents’ needs**

As a measure of the respondents’ short term needs, respondents were asked to identify the most important MS-related concern or problem that they needed help with in the last year. Respondents report they encountered the following problems during the last year: managing MS symptoms; accessing financial support; making decisions related to MS; accessing medical care and the poor quality of medical care; and obtaining special assistance for the person with MS (personal and home care).

The most useful supports respondents have used in order to address the above short-term needs are: unpaid caregivers; mobility aids; personal networks; MS clinics; accessible transportation and paid caregivers. The least useful support identified by respondents is government programs; followed by
support at work or to find work; respite care or short-term care; long-term facilities; and lack of programs in the area run by other charities other than the MS Society.

Barriers to meeting these short-term needs include respondents’ self-reported poor coping skills with MS (denial, caregiving stress, or not being able to ask for help); lack of money for supports or services; not knowing where to go for help; support or services not available at the time; and MS symptoms getting in the way.

5. Gap analysis: met and unmet needs

For each of the ten QOL principles identified we are discussing below the met needs and the gaps identified (un-met needs). Overall disease progression is a key factor that seems to increase gaps and the need for support.

1. Access to medical care

Most respondents with MS report that they have access to medical care, treatments, and therapies appropriate to their needs. From a provincial perspective, Québec rates highest on access to medical care. Respondents with progressive MS indicate lower levels of access to medical care lower than those with relapsing-remitting MS (RRMS).

- Most respondents had access to health care professionals in the past year: 87% have seen a neurologist and 76% have seen a family doctor. Respondents note a number of challenges related to access to medical care: finding a new family doctor or neurologist; obtaining timely referrals to a specialist; getting a second medical opinion; having access to medical tests such as MRI. They also comment on the poor quality of care: neurologists do not take sufficient time to give advice; poor knowledge of MS among health care professionals; and lack of support for people with progressive MS. Respondents also reference inconsistency in diagnosis and lack of effective treatments for their MS.

- Most respondents with MS (78%) received the support necessary from their health care professional at the time of their diagnosis. Those who did not receive this support identify it as an important problem they had to deal with.

- Three quarters of respondents with MS (73%) have access to disease modifying treatments; drugs to manage symptoms; and rehabilitation services approved in Canada. Men diagnosed with primary or secondary progressive MS who are either on long term disability or retired are more likely to report that they do not have access to disease modifying therapies. This group tends to report a fair or poor quality of life, to use mobility aids, to live at home by themselves or with young kids. They are more likely to receive care from a paid or unpaid caregiver and to need more care then they currently receive.

- Over two thirds of respondents with MS (69%) feel their healthcare team cares about their overall well-being and does not focus solely on treating their disease.

- Under two thirds of respondents with MS (63%) were referred to the MSSOC at the time of their diagnosis. Those who report they were referred to the MS Society are significantly more likely to
be diagnosed with relapsing remitting MS, to use the MS Clinics as a main source of information and to be a member of the MS Society.

- Under two thirds of respondents with MS (61%) indicate their family doctor is knowledgeable about MS.

2. Support for family members and caregiver to mitigate the effects of MS.

The vast majority of respondents worry about the impact of MS on their family. They do not want to become a burden to their family. They feel that if they are not able to support and care for their family, the QOL of the family as a whole will decrease. Many report MS impacts their relationships and marriage.

Caregivers play a major role in the care of the person with MS. Unpaid caregivers are the most helpful support respondents used over the last year to help with an MS-related problem or concern. Paid caregivers and personal networks are also among the most helpful supports reported.

Respondents with MS worry about the health of their caregiver. Caregivers worry about their own health and their ability care for the person with MS. Respondents indicate caregiving brings increased levels of stress, risk of injury, as well as emotional and financial problems.

While support for family members and caregivers is important and highly valuable, caregivers do not appear to be well supported. Least supported appear to be respondents reporting substantial or considerable use of CS and those with progressive MS.

- Less than half of respondents (45%) and under one third of caregivers can find the support they need as a caregiver or family member.
- Less than half (42%) of respondents have someone to talk to when they feel tired or when negative feelings arise.
- One quarter (26%) of respondents’ children have caregiving responsibilities.
- Under one quarter of respondents (23%) have access to respite services that allow them to take breaks from caregiving. Those who have used such services rate them among the least helpful programs.
- Under one quarter of caregiver respondents (21%) have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving.
- Most caregivers have seen a professional for their role as caregiver in the past year: family doctor (51%), massage therapist or chiropractor (24%), nurse (14%), occupational therapist or social worker (12%).
- 42% of caregivers and those close to a person with MS to whom this statement applies indicate their boss gives them time off, as needed, so they can care for the person with MS in their life.
3. Health promotion and disease prevention

Overall, people with MS appear to have the information and services they need to maintain positive health practices and a healthy lifestyle.

Over two thirds of respondents (69%) have access to information and advice about exercise, nutrition, and ways to manage stress. However, one of the things that would improve respondents’ quality of life is more information and education about the disease in general and health promotion for people with MS, health care professionals, governments, family and friends.

Respondents were asked where they get information about MS. Two thirds of respondents note they get information from health care professionals. The MS Society is the second most important source of information about MS (for 45% of participants). MS Clinics and online and printed news stories are referenced by one third of respondents.

The majority of respondents with a confirmed diagnosis of MS (80%) indicate their health care provider(s) offers them routine medical care that is not related to their MS.

4. Independence and empowerment

The majority of respondents worry about losing their independence. They fear that as the disease progresses they will lose their mobility and abilities, will no longer be able to care for themselves and will have to depend on others. Most respondents do not require supports to remain mobile at this time; therefore while independence may not be an issue today for respondents, it is top of mind as they think about their future with MS.

Most respondents participate in their communities and in decision-making about the management and treatment of the disease. Respondents with progressive forms of MS and those reporting substantial use of CS tend to rate lower on this dimension.

- The vast majority of respondents (88%) feel they help decide on medical treatments or other aspects of living with MS.
- Over three quarters of respondents (79%) have access to information and advice about MS. Respondents need information and advice about how to choose a treatment, how to manage the side effects of the treatments (injections a recurrent mentions), changes in medications and in therapies. Respondents have questions related to pregnancy and MS and about breastfeeding and MS.
- Almost three quarters of respondents (70%) have access to treatments, programs and services whether they can pay for them or not. However, access to treatments and medication are also barriers that respondents identify. Most respondents report in the past year they encountered problems with paying for MS-relate medication, services, and treatments. As the disease progresses (and more people retire or get on long-term disability) the need for access to treatments, programs and services, irrespective of their ability to pay, also increases.
- Over two thirds of respondents are able to be part of community life as much as they want. Respondents worry about social isolation and losing their friends. They suggest that increased
accessibility and home adaptations as well as transportation services can help increase their participation in community life.

- Less than two thirds of respondents (62%) have access to equipment and technology that they can afford and that helps them maintain their independence (such as mobility aids and changes to their car or home). One of the main problems respondents dealt with in the past year is the ability to obtain or pay for mobility aids (walker, wheelchair, power chairs); repairs and replacement parts (batteries) for mobility aids; home adaptations for accessibility; orthotic aids, and air conditioning.

5. Continuing (long-term or social) care

While a very small number of respondents indicate they live in a long-term facility (0.6%, 20) or in supportive housing that provides health care and services (0.8%, 26), the issue of long-term care is an important and frequent concern for all respondents. The majority of respondents with MS feel that they have the support they need to stay in their home as long as possible. However, people with MS and caregivers worry about disease progression, increased levels of disability and eventually having to move the person with MS into a long-term care facility. People with MS do not seem to have access to a wide range of age-appropriate care services that enable them to function as independently as possible.

- Long-term facilities are one of the least helpful programs
- More than half of respondents (56%, 345) indicate the people who are paid to care for them are knowledgeable about MS. This is least likely to be true for residents in Saskatchewan and for those with progressive MS.
- Only one third of respondents (34%, 59) agree that other people their age live in the same long-term care facility where they live.
- Under one third of respondents with MS (30%, 84) indicate their long-term care facility provides activities and supports that engage and interest them. Those reporting substantial use of CS and those living in rural areas are less likely to agree with this statement.

6. Housing and accessibility of buildings in the community

Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to the independence of people with MS.

- Three quarters of all respondents (75%, 2975) indicate community buildings such as government offices, hospitals, clinics, and schools are accessible all the time or most of the time.
- Almost two thirds of the respondents to whom this question applies (62%, 897) indicate their home has been adapted to make it easier to live with MS. Many respondents note they were not able to pay for home adaptations and or to access buildings in a community in the past year.

Accessibility needs are less likely to be met for respondents reporting substantial use of CS and those with progressive forms of MS.
7. Disability benefits and cash assistance

Survey respondents indicate that disability entitlements and services should be available to those in need, that they should provide an adequate standard of living and should have flexibility to allow for disease variability that is characteristic of MS.

The financial burden of the disease on the person with MS and the family as a result of loss of work and income is a major worry for respondents. The cost of the disease is high: from cost of treatments and medications, to home adaptations, and symptom management. Financial support is the second most important issue that would help improve the respondents’ quality of life today (the first being finding a cure). Respondents need help to pay for medication, services, equipment, treatments, and transportation. They have challenges navigating the system to get financial support: how to get medication covered, apply for disability pension or for Trillium funding in Ontario; fill out forms; and apply for disability tax and insurance. Some suggest that the Society should work to influence policy and legislation dealing with disability, cost and coverage of drugs. They comment that the definition and tests to qualify for long term disability do not seem to take into account the symptoms and variability of MS. The legislation that prevents people on disability to work is also something that respondents suggest needs to be addressed.

Financial support needs are more likely to be met for respondents from Alberta and Québec, and less likely to be met for respondents reporting substantial, high and moderate use of CS, as well as for those with progressive forms of MS.

- The ability to work full-time and part-time decreases with the progression of the disease. Overall, one quarter of respondents receive long- or short-term disability and 5% do not have a paid job. More respondents with progressive forms of MS are on long-term disability or are retired when compared with respondents with other forms of MS. Respondents with MS who receive long term disability or short term disability are more likely to be aged 44 to 64 years old therefore still in their prime working years.

- Only half of respondents with MS to whom the question applies (51%, 889) indicate their disability benefits (public or private) allow them to maintain a standard of living that is good enough.

- Almost one half of respondents to whom the statement applies (42%, 1085) find it difficult to get financial assistance for MS-related issues.

- One third of respondents with MS to whom the question applies (30%, 982) relied on financial help outside of their own personal resources to help with issues linked to MS in the past year (family members, provincial financial support for programs and services, insurance and employment benefits and federal income support.) The level of reliance on financial help outside of personal resources increases is highest for those who report substantial use of client services.
8. Transportation

Accessibility-related issues are another frequent problem respondents dealt with in the last year. They indicate that people with MS need access to their communities through accessible public transportation and assistive technology for personal automobiles. Access to transportation is a bigger priority for caregivers and those close to the person with MS, and for those with progressive forms of MS.

Where accessible transportation services are available, they are one of the most useful supports identified by respondents, in particular for those residing in Québec. Where such services are not available, respondents, in particular for those with progressive MS, and those living in rural areas, note that financial support to help with transportation is an important unmet need.

- While two thirds of respondents to whom the question applies (60%, 626) note the transportation statement does not apply to them, almost two thirds of those to whom it applies say transportation services where they live allow them to travel around.
- Over one quarter of respondents to whom the question applies (27%, 175) indicate their car has changes made to it so they can still drive it.

9. Employment and volunteer activities

The ability to maintain employment after being diagnosed with MS is another important worry for respondents. Apart from the obvious financial implications of losing one’s job, respondents speak about the importance of work to their quality of life: being able to fulfill one’s purpose, contribute to society and support their family.

Over half of respondents work either full- or part-time. Significantly fewer respondents with progressive forms of MS work full-time (10%) when compared to respondents with relapsing-remitting MS (43%).

- Only half of respondents with MS to whom this question applies (54%, 482) indicate their workplace makes changes so that they can still work despite their MS.
- Half of respondents with MS who are not currently employed (55%, 946) indicate they are retired from work but they feel fulfilled by volunteer work, hobbies or domestic life. Respondents reporting considerable and no use of CS are more likely than those reporting substantial or moderate use of CS to agree with this statement.
- Under half of caregivers and family members (42%, 154) indicate their boss gives them time off, as needed, so they can care for the person with MS in their life.

10. Education

Accessing education despite the challenges presented by MS is a priority for a very small number of respondents. The questions regarding education do not apply to the vast majority (96%) of respondents. Of those respondents with MS to whom the statements apply, half indicate their school accommodates their MS so they can continue with their education.
1. BACKGROUND AND CONTEXT

Listening to People Affected by MS Initiative is a multi-pronged evaluation conducted by MS Society of Canada between 2012 and 2013. The Initiative aims to hear from Canadians affected by MS about their quality of life short- and long-term priorities, their MS-related needs, and about barriers to having their needs met so that the MS Society of Canada can better inform decisions that relate to programs, services and advocacy. The MS Society has sought input in a number of ways: a web-based survey and a poll (conducted in November 2012). In addition several focus groups as well as an environmental scan will help further explore aspects of quality of life and MS. This report focuses on the results and findings of the web-based survey.

Objectives of the Initiative

1. Understand the characteristics and quality of life (QOL) needs of people whom the MS Society currently serves as well as those it currently does not serve.
2. Determine the extent to which Quality of Life principles and needs are being met in Canada; identify barriers preventing QOL needs being met for people affected by MS; and identify gaps in services and policies related to QOL needs / principles.
3. Develop recommendations with respect to what the organization needs to do, either directly through programs and services or indirectly through advocacy, in order to enable Canadians affected by MS to have their QOL needs met.

Primary Audience

The Initiative sought input from those defined as ‘Primary Clients’ by the MS Society of Canada. These are defined as individuals:

- Living with MS or Clinically Isolated Syndrome (CIS)
- Awaiting a diagnosis with respect to MS or CIS
- A caregiver of person with MS or CIS
- A close friend or family member of a person with MS or CIS

Evaluation Questions addressed by the Initiative

3. What are the QOL priorities for Canadians affected by MS?
   a) What MS QOL principles are most important / relevant to Canadians living with MS?
   b) How does each QOL principle relate to Canadian laws, policies, and realities?
   c) What do people affected by MS believe is the best investment of MS Society resources?

4. What are the current QOL needs, barriers and gaps experienced by Canadians?
   d) What are the most urgent unmet needs of Canadians affected by MS?
   e) What barriers to meeting QOL needs are currently experienced by Canadians affected by MS?
   f) What are the gaps in Canada between QOL unmet needs and MS QOL principles?
   g) What sources of supports do Canadians affected by MS find effective?

5. Who is the MS Society serving and who are the people affected by MS who do not use the programs and services of the MS Society?
   h) What are the socio-demographic, geographic and disease-related characteristics of people affected by MS?
   i) Why are primary clients not accessing MS Society programs and services
j) Are there socio-economic, geographic, or disease-related differences between those who currently use the programs & services of the MS Society and those who do not?

6. Taking action

k) Is MSSOC able to deliver the quality of life priorities/self-identified needs to those affected by MS? If so, what is best way to deliver (advocacy, direct services, etc.)? If not, what do we need to do?

l) Where does the MSSOC have the greatest potential to influence positive change to the greatest number of people?

m) Given that this initiative will provide meaningful baseline information, where do we go from here in terms of an ongoing evaluation plan?

Defining Use of MS Society Client Services

For analytical purposes respondents to the poll and the web-based survey were broken down into usage categories based on a question which asked which MS Society programs or services each respondent had used within the past year. Respondents were able to select any number of answer categories that applied to them from a variety of statements which are listed below. The use of MS Society client services was defined as follows:

**Substantial use of client services** answered yes to:
- I received financial assistance or equipment provision (loan or purchase or special services (snow removal, etc.) from the MS Society

**Considerable use of client services** answered yes to any of the following:
- I attended a presentation, workshops or conferences (in person, online or on the phone) offered by the Society
- I participated in a exercise/recreation/social programs (e.g. yoga, swimming Tai Chi, holiday dinner) offered by the MS Society
- I attended a support/self-help group or peer support (getting together with other people affected by MS to support one another) of the MS Society of Canada

**Moderate use of client services** answered yes to any of the following:
- I called the MS Society to ask for information/support/referrals
- I received in-person information/support/referrals/visit from my local MSSOC chapter / Division

**Some use of client services** answered yes to any of the following:
- I received print newsletters or print publications about MS from the MS Society
- I accessed online publications and newsletters from the MS Society
- I went to the MS Society website for information about MS

**No use of client services** had used any of the following:
- I participated in the MS Walk
- I participated in the MS Bike
- I participated in other fundraising events
- I volunteered for the MS Society
- I donated
- None
2. SURVEY METHODOLOGY

2.1. Sampling, design and data collection

The web-based survey was open from November 2012 to January 2013. Hard copies of surveys were made available to those responders who do not have computer and/or Internet access and were further entered manually into the database. Moreover, respondents were able to call in and dictate their responses to a staff that entered them in database.

The survey was available on the website of the MS Society of Canada (both online and in printable format for paper versions) and was promoted at the national, division and chapter levels. Information and promotional materials including posters and postcards were sent to Divisions who distributed the materials in various ways including at Chapter offices, group support meetings, recreational programs, in MS Clinics, etc. Division and Chapter newsletters included articles about the survey and how to participate. A radio announcement and newspaper advertisements promoted the survey in local communities and updates on the MSSOC Facebook page and Twitter feeds were also utilized. Additionally, a direct email invitation to participate in the survey was sent using the MS Society database to reach a broad base of Canadians affected by MS.

No sampling strategies were used for this survey. Response to the survey was voluntary. There were no incentives provided to survey respondents.

2.2. Survey response rate

A total of 5,497 surveys have been submitted and analysed for this report. The number of responses to each question varies either due to skip logic (questions that apply only to select groups of respondents) or questions that were left unanswered by respondents.

A total number of 292 surveys (not including the 5,497 above) have been eliminated from the database as respondents answered less than the first three questions of the survey (See Appendices). Some respondents dropped the survey later on, however they were deemed suitable to be included in the data analysis. Testing the survey before launch indicated that this 32-question survey took on average 20 minutes to complete, which might explain why some respondents dropped out.

Efforts have been made to determine the response rate relative to the Society’s primary client population. A number of challenges were encountered. While there are rather wide estimate ranges of the number of people who have MS in Canada, there is no definitive information about the number of people with a confirmed diagnosis of MS in Canada and even less information about the population size of caregivers, people awaiting a diagnosis or who have a close relationship to someone with MS.

To determine whether the number of responses of people with MS in each province are representative of the MS population in that particular province, we referred to the study “Regional variation of multiple sclerosis prevalence in Canada” by Cynthia Beck, Luanne Metz, Scott Patten, Lawrence Svenson published in Journal Multiple Sclerosis (2005: 11). See table below.
Survey results may over-represent the views / experiences of those living in Québec (23.3% of respondents were from Québec but only 17.3% of Canadians with MS live in Québec). Survey results may under-represent the views of those living in Atlantic Canada (6.4% of sample vs. 9.9% of Canadians with MS live in Atlantic) and Alberta (11.4% responded but 17.2% people with MS live in Alberta).

Based on this study, it appears that the number of responses this survey received is equal to a sample size with a 5% margin of error and 99% confidence interval for Canada, the Prairies (Alberta, Manitoba and Saskatchewan), Québec, Atlantic, British Columbia and Ontario. For Alberta, the number of responses is equal to a sample size with a 5% margin of error and 95% confidence, while for Atlantic the number of responses is equal to a sample size with a 5% margin of error and 90% confidence. (See table)

<table>
<thead>
<tr>
<th>Region</th>
<th>Prevalence of MS as per study</th>
<th>Population - Stats Can (July 2012)</th>
<th># people with MS by region (prevalence x population)</th>
<th># of MSSOC survey responses from PwMS</th>
<th>Minimum recommended sample size</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5% margin of error &amp; 90% confidence level</td>
</tr>
<tr>
<td>Canada wide</td>
<td>240/100000</td>
<td>34 880 491</td>
<td>83 713</td>
<td>3 194</td>
<td>383</td>
</tr>
<tr>
<td>Prairies (AB, MB, SK)</td>
<td>340/100000</td>
<td>6 264 055</td>
<td>21 298</td>
<td>703</td>
<td>377</td>
</tr>
<tr>
<td>Alberta</td>
<td>368/100000</td>
<td>3 917 094</td>
<td>14 415</td>
<td>363</td>
<td>266</td>
</tr>
<tr>
<td>Québec</td>
<td>180/100000</td>
<td>8 054 756</td>
<td>14 499</td>
<td>745</td>
<td>375</td>
</tr>
<tr>
<td>Atlantic</td>
<td>350/100000</td>
<td>2 363 409</td>
<td>8 272</td>
<td>205</td>
<td>368</td>
</tr>
<tr>
<td>BC</td>
<td>240/100000</td>
<td>4 658 674</td>
<td>11 181</td>
<td>503</td>
<td>372</td>
</tr>
<tr>
<td>Ontario</td>
<td>230/100000</td>
<td>13 539 597</td>
<td>31 141</td>
<td>1 038</td>
<td>380</td>
</tr>
</tbody>
</table>

To determine whether the responses of people with MS or CIS are representative of the general Canadian MS population from a gender and age perspective, we have used the data provided by the most current Statistics Canada’s Canadian Community Health Survey (CCHS), Table 105-1300 - Neurological conditions, by age group and sex, household population aged 0 and over, 2010/2011. This study states the total population of people with a confirmed diagnosis of MS in Canada is 93,535. Below is a comparison of the percent of Canadians with MS by sex and age between the Statistics Canada study and the number of responses for the web-based survey. See table on following page.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Canadians with MS (Stats Canada)</th>
<th>MSSOC Survey Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>number</td>
<td>Percent</td>
</tr>
<tr>
<td>Sex</td>
<td>% male</td>
<td>25 425</td>
</tr>
<tr>
<td></td>
<td>% female</td>
<td>68 111</td>
</tr>
<tr>
<td>Age</td>
<td>18 - 44</td>
<td>28 157</td>
</tr>
<tr>
<td></td>
<td>45 to 64</td>
<td>44 481</td>
</tr>
<tr>
<td></td>
<td>65 and over</td>
<td>18 538</td>
</tr>
</tbody>
</table>

In conclusion, the number of responses in most provinces is large enough to secure a sample size that provides a 5% margin of error & 99% confidence level (which means that if we were to repeat the survey 100 times, in 99 of the cases the real results will be 5% above and below the response rate for the survey). Respondents with MS from Québec appear to be overrepresented while people with MS in Atlantic and to a lesser degree in Alberta appear to be underrepresented. Women with MS are overrepresented. People with MS age 65 and over are underrepresented while people with MS age 45 to 64 are overrepresented. The data has not been adjusted to address these potential over-and under-representations.

Despite these limitations, given the significant number of responses to the survey (over 5,400), the relative similarity with the MS population overall and on a province by province basis, we have confidence that our sample provides an accurate representation of people living with MS in Canada.

2.3. **Data analysis**

Qualitative and quantitative data was analyzed using the data analysis features offered by Survey Monkey, an online survey tool which was also used to design the web-based survey and collect the survey data, and other statistical analysis calculators. The survey was conducted in both English and French via two separate data collectors. The data was then collated in Excel and the standard statistical tests were applied to the entire data set. These tests are:

- **Quantitative data:**
  - Frequencies (number of responses and percent of total responses)
  - Mean and median
  - Cross-tabulations (a joint distribution between two (or more) discrete variables reported as frequencies and number of occurrences of the corresponding pairs of values of the selected variables.) Statistical significance was calculated for all comparisons between sub-groups (cross tabulations).
  - Distribution of data was calculated for several questions.

- **Qualitative data:**
  - Code and filter respondents' answers, allowing to determine frequencies of themes for overall data, filters and cross-tabulations

Quantitative and qualitative data regarding each evaluation question were compared and are presented in this report.
2.4. **Limitations and potential biases**

- Survey response was voluntary and respondents are self-selected; self-selected surveys may introduce a number of biases to the data.
- Respondents are not a representative sample of the Society’s primary clients groups.
3. SURVEY RESPONDENTS

Profile of respondents

Over three quarters (76%) of respondents are female. Sixty-three per cent are over the age of 44 years old with the single largest age group being the 45-54 years category (28%). The average age of respondents is 50 years old. The category of primary clients influences the gender and age of respondents.

Eighty-five per cent of respondents gave an urban area postal code. The majority of individuals are from Ontario (34%) and from Québec (20%). The response rate by MS Society division are as follows:

![Number of respondents by MS Society of Canada Division](image)

Sixty two percent of respondents report a very good or good quality of life, with the single largest group being good quality of life (32%). Below is a comparison between the self-reported QOL of all respondents, people with a diagnosis of MS or CIS, and caregivers.

![Self-reported quality of life in the past year](image)
Over half of respondents (51.5%) work either full-time or part-time. 23.5% receive long-term disability and 15.6% are retired.

The overwhelming majority of respondents use the Internet on a daily basis (86.3%) or a few times a week (10.9%), which can be expected given that this was a web-based survey advertised mostly through electronic media.

**Primary client categories**

The ‘Primary Clients’ of the MS Society of Canada are defined as individuals who are:

- Living with MS or Clinically Isolated Syndrome (CIS)
- Awaiting a diagnosis with respect to MS or CIS
- A caregiver of person with MS or CIS
- A close friend or family member of a person with MS or CIS

The greatest proportion of survey respondents (72.5%) has a confirmed diagnosis of MS or CIS followed by those who have a close relationship with the person with MS (22%). Other primary client groups appear in the survey in much smaller proportions: 3.7% caregivers and 2% for those waiting for a diagnosis of MS.

Of the group with a confirmed diagnosis of MS, over half (55.4%) have relapsing remitting MS, 19.1% have secondary-progressive MS, 9.3% primary-progressive MS and 2.8% progressive relapsing MS. A very small percentage (1.8%) has Clinically Isolated Syndrome. On average, an equal number of respondents have lived with MS for up to 5 years (24.2%), 6 to 10 years (22.9%) or more than 20 years (23.2%), while the largest number of respondents has lived with MS for 11 to 20 years (29.7%).

Among respondents waiting for a diagnosis of MS, half have been waiting for a diagnosis for less than 2 years (out of which 30% for less than one) while 18% have been waiting for more than 10 years.

**Living arrangements**

Living arrangements were only asked of the group with a confirmed diagnosis or waiting for a diagnosis of MS. Almost all respondents (97%) live in a private residence either alone or with family, with only a small minority of those with MS (1.5%) living in long term care or supportive housing. Of those who indicate they live at home by themselves, they are more likely to be aged 65 or over and to be on long term disability and are less likely to have relapsing remitting MS.
Use of MSSOC client services

One third of respondents report some use of CS. An equal number of respondents (26%) report considerable use or no use of CS. 11% of respondents report moderate use of CS while 8% report substantial use of CS. The profile of the respondents by use of MS Society client services is:

No use of CS
This is the youngest group (43% under 44) with an average age of 50 years old. Most (60%) work full time or part time. Over half report high quality of life (53% excellent or very good). The group includes more people close to a person with MS or family members (33%). Those with MS are more likely to have been diagnosed in the last 5 years with relapsing remitting MS and to live at home with others. The majority of respondents in this category do not receive care from caregiver, however almost one quarter (22%) need this kind of care. This group is the most likely to report they have not been in touch with the MS Society in the last year.

Some use of CS
This group has a similar profile to those reporting no use of CS. They are fairly young (41% up to 44 years old) with an average age of 49 years old. Most work full time or part time (58%). They report excellent or very good QOL (46%), and are less likely to report poor or fair QOL. Most have MS (70%) or are a family/ close to a person with MS (24%). Those with MS are more likely to have been diagnosed with relapsing remitting MS in the last five years, however one quarter of respondents have a progressive form of MS. The majority do not receive care from paid /unpaid caregiver (82%); and report the lowest need for more care than they currently receive (15%). The group is the second most likely to report they have not been in touch with the MS Society in the last year (after those who report no use of services.)

Moderate use of CS
Similar to the previous groups, 41% of respondents reporting moderate use of CS are age 18 to 44 years old with an average age of 49 years old. More work full time or part time (58%). They report excellent or very good QOL (46%), and are less likely to report poor or fair QOL. Most have MS (70%) or are a family/ close to a person with MS (24%). Those with MS are more likely to have been diagnosed with relapsing remitting MS in the last five years, however one quarter of respondents have a progressive form of MS. The majority do not receive care from paid /unpaid caregiver (82%); and report the lowest need for more care than they currently receive (15%). The group is the second most likely to report they have not been in touch with the MS Society in the last year (after those who report no use of services.)

Considerable use of CS
This group is older than the previous groups but they are still in the workforce. 64% are aged 45-64; with an average age of 54 years old. More live in Québec or British Columbia. Over one third (36%) work full or part time and an equal number are on LTD (37%). More are retired (21%). They report very good or good QOL (59%), however they are least likely to report excellent QOL. The majority have MS (81%), an increasing number (38%) have progressive MS or have lived with MS for over 20 years (29%). Most live home with others (80%). One quarter receive care from paid or unpaid caregiver. They are the largest group reporting they receive enough to meet their needs (83%). Of those who do not receive care, they are less likely to need this kind of care. The group is more likely than respondents reporting no, some or moderate use of CS to be a member of the MS Society. Also, the group is most likely of all groups to have:
donated money to the MS Society in the past year, volunteered in a non-fundraising capacity, involved in other MSSOC fundraising events, and participated in the MS Walk. They are as likely as those reporting substantial use of CS to have volunteered at MSSOC fundraising events.

**Substantial use of CS**
Similar to those reporting considerable use of CS, this group is older but still in the workforce. 65% are aged 45-64, with an average age of 53 years old. More live in Atlantic and Ontario. Less than one quarter work full time or part time. Over half (52%) are on LTD (52%) and one quarter (24%) are retired. Most report a fair or poor QOL (44%). The majority have MS (87%) or are a caregiver (6%). Those with MS have lived with the disease the longest (34% over 20 years). Over half (53%) of respondents have progressive MS. Two thirds (66%) live with others but over one quarter (27%) indicate they live alone. Half receive care from a paid or unpaid caregiver (50%); one third (30%) say they need more care than they currently receive; of those who do not receive care, they are the most likely to need such care (18%). The group is most likely of all categories to be a member of the MS Society. Also, the group is as likely as those reporting considerable use of CS to have volunteered at MSSOC fundraising events. The group is second most likely (after those reporting considerable use of client services) to have volunteered for the MS Society in a fundraising or non-fundraising capacity, participated in programs such as support groups or peer support groups, exercise, recreation or social program, or gone to MS presentations.
KEY FINDINGS

4.1. What are the quality of life priorities for Canadians affected by MS?

What does quality of life mean in this report?
The World Health Organization (WHOQOL-100) defines quality of life (QOL) as an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected by the person’s physical health, psychological state, level of independence, social relationships and to salient features of their environment. The definition reaches beyond medical care to a broad range of other domains.

How were the QOL priorities in this survey identified?
The MS Society of Canada (MSSOC) has endorsed the Principles to Promote the Quality of Life (QOL) of People with Multiple Sclerosis identified by the Multiple Sclerosis International Federation (MSIF) which are built on WHOQOL-100. The principles are the result of extensive key informant interviews, literature review, the clinical, programmatic, and research experience of the authors and their reviewers. The 10 principles are:

1. **Independence and empowerment**: People with MS are empowered as full participants in their communities and in decision making about the management and treatment of the disease
2. **Medical care**: People with MS have access to medical care, treatments, and therapies appropriate to their needs
3. **Continuing (long-term or social) care**: People with MS have access to a wide range of age-appropriate care services that enable them to function as independently as possible.
4. **Health promotion and disease prevention**: People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle
5. **Support for family members**: Family members and caregivers receive information and support to mitigate the effects of MS
6. **Transportation**: People with MS have access to their communities through accessible public transportation and assistive technology for personal automobiles
7. **Employment and volunteer activities**: Support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work
8. **Disability benefits and cash assistance**: Disability entitlements and services are available to those in need, provide an adequate standard of living and have flexibility to allow for disease variability that is characteristic of MS
9. **Education**: MS does not inhibit the education of people with MS, their families or careers.
10. **Housing and accessibility of buildings in the community**: Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS
What QOL principles are most important / relevant to Canadians living with MS?

Long-term priorities

Respondents indicate the following factors have been important to their day to day lives in the past year (listed in decreasing order from the most important to the least important):

<table>
<thead>
<tr>
<th>Quality of life statements</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having access to medical care</td>
<td>68%</td>
<td>3433</td>
</tr>
<tr>
<td>2. Being able to make decisions about treating and managing MS*</td>
<td>55%</td>
<td>2804</td>
</tr>
<tr>
<td>3. Having support for family members and caregivers</td>
<td>54%</td>
<td>2713</td>
</tr>
<tr>
<td>4. Being able to find information and services that encourage physical, emotional, mental and/or spiritual wellness</td>
<td>50%</td>
<td>2525</td>
</tr>
<tr>
<td>5. Getting services that allow the person with MS to be as independent as possible (i.e., allow someone to remain at home for as long as possible)</td>
<td>46%</td>
<td>2325</td>
</tr>
<tr>
<td>6. Being able to be part of the community where I live*</td>
<td>42%</td>
<td>2124</td>
</tr>
<tr>
<td>7. Being able to enter and exit buildings easily, both public (e.g., schools or government buildings), and private (e.g., homes or apartments)</td>
<td>36%</td>
<td>1814</td>
</tr>
<tr>
<td>8. Getting financial help</td>
<td>35%</td>
<td>1790</td>
</tr>
<tr>
<td>9. Having access to transportation that allows a person with MS to get around easily</td>
<td>28%</td>
<td>1434</td>
</tr>
<tr>
<td>10. Getting support in the workplace</td>
<td>20%</td>
<td>1015</td>
</tr>
<tr>
<td>11. Accessing education despite challenges of MS</td>
<td>11%</td>
<td>546</td>
</tr>
</tbody>
</table>

answered question 5064

skipped question 432

*These two statements refer to the Independence and empowerment QOL principle. To rank the ten QOL principles listed on the previous page, the rank for “Independence and empowerment” was calculated as the average of the two percentages.

Priorities by type of primary client

Respondents living with MS and those waiting for a diagnosis of MS have similar priorities; these are (listed in decreasing order their importance):

1. Access to medical care.
2. Being able to make decisions about treating and managing MS; and being part of the community where I live (independence, empowerment).
3. Support for family members and caregivers.
4. Being able to find information and services that encourage physical, emotional, mental and/or spiritual wellness.
5. Getting services that allow the person with MS to be as independent as possible.
The perspectives of respondents who are caregivers and those close to a person with MS (family, friends) are very similar. Their priorities (listed in decreasing order their importance) are:

1. Services that allow the person with MS to be as independent as possible.
2. Support for family members and caregivers.
3. Access to medical care.
4. Access to transportation that allows the person with MS to get around easily.
5. Ability to make decisions about treating and managing the disease.

People with MS are more likely than other categories to value being able to be part of the community where they live. Also, they are more likely than caregivers and those close to a person with MS to value the ability to make decisions about treating and managing MS and having access to medical care. Caregivers are most likely to prioritize accessibility of public buildings and getting services that allow the person with MS to be as independent as possible. Also, caregivers are more likely than respondents with MS or waiting for a diagnosis of MS to value transportation that allows a person with MS to get around easily.
**Priorities by MS Society Division:**

- There are no major differences among the top 5 priorities identified above.
- Being able to be part of the community is a bigger priority in BC than it is in Alberta, Manitoba, Ontario and Québec.
- Being able to make decisions about treating and managing MS is a bigger priority for respondents in Ontario than for those in Alberta, Manitoba, Québec and Atlantic.
- Financial support is a higher priority in Atlantic, Saskatchewan, Ontario and BC than in Alberta, Québec and Manitoba.
- Accessibility is a higher priority in Manitoba, Alberta, Saskatchewan, and Ontario than in Atlantic, BC or Québec.
- Transportation is the least of a priority in Québec.
- Being able to find information and services is a higher priority in BC, Alberta, Manitoba, Ontario and Saskatchewan than it is on Ontario and Québec.

Access to transportation that allows the person with MS to get around easily is a higher priority for respondents in urban areas than for those in rural communities.

**Priorities by use of client services:**

- Access to medical care, being able to make decisions about managing and treating the disease, support for family members are the top priorities for all users of client services.
- The higher the use of services, the more priorities the respondents have identified.
- Respondents reporting substantial use of CS are more likely to prioritize accessibility, financial supports, transportation and services that allow the person with MS to be as independent as possible.
- Respondents reporting considerable use of CS rate higher being able to be part of the community.
- Respondents reporting moderate use of CS rate higher financial support.
- Getting support in the workplace is a higher priority for those reporting no, some or moderate use of CS than for those reporting considerable or substantial use of CS.

**Priorities by gender:**

- Women (more than men) feel it is more important to: be able to make decisions about MS, access to medical care; find information and services that encourage physical, emotional, mental and/or spiritual wellness; and get support in the workplace (this may explained by the fact that more male respondents are older and more are retired or on long term disability).
- Men are more likely to place priority on services that allow the person with MS to be as independent as possible and support for family members and caregivers to be more important than women do.

**Priorities by type of MS (Relapsing-remitting vs. progressive MS):**

- Access to medical care is the first priority for both respondents with relapsing remitting MS (RRMS) and those with a form of progressive MS (primary progressive, secondary progressive or relapsing progressive).
- There are notable differences between the priorities of respondents with RRMS and of those with progressive MS.
  - RRMS priorities: (1) access to medical care, (2) ability to make decisions about treating and managing MS, (3) ability to be part of the community where I live; (4) getting
financial help and (5) getting services that allow the person with MS to be as independent as possible

- Progressive MS priorities: (1) access to medical care, (2) services that allow the person with MS to be as independent as possible, (3) being able to enter and exit buildings easily, both public and private; (4) ability to make decisions about treating and managing MS; and (5) ability to be part of the community where I live.

**Short term priorities**

Respondents were asked what is the most important thing that would help them improve their quality of life today. While this question is not directly related to QOL priorities, it is an indicator of respondents’ short term priorities. Financial support is the second strongest theme of the qualitative data (after finding a cure), followed by information and support.

Specifically the short term priorities themes are:

1. **Financial support:**
   - To cover for cost of care, retirement, and home renovations. Government support for disability pensions, and to help with the cost of medication. Lower cost of treatments and medications. Need to influence policy and legislation dealing with disability, cost and coverage of drugs.  
     
     *My life would be VASTLY improved if I were allowed to work in Canada as a person with a disability. I can work full time. My employer knows I live in poverty and am on welfare, they are waiting until I quit, get sicker or die. I cannot afford to move.*
2. **Information / education:**
   - About the disease, treatments, supports and services available, diet, lifestyle, and research progress. For the person with MS, families, doctors, governments.

3. **Support for the person with MS:**
   - More services, support in the workplace, general awareness, access to caregivers and support for caregivers. Special assistance and equipment support. Help to cope with the disease: education, support, exercise, emotional support, “help me help myself”.

4. **Community access:**
   - Increased accessibility, reduce isolation, home adaptations.

5. **Health care:**
   - Access to health care, to medications, improved quality of care.
     
     Care is not sufficient to help those afflicted, cure will not come soon enough for my loved ones
     
     Lack of care and services with our ageing population and more heavily stressed medical system

6. **CCSVI (130 comments out of 2658):**
   - Advocate, test, research and treatment of CCSVI, acknowledge the vascular connection, allow patients to choose therapy
     
     Genuine support and transparency relating to CCSVI testing, treatment and studies. Putting the interest of MS patients as priority instead of focusing on being a professional fundraising organization that is controlled by MS Neurologists who have personal self-serving reasons to roadblock and discredit proper CCSVI research.

     Your mission is to find a cure for MS, then listen to the all the information from the actual people who have MS and have been helped by the angioplasty procedure and the vascular surgeons. Allow the CCSVI procedure like 90 other countries in the world Angioplasty is not a new procedure

     Availability of CCVSII!!! Why would a person with vein blockages be helped but I cannot be. Is it because of my MS or “research” or drug companies or perhaps because I have MS I am somehow not a person
**What do people affected by MS believe is the best investment of MS Society resources?**

Respondents were asked to imagine they donate $100 to MS Society and were asked to tell how they would spend the money between two categories

1) Research related to preventing MS, stopping MS, restoring damage in MS, or living well with MS, and
2) Programs and Services & Governmental Relations: e.g., Recreational, social and wellness programs, Financial assistance, Information, supportive counseling, Support and self-help groups, Education, Governmental relations and social action, Individual advocacy

52% of respondents (n=4333 respondents who answered this question) would allocate more than half of the amount to research, 35% would allocate it equally between the two categories and 13% would allocate more than half of the amount to programs, services and government relations.

Overall, respondents would allocate on average **$60 to research** and **$40 to programs, services and government relations** (normal distribution of values, no difference between mean and median).

There are a number of differences between various categories of respondents:

- **Category of primary clients**
  - Respondents close to a person with MS are more likely to favor balanced spending than respondents with MS
  - Caregivers are more likely to allocate more to services than respondents with MS

- **Regional / MSSOC division**
  - Québec would allocate most to research (62% over $51)
  - BC would allocate least to research (44% over $51)
  - About 38% of respondents in most provinces favor equal spending, with Québec the least (25%) and Saskatchewan the most (42%)
• **By use of MS Society client services (CS)**
  - The lower the level of use of CS, the higher the percentage of respondents who would allocate more than $51 to research. The higher the use of client services, the higher the percentage of respondents who would invest more in services. Respondents reporting substantial use of CS are more likely than the other categories to invest in services or to favor equal spending between research and services.

  **Investment in research vs. services, programs and government relations by use of MSSOC client services**

  ![Bar chart showing investment patterns by level of CS use](chart.png)

  - Volunteers for the MSSOC in a non-fundraising capacity (n=287 respondents) (boards, committees, others) would invest on average $52 in research and $48 to services. They are more likely to invest equally in research and programs (42%) or in services (22%).

  **How MSSOC volunteers in a non-fundraising capacity would spend $100 for research and services**

  ![Bar chart showing how volunteers would spend $100](chart2.png)
Respondents from urban areas are more likely to invest in services than those in rural areas.
Women are more likely to favor a balanced spending than men, while men are more likely to invest more in research.
Respondents with RRMS are more likely to invest in research than those with progressive MS.

These findings are supported by qualitative data. When asked what would help improve their quality of life today, the majority of respondents spoke about the need to find a cure, to repair the damage of the disease and reverse its effects, as well as treatment of MS and symptom management. Respondents speak about the need to accelerate research, find new treatments (with an emphasis on oral treatments), about alternative treatments, preventing of MS, discovering new drugs for symptom management, reversing the damage done by MS and eliminating symptoms, and discovering effective treatments for progressive MS.

Finding a treatment or a cure, so I could move and dance as before.
FINDING A WAY TO REPAIR MYELIN.
More emphasis put on treating and alleviating the symptoms of people like me who are long past the relapsing-remitting phase of MS. The MS population, like the rest of society, is aging and there are more of us. People with progressive MS would be less of a burden on the health care system if there was better recognition and management of their problems.
Finding an effective med that that lessened symptoms such as fatigue rather than compounding them
Finding a cure for MS. I have my husband and daughter who are stricken with this disease. It would help with the mental strain of the unknown. The research is not coming fast enough, of finding a cure.
Having an oral medication with no or only one or two minor side effects
Effective treatment for progressive form of MS
The big question - WHY, what caused it. All the unknown's. We don't know what lies ahead for our son. The medication he is on is expensive and worrisome. MS is for the most part an unknown disease and knowing where to start looking for information to understand it when the Dr. tells you your son has MS is hard. We just all need to work toward finding a cure!

Moreover, when asked what worries them most about having MS in their life, one of the central themes in the qualitative data is the fact that there is currently no cure for MS. Respondents’ note they fear a cure will not be found soon enough. They speak about their hopelessness and fear of death either for themselves or their loved one with MS. Respondents with progressive MS are more concerned with the lack of treatment options than other categories of respondents.

Praying that a cure comes soon before his MS gets worse
That it will never get better
That once you pass the relapsing/remitting stage there is not much out there for the primary or secondary progressive stages
That we will lose the person to MS before a cure is found.
4.2. What are the current QOL needs, barriers and gaps experienced by Canadians?

Respondents were asked what worries them most about having MS in their life as an indicator of their MS-related long term priorities. Respondents worry most about:

a) The impact of the disease on their family
b) The future (unpredictability, uncertainty and unknown of the disease)
c) Increased levels of disability (loss of mobility and vision)
d) Overall quality of life of the person with MS
e) Loss of independence

Responses are consistent among geography, category of primary clients, use of client services, and genders.

Respondents also worry about the progression of the disease, managing MS symptoms, finances, caregiving and the fact that there is no cure for the disease. Other worries include inheriting or passing the disease to their children; access to and the quality of health care. Long term care, social isolation, workplace issues, lack of support and understanding, aging with MS and CCSVI are other worries mentioned.

Respondents’ type of MS impacts their perspective. Respondents with relapsing-remitting MS (RRMS) worry more about their future, MS symptoms, and progression of the disease. Respondents with progressive forms of MS worry more about disability, long-term care, caregiving and loss of independence.

Below are details about the above-mentioned qualitative themes:

a) The impact of MS on the entire family

Being a burden to one’s family is a major worry for all respondents living with the disease. Many speak about the loss of quality of life for the entire family as a result of MS. Not being able to financially care for one’s family, to support and care for their wellbeing is a concern for many. Respondents speak about the fear of losing a parent or a child who has MS. Elderly parents of a child with MS worry about what will happen to their kids after they pass away. Parents with MS speak about the fear of not being there for their children, not being able to care for and raise their children because of their MS. Respondents fear about the impact of MS on relationships and marriage. Some fear that their spouse will leave them because of their MS. Others fear they will not be able to find someone to be in a relationship with because of their MS.

That MS will take my mother away from me (change who she has been my whole life as an upbeat and happy person). She has had MS her whole life and recently the anxiety caused from MS has really taken a toll on her and her day to day life. I worry that I will lose her and that eventually I too will be in her shoes.

My mother has MS and it is hard seeing her struggle. [...] I have two younger sisters and I cannot imagine let alone even think about our family without my mom. She is such an amazingly strong willed person and without her we would truly be lost. My worry is that no one will ever care to help her try and fix what she has and the damage already done. It’s become a way of life having to push my mom in a wheel chair or set up her scooter. I don’t
even remember her able to walk anymore and it hurts so badly inside. We used to do a lot as a family.

That I will not be able to parent my young children in the way I want to and that I will not be able to fully focus on my career. I didn’t want to be a burden but I also need help from those in my life

Not being able to bring up my children the way they deserve. Not being around for them

It wrecked my marriage

That my spouse (husband) will leave me, because of my MS getting worse of me, no longer being able to take care of myself and my MS gets worse?

I worry about finding someone who is willing and able to adjust to a life with an unpredictable disease

b) The future

Respondents are worried about the unpredictability and uncertainty of the disease. Many worry every time there is “a tingle in their feet” or another symptom that they do not know if it is related to MS or not. Respondents speak about the fear of future disease progression, increased levels of disability, not being able to care for themselves and eventually having to move into long term care facility.

Respondents are worried by the unknown of the disease; what the future will bring “what will happen to me” “how my health will be”. For some the disease is rather new and they do not know what to expect and what accommodations they might need in the future. They worry about having a family and how the disease will impact their ability to support their family, and how the disease will impact their spouse, children, parents and other family members. They are concerned about keeping their job and their future job prospects. They worry about their overall health and quality of life, including the damages that MS and MS drugs may have had on their body. Some speak about the fact that the fear that their current lifestyle choices might impact their future progression of the disease, in particular a busy or stressful life. Respondents note they feel helpless when faced with this unpredictable disease. The constant worry about the future adds significant amount of stress on all affected by MS.

Not always knowing when something might happen, whether it be a relapse or just a bad day.

What’s going to happen to me

What shape will I be in next time I wake up

I am mostly worried about my future. Overall right now I can still lead a healthy life. I am active, I travel, I work full-time. So what worries me most is the progression of my disease and slowly, over time, not being able to do the things I want to do like work full-time, and travel, and maybe have a family and being paralyzed and the impact of all this on my loved ones.

Will we be able to stay in our home? How much additional help will we need? How much more can I do?

Worry about the future when I will not be here for her [my daughter with MS]. So far she copes quite well but what may be ahead is a worry.

Its beyond my control
c) Disability
The prospect of increased disability is also a major worry for respondents. Respondents worry about losing their mobility, ending up “in a wheelchair”. They worry they will become paralysed or severely handicapped, will eventually be bed ridden and become “a vegetable”. Respondents are worried that they will lose their vision and about the cognitive impact of the disease. They worry they will not be able to speak or hear. A couple notes that they worry they will not be able to end their own lives when the disease has rendered them severely disabled.

d) Quality of life
Decreased quality of life for the person with MS and for the entire family is another worry for survey respondents. They worry they will no longer be able to enjoy life to the fullest, reach their potential, do the things they want to / used to do / enjoy doing such as: travelling, caring for grandchildren, exercising, working, etc.

I used to line-dance 4 or 5 times a week, garden, take long walks and drive. But the only thing I can do is garden but that is getting even harder.

The sadness of watching someone’s quality of life disintegrate slowly over such a long period of time

Not being able to do the things that I usually take for granted every day.

Losing myself

e) Loss of independence
Respondents speak about the fear of loss of independence, having to depend on others, not being able to care for themselves in particular for personal hygiene.

That I will not be able to take care of myself, lose my independence and become a burden on my family and friends

f) Disease progression
Respondents worry about the progression of the disease and the fast decline in their abilities, such as loss of bodily functions, depression, and cognition.

They worry about loss of dignity

Getting worse with no treatment options

g) Respondents worry about dealing with MS symptoms and side effects of disease treatments
Symptoms most frequently mentioned are chronic pain, fatigue, depression, cognition, bladder and bowel, and sleep problems. Respondents are afraid of falling because of their MS symptoms. They are concerned about the daily injections and their side effects, and about the side effects of the treatments.

Watching my mom suffer with pain, fatigue, decreased confidence and decreased quality of life. It makes me sad and worries be about her happiness and comfort.

That the chronic pain in my feet will never stop!
h) The financial impact of the disease
Loss of work and income, poverty, ability to provide for one’s family, and ability to provide for oneself to save money for retirement are frequent concerns for respondents. Family members fear about the financial implications should they no longer be able to provide care for the person with MS – either their child or an elderly parent. Many speak about the financial burden of the disease on the person with MS and on their family: the cost high cost of the disease, from cost of treatments and medications, loss of income, home adaptations, symptom management, etc.

Never living above poverty level

We struggle all the time and the drug costs just about kill us

Poverty. I’m unable to bring in $. My partner and caregiver has to stay home to take care of me and cannot earn $.

Unable to get or hold a job so I am unable to contribute to our house causing my husband to be solely responsible for our income plus looking after me and everything else......so sad!!!

i) Caregiving impact and support
People with MS indicate they worry about the health of their caregiver. Caregivers worry about their own health and the ability to be there for the person with MS. They speak about the impact of caregiving: stress, risk of injury, emotional, and financial. They worry that the disease progression will make it more difficult for them to care for the person with MS. The prospect of placing the person with MS in long term care is a concern for both the person with MS and their caregivers.

What if something happens to my wife who is my caregiver?

The long term debilitating effects of the disease and the impact they have on the quality of life of the person with MS and their caregiver(s).

I’m the caregiver for my mom. If something happens to me????

The daily ups and downs of being an MS caregiver

I worry about my dad burning out or getting injured assisting my mom (with MS)

The ability to provide care if primary caregiver can no longer provide support. The wellbeing of the primary caregiver and ensuring that their needs are being met and that caregiving does not become all-consuming or too much to handle.

That my daughter (who has MS) will be able to take care of herself & will have a decent life after I have passed away

Only a small number of respondents note CCSVI (about 20 respondents to this question) as one of their worries. They talk about the lack of recognition of CCSVI as a valid treatment for MS, access to CCSVI procedure in Canada, impact of CCSVI procedure, and the MS Society blocking access to CCSVI procedure.

Having my wife stuck with the label of MS when she is suffering from CCSVI and not being able to have tests done regarding CCSVI.
Not being able to work and provide for my family; my wife is under a lot of financial stress. CCSVI treatment was done on me last year, worked amazing for 9 months; we need stents that are safe, and we need this available in Canada NOW. The discrimination and politics over this issue is sinful

That my WIFE WHO HAS MS IS REFUSED ANGIOPLASTY FOR CCSVI IN CANADA: by the MSSC, the neurologists, the governments of all stripes, all getting only input and, in some cases, money from the pharmaceuticals [...]

Living with MS is not an easy task. I fear that there will become a point where I become obsolete. Unable to do small tasks that make me who I am. I had 10 awful years with very little quality of life. I had CCSVI in Sept 2010 and my life changed sososo much. CCSVI saved my life. I have quality and smile everyday. I do have fears of the future if it is anything like the past

What are the most urgent met and unmet needs of Canadian affected by MS?

Respondents were asked to select the three most important factors that help improve the quality of life of people affected by multiple sclerosis. Listed in decreasing order of their importance, the 5064 respondents prioritize the QOL factors as follows:

<table>
<thead>
<tr>
<th>QOL priorities</th>
<th>% of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Medical care</td>
<td>68%</td>
</tr>
<tr>
<td>2 Support for family members</td>
<td>54%</td>
</tr>
<tr>
<td>3 Health promotion and disease prevention</td>
<td>50%</td>
</tr>
<tr>
<td>4 Independence and empowerment*</td>
<td>49%</td>
</tr>
<tr>
<td>5 Continuing (long-term or social) care</td>
<td>46%</td>
</tr>
<tr>
<td>6 Housing and accessibility of buildings in the community</td>
<td>36%</td>
</tr>
<tr>
<td>7 Disability benefits and cash assistance</td>
<td>35%</td>
</tr>
<tr>
<td>8 Transportation</td>
<td>28%</td>
</tr>
<tr>
<td>9 Employment and volunteer activities</td>
<td>20%</td>
</tr>
<tr>
<td>10 Education</td>
<td>11%</td>
</tr>
</tbody>
</table>

The QOL principles are discussed below in the order of their priority identified by survey respondents (where 1 is the most important and 10 is the least important). Within each principle there is discussion of the respondents’ met an unmet needs.

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Independence and empowerment is defined as: people with MS are empowered as full participants in their communities and in decision making about the management and treatment of the disease. To rank of Independence and empowerment was calculated as the average of the percentages to two statements: (1) Being able to make decisions about treating and managing MS and (2) Being able to be part of the community where I live.
1. Medical care

- 68% of respondents identified access to medical care as a quality of life priority

- Respondents with MS and those awaiting a diagnosis were asked which professionals they have seen for their MS or probable MS in the past year
  - 87% (2864) of respondents saw a neurologist
    - 73% of those waiting for a diagnosis have seen a neurologist
    - Highest percentage in Québec (95%) and Manitoba (92%); lowest percentage in Saskatchewan (75%)
  - 76% (2492) of respondents saw a family doctor
    - 88% of those waiting for a diagnosis have seen a family doctor
    - 84% of respondents in rural areas have seen a family doctor
    - Lowest percentage in Québec (60%)
  - Between 20-30% of respondents saw each of the following professionals: massage therapist or chiropractor; nurse; physiotherapist; occupational therapist, ophthalmologist or optician.
    - Nurse: more likely in Alberta, Atlantic of BC than in other provinces
    - Occupational therapist: highest percentage in Manitoba (34%)
    - Massage therapist or chiropractor: highest in Saskatchewan (37%) and Alberta (36%) and Manitoba; lowest in Atlantic (19%); higher for women (38%)
    - Ophthalmologist or optician: higher for women (24%) and progressive MS (23%) (compared to 8% RRMS) and respondents from BC
    - Urologist: 8.5% RRMS vs. 23% progressive MS
  - Vascular surgeon:
    - Highest number of people from Ontario (51), lowest from Québec (6)
    - 67 respondents reporting considerable use of CS have seen a vascular surgeon, compared to 15 of respondents reporting substantial use of CS

- Respondents reporting substantial use of CS are significantly more likely to have seen a physiotherapist or an occupational therapist. Respondents reporting substantial or considerable use of CS are more likely to have seen a financial planner, a fitness professional than other categories of respondents. The lower the use of CS, the less likely the respondent sought help from the various professionals listed.
- Respondents in rural communities are more likely to have seen their family doctor or a radiologist in the past year, whereas respondents from urban communities are more likely to have seen a psychiatrist, psychologist or therapist in the last year.

Other professionals seen by respondents include other specialists, alternative therapists, osteopaths. Eight (8) respondents indicated they saw specialists related to CCSVI other than vascular surgeons.

- 78% (3190) of respondents\(^5\) indicate they received the support they needed from their health care professional(s) when they first learned that they had MS.

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\(^5\) Percentages represent the sum of the “all the time” and “most of the time” answers categories. The questions were answered by respondents with MS or awaiting a diagnosis of MS.
73% (1990) of respondents with MS indicate they have access to disease modifying treatments, medicine to manage symptoms and rehabilitation services approved in Canada.
- Higher percentage in Atlantic (83%) and Ontario (81%)
- Lowest percentage for respondents reporting substantial use of CS (64%)
- Higher percentage for RRMS (82%) vs. progressive MS (59%)
- Lower percent of men (65%) vs. women (75%)
- Men diagnosed with primary or secondary progressive MS who are either on long term disability or retired are more likely to report that they do not have access to disease modifying therapies. This group tends to report a fair or poor quality of life, to use mobility aids, to live at home by themselves or with young kids. They are more likely to receive care from a paid or unpaid caregiver and to need more care than they currently receive.

69% (2159) of all respondents with MS feel that their healthcare team cares about their well-being, and does not just focus on treating the disease.
- Lowest percentage in Manitoba (54%), highest percentage in Québec (79%)

63% (3158) of respondents with MS indicate they were referred to the MS Society at the time of diagnosis.
- Those who report they were referred to the MS Society are significantly more likely to be diagnosed with relapsing remitting MS, to use the MS Clinics as a main source of information and to be a member of the MS Society.

61% (1857) of respondents with MS indicate their family doctor is knowledgeable about MS all the time or most of the time.
- Highest percentage in Atlantic (69%)

2. Support for Family Members

- 54% of respondents identified support for family members as a quality of life priority

45%6 (370) of respondents indicate they can find the support they need as a caregiver or family member.
- Less likely to be true for caregivers (28%) than respondents close to the person with MS (49%)

42% (326) of respondents to whom this question applies feel that they have someone to talk to when they feel tired or when negative feelings arise.
- Significantly lower for caregivers (23%) compared to respondents close to a person with MS (46%)
- Significantly lower in Québec (32%)
- Significantly lower for respondents reporting substantial use of CS (27%) followed by considerable use of CS (37%)
- Lower for men than for women

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6 Percentages represent the sum of the “all the time” and “most of the time” answers categories. The questions were answered by caregivers and family members/ close to a person with MS.
• 26% (287) respondents indicate their children (under the age of 18) have caregiving responsibilities
  - Significantly higher for respondents reporting considerable and moderate use of CS
  - Significantly higher for respondents with progressive MS (32%)

• 23% (87) of respondents to whom this question applies have access to respite services that allow them to take breaks from caregiving (Does not apply to 64% (1087) of respondents)

• 21% (111) of respondents indicate that, as a caregiver, they have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving all the time or most of the time. (Does not apply to 53% (1090) of respondents)
  - Significantly lower for caregivers (14%)

How often have the following statements been true for you?

<table>
<thead>
<tr>
<th>Statement</th>
<th>All the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can find the support I need as a caregiver or family member. (n=818)</td>
<td>12%</td>
<td>43%</td>
<td>31%</td>
<td>14%</td>
</tr>
<tr>
<td>I have access to respite services that allow me to take breaks from caregiving. (n=386)</td>
<td>10%</td>
<td>46%</td>
<td>32%</td>
<td>13%</td>
</tr>
<tr>
<td>As a caregiver, I have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving. (n=516)</td>
<td>7%</td>
<td>45%</td>
<td>33%</td>
<td>14%</td>
</tr>
<tr>
<td>I feel that I have someone to talk to when I am feeling tired or when negative feelings arise. (n=779)</td>
<td>24%</td>
<td>23%</td>
<td>24%</td>
<td>30%</td>
</tr>
<tr>
<td>My boss gives me time off, as needed, so I can care for the person with MS in my life. (n=367)</td>
<td>18%</td>
<td>28%</td>
<td>18%</td>
<td>36%</td>
</tr>
</tbody>
</table>

• Which of the following professionals have you seen for support in your role as caregiver to someone with MS in the past? (answered by caregivers and people close to a person with MS, n=1063)
  - Does not apply to 49% of all respondents, the majority of which are close to a person with MS
  - More caregivers have seen the following professionals for support in their role as caregiver (when compared to close to a person with MS). Specifically, caregivers are more likely to be seen by a family doctor (51%); a massage therapist or chiropractor (24%); a nurse (14%); an occupational therapist (12%) or a social worker (12%)
  - The higher the use of CS, the higher the percent of respondents who have seen any of the categories of professionals listed. Of the respondents reporting substantial use of
CS, 62.5% have seen a family doctor; 32.5% have seen a massage therapist or chiropractor; and 20% have seen a nurse.

- No differences between urban and rural communities.

3. Health Promotion and Disease Prevention

- 50% of respondents identified health promotion and disease prevention as a QOL priority.

- 80%\(^7\) (2159) of respondents indicate their health care provider(s) offers them routine medical care, like flu shots, pap smears, or other tests that are not related to MS:
  - Significantly lower in Québec (64%), and significantly higher in Ontario (89%) and Alberta (86%)
  - Significantly higher for women and respondents with RRMS

- 69% (3185) of respondents have access to information and advice about exercise, nutrition, and ways to manage stress.

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\(^7\) Percentages represent the sum of the “all the time” and “most of the time” answer categories to which the question applies.
4. Independence and empowerment:

- 49% of respondents identified independence and empowerment as a QOL priority
- 88% (2650) of respondents **help to decide on medical treatments or other aspects of living with MS that affect their life**
  - Significantly lower in Saskatchewan (81%)
- 79% (3769) have access to **information and advice about MS**
  - Significantly higher for respondents with RRMS;
    - true “all the time” for 45% of RRMS vs. 29% of progressive MS
- 70% (1996) of respondents have **access to treatments, programs and services whether they can pay for them or not**
  - Significantly higher in Québec (815) and Alberta (77%)
  - Lowest percentage for substantial use of CS (58%)
  - Significantly lower for respondents with progressive MS (61%) vs. RRMS (77%)
- 67% (3007) of respondents are able to **be part of community life as much as they want**
  - Significantly higher for respondents close to a person with MS (79%) followed by the person with MS (66%)
  - Significantly higher for respondents reporting low or no use of CS (71-73%)
  - Significantly lower in Ontario (43%)
- 62% (1093) of all respondents **have access to equipment and technology that they can afford and that helps them maintain their independence** (such as mobility aids and changes to the car or home)
  - Significantly higher in Alberta and Québec (68%)
  - Significantly lower for respondents reporting substantial (53%) and moderate (51%) use of CS
  - No major difference between RRMS and progressive MS

5. Continuing (Long-Term or Social) Care

- 46% of respondents identified continuing (long-term or social) care as a quality of life priority
- 0.6% (20) **live in a long term facility** and 0.8% (26) **live in supportive housing that provides some health care as well as services**. The number of responses is very low which may indicate that the survey has not reached this particular population
  - The majority of those living in long term care or supportive housing are in urban areas; only 1 respondent lives in a rural area in supportive housing.
  - Higher in Ontario and BC
  - Higher for respondents reporting moderate and considerable use of CS
- 83% (2031) of respondents **feel that they have the support they need to stay in their home as long as possible**
  - No difference between respondents from urban and rural communities
56% (345) of respondents indicate the **people who are paid to care for them are knowledgeable about MS** (Does not apply to 80% (2555) of respondents)
- Significantly lower in Saskatchewan (29%) and higher in Québec (68%)
- Significantly higher for respondents reporting considerable, moderate or some use of CS compared to substantial use of client services
- Significantly higher for respondents with RRMS (67%) vs. progressive MS (46%)

34% (59) of respondents to whom the question applies agree that other **people their age live in the same long-term care facility where they live.** (Does not apply to 94% (3192) of respondents with MS)

30% (84) of respondents indicate their **long-term care facility provides activities and supports that engage and interest them** (Does not apply to 91% (2872) of respondents)
- Significantly lower for respondents reporting substantial use of CS (14%)
- Significantly lower in rural areas (11%)

22% (715) of all respondents with MS and those awaiting a diagnosis **receive care at home from an unpaid or paid caregiver**
- Significantly higher in BC (27%)
- Significantly higher for those reporting substantial use of CS (50%) followed by those reporting considerable use of client services (25%)
- No difference rural vs. urban

Of those who answered they receive care at home or are in supporting housing or long term care 79% (599) **receive enough care to meet their needs** while 21% (164) need more care than they currently receive

Of those who said they do not receive care from a paid or unpaid caregiver, 90% (2230) said they **do not need care** while 10% (237) said they **do need this kind of care**
- Respondents reporting substantial use of CS (18%) more likely to need this kind of care.

6. Housing and Accessibility of Buildings in the Community

36% of respondents identified housing and accessibility of buildings in the community as a quality of life priority

75% (2975) of respondents indicate **community buildings such as government offices, hospitals, clinics, and schools (at all levels) are accessible**
- Significantly less likely to be true for respondents reporting substantial use of client services, and for respondents with relapsing remitting MS (83%) vs. progressive MS.

62% (897) of respondents to whom this question applies indicate their **home has been adapted to make it easier to live with MS.** (Does not apply to 55% (1749) of respondents)
- Significantly higher for respondents reporting substantial use of client services and considerable use of client services
- Significantly higher for respondents with progressive MS (69%) vs. RRMS
7. Disability Benefits and Cash Assistance

- 35% of respondents identified disability benefits and cash assistance as a quality of life priority.

- More respondents with progressive forms of MS are on long-term disability or are retired when compared with respondents with other forms of MS. Respondents with MS who receive long term disability or short term disability are more likely to be aged 44 to 64 years old therefore still in their prime working years.

- 51% (889) of respondents to whom it applies indicate their disability benefits (public or private) allow them to maintain a standard of living that is good enough. (Does not apply to 45% (1425) of respondents)
  - Significantly higher for respondents in Alberta (60%) and Québec (58%)
  - Significantly lower for respondents reporting moderate use of CS (43%) and substantial use of CS (35%)

- 42% (1085) of respondents to whom it applies indicate they find it difficult to get financial assistance for MS related issues all the time or most of the time. (Does not apply to 47% (2303) of respondents)
  - Significantly higher for respondents close to the person with MS (50%)
  - Higher for respondents in BC (45%), Manitoba (48% and Ontario (43%) than for respondents in Atlantic (32%)
  - Significantly higher for respondents reporting moderate use of CS (49%) than all other categories of use of CS

- 30% (982) of respondents with MS relied on financial help outside of their own personal resources to help with issues linked to MS in the past year. They relied on family members, provincial financial support for programs and services, insurance and employment benefits and Federal income support. Over fifty respondents reference they relied on MSSOC for financial support.
  - Significantly higher for respondents with MS (30%) than those waiting for a diagnosis (18%)
  - Significantly more respondents reporting substantial use of CS (65%) have relied on financial help outside their own personal resources, when compared to all other categories
  - More respondents with progressive MS have used federal income supports

8. Transportation

- 28% of respondents identified transportation as a quality of life priority.

- 60% (626) of respondents to whom the statement applies indicate transportation services where they live allow them to travel around, as they need to (67% (2126) of respondents answered “Does not apply to me”)
  - Higher for respondents from Québec (70%)
  - Significantly lower for respondents in rural areas (29%)
  - No difference by gender or type of MS
• 27% (175) of respondents to whom this statement applies indicate their car has changes made to it so they can still drive it. (It does not apply to 80% (2556) of respondents with MS)
  – Significantly higher for respondents in Québec (40%) than all other provinces except Alberta.
  – Significantly higher for men (34%) than women

9. Employment and Volunteer Activities

• 20% of respondents identified employment and volunteer activities as a quality of life priority

• 55% (946) of respondents to whom the statement applies are retired from work but they feel fulfilled by volunteer work, hobbies or domestic life (does not apply to 65% (3151) of respondents)
  – Respondents from Québec are significantly more likely to agree with the statement all or most of the time (64%)
  – Respondents reporting considerable and no use of CS are more likely to agree with the statement than respondents reporting substantial or moderate use of CS.

• 54% (482) of respondents with MS to whom the statement applies indicate their workplace makes changes so that they can still work despite MS (Does not apply to 72% (2261) of respondents)

• 42% (154) of caregivers and close to a person with MS to whom this statement applies indicate their boss gives them time off, as needed, so they can care for the person with MS in their life (Does not apply to 66% (723) of respondents)

10. Education

• 11% of respondents identified education as a quality of life priority

• 53% (73) of respondents with MS to whom the statement applies indicate their school accommodates their MS so they can continue with their education (Does not apply to 96% (3027) of respondents)
What barriers to meeting QOL needs are currently experienced by Canadians affected by MS?

Respondents were asked what was the most important MS-related problem or concern that they needed help with in the last year. This question was used as an identifier of the respondents’ short-term needs. The themes in the qualitative data are:

1. **Symptom management:** Respondents needed help with MS symptom-related issues: dealing with fatigue and loss of energy, chronic pain and trigeminal nerve pain; depression, moods and loss of temper; loss of vision or vision problems, dealing with heat, loss of cognitive function and adjusting to cognitive loss; problems with balance; bladder and bowel problems such as incontinence. Dealing with tingling, spasms, seizures, numbness, vertigo, hearing loss, speech loss. Dealing with relapses.

2. **Financial support:** Respondents had challenges paying for medication, services, equipment, treatments, transportation. They had challenges navigating the system to get financial support: how to get medication covered; applying for disability pension or Trillium funding in Ontario; filling out forms; support with disability tax and insurance.

3. **Managing MS in general and making decisions related to MS:** Respondents needed help to choose a treatment, to deal with the side effects of the treatments (injections are frequently mentioned), with changes in medications and therapies. They speak about issues related to pregnancy and MS, breastfeeding and MS. Many speak about the need to deal with the effects of an MS-related fall.

4. **Medical care.** Respondents report challenges related to accessing medical care: finding a new family doctor or neurologist, access to a neurologist, getting timely referrals to a specialist, getting a second medical opinion, getting access to medical tests such as MRI. Some reference the lack of medical care as they were being diagnosed with MS. Access to treatments and medications (medications not on formulary) are other concerns. Respondents comment on the poor quality of care: neurologists do not take sufficient time to give advice, short meetings, lack of knowledge of MS among health care professionals, poor medical support (in particular for progressive MS for which there are no treatments), failing to help them to understand if certain symptoms are MS or not. They report challenges accessing rehabilitation services, physiotherapy, and exercise classes.

5. **Special assistance**
   - **Personal care – services:** help needed to dress, shower, write, pick up things, get in out of bed, transfer in and out the wheelchair, personal care and grooming
   - **House care – services:** Help needed for home cleaning, yard work, everyday chores, cooking, laundry, grocery shopping, etc.
   - A more prevalent issue for respondents with progressive MS than for those with RRMS

Other themes present in the qualitative data include: information, transportation, work and employment support, equipment, emotional support, and accessibility, caregiving, CCSVI and community access. Those with progressive MS put more emphasis on transportation, equipment and accessibility which is consistent with quantitative findings.
When asked what supports they tried for the concern or problem identified and how helpful they were, a large percentage of the respondents indicate they did not use these supports:

<table>
<thead>
<tr>
<th>Multiple choice question</th>
<th>Did not try this support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-term care facility</td>
<td>95%</td>
</tr>
<tr>
<td>Respite care or short-term care (temporary help)</td>
<td>93%</td>
</tr>
<tr>
<td>Paid caregiver</td>
<td>88%</td>
</tr>
<tr>
<td>Religious or spiritual groups that provide support, such as a church, temple or meditation group.</td>
<td>82%</td>
</tr>
<tr>
<td>Accessible transportation</td>
<td>78%</td>
</tr>
<tr>
<td>Support at work or support to find work</td>
<td>78%</td>
</tr>
<tr>
<td>Programs and services in my area run by charities or agencies other than the MS Society</td>
<td>76%</td>
</tr>
<tr>
<td>Self-help, support groups, or online groups that offer support</td>
<td>71%</td>
</tr>
<tr>
<td>Government programs such as subsidies, financial assistance or training programs</td>
<td>67%</td>
</tr>
<tr>
<td>Mobility aids</td>
<td>66%</td>
</tr>
<tr>
<td>Unpaid caregiver (close friend or family that sometimes or always provides care to a person with MS)</td>
<td>63%</td>
</tr>
<tr>
<td>MS Society of Canada staff and volunteers</td>
<td>63%</td>
</tr>
<tr>
<td>Personal financial resources</td>
<td>54%</td>
</tr>
<tr>
<td>MS Society of Canada online or print resources</td>
<td>47%</td>
</tr>
<tr>
<td>MS clinics</td>
<td>47%</td>
</tr>
<tr>
<td>Health care professionals outside of MS clinics</td>
<td>37%</td>
</tr>
<tr>
<td>Personal networks (friends and family who provide help)</td>
<td>32%</td>
</tr>
</tbody>
</table>

For those who indicated they used these supports, most helpful were:

- **Unpaid caregiver** (59%, 872)
  - Higher for respondents close to a person with MS than for respondents with MS; significantly higher for respondents in rural areas (67%) and Québec (70%)

- **Mobility aids** (50%, 652)
  - Significantly higher for respondents in urban areas (52%)

- **Personal networks** (48%, 1341)
  - Higher in Québec (58%) than in most other provinces

- **MS Clinics** (42%, 896)
  - Significantly higher in Québec (58%) followed by Atlantic (49%) provinces

- **Accessible transportation** (41%, 362)
  - Significantly higher in Québec (60%) than most other provinces

- **Paid caregivers** (40%, 196)

Religious or spiritual groups that provide support are more significantly more helpful to women (41%) than to men.

Other sources of support mentioned by respondents in all categories are pharmaceutical companies or programs offered by pharmaceutical companies.

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8 Percentages represent the answer option “tried, very helpful” for those who indicate they tried the support.
Overall Québec respondents rate higher than the other provinces in terms of very helpful supports.

Least helpful supports⁹ identified by respondents are government programs (47%, 642) (except for Québec 29%).

Other programs that over one third found did not find helpful include support at work or to find work; respite care or short term care; long term facilities; and programs in the area run by other charities other than MSSOC.

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⁹“Tried, not at all helpful”
More respondents with RRMS than with progressive MS find the services and supports of the MS Society useful.

When asked about the particular barriers that prevented them from solving the concern or problem identified, here are the most frequent barriers reported by respondents:

- **24.5% (1027)** had **problems coping with MS in my life** (such as denial, caregiving stress, or not being able to ask for help that I need)
  - Lowest for respondents close to a person with MS (20%) and respondents reporting moderate use of CS (37%)

- **24% (996)** had a **lack of money for needed supports or services**
  - Highest for respondents reporting substantial use of CS (49%) and caregivers (34%) and those with progressive MS (29%)
  - Lower in Québec (15%)

- **23% (948)** say **there were no barriers**
  - Higher in Québec (33%) and for respondents with RRMS (27%)

- **19% (795)** did not **know where to go for help** (information)

- **16% (680)** indicate **a support or service needed was not available at the time**
  - Highest for respondents waiting for a diagnosis (26%), caregivers (27%), respondents with progressive MS (19%) and those reporting substantial use of CS (25%)

- **16% (677)** indicate **their MS symptoms got in the way**
  - Higher for respondents reporting substantial use of CS (28%), moderate use of CS (25%) and progressive MS (24%)
In general there are no other major differences between genders, provinces / MSSOC divisions, type of community (urban vs. rural), other than the differences highlighted above.

Respondents with progressive MS are more likely to report that a support or service was not available at the time or in their community, a lack of money, problems with accessing Internet or technology, MS symptoms getting in the way and problems moving around. RRMS respondents are more likely to report lack of support at work, or to say there were no barriers.
What sources of information do Canadians affected by MS find effective?

The top three sources of information about MS identified by survey respondents are:

- **Health care professionals (61%, 3324)**
  - Highest for respondents waiting for a diagnosis (73%), in Québec (72%), RRMS (72%)

- **The MS Society of Canada (45%, 2476)**
  - Highest for caregivers, respondents with RRMS
  - Men are more likely to get information from MSSOC staff and volunteers and women more likely to get info from MSSOC online and print resources;
  - Respondents reporting substantial and considerable use of CS are more likely to get their information from MSSOC staff and volunteers, whereas respondents reporting some use of CS are most likely to report they get their information from MSSOC online or print resources.

- **MS Clinics (34%, 1866)**
  - Significantly higher for respondents with MS (43%), women (35%), from BC (51%) or Manitoba (49%). Respondents reporting substantial, considerable or moderate use of CS are more likely to report MS Clinics than those reporting some or no use of CS.

- **Online news stories or printed newspapers (34%, 1838)**
  - Significantly higher for respondents from urban areas (34%) and for men (37%)
  - Respondents reporting some or no use of CS are more likely to refer to online news stories and printed newspapers than for those reporting considerable, substantial or moderate use of CS.

There are no major differences between rural and urban communities.

In addition to the differences identified in the top sources of information above, here are some other differences between different groups ‘perspectives”.

Respondents from Québec are more likely to report they get information from product, health or disease websites and MSSOC Facebook or Twitter page. Respondents from Alberta are more likely to report they get their information from friends and family. Respondents with progressive MS are more likely to report they get information from exercise professionals, face to face support groups or online groups and magazines and books. RRMS respondents are more likely to report they get their information from MSSOC Facebook / twitter page.

Women are more likely to report they get information from magazines and books, while men are more likely to report they get their information from friends or family.

Respondents reporting substantial and considerable use of CS are more likely than the other categories to report they get their information from exercise professionals or therapists, face to face support groups or online groups for people with MS. Respondents reporting some use of CS are most likely to use product, health or disease websites. Respondents with no use of CS are most likely to report they get their information from family and friends.
Over half of the respondents close to the person with MS get their information from family and friends.

The most frequent other sources referenced by respondents include their internet research (Google), scientific journals and literature, people with MS, and pharmaceutical companies. MS Society sources of information are also mentioned among others. Also referenced by a small number of respondents are other MS Societies, social media, other health care or health related professionals or and CCSVI information (8 respondents).

The vast majority of respondents use the Internet on a daily basis or a few times a week.
Feedback on reasons for not accessing MS Society of Canada programs and services

85% of all respondents have been engaged in the past year with the MS Society in some form. Only 15% (560) of all respondents have not been in touch with the MSSOC in the past year and 489 of these provided comments about their reasons.

The most frequent reason for not having been in touch in the past year with the MSSOC is respondents did not need support in the past year. Respondents comment their MS is stable; they have other supports available or found supports elsewhere. A couple noted that their doctor thought they would not benefit from connecting with the MS Society.

The second most frequent reason, brought up by about 50 respondents is the Society’s attitude in relation to and lack of support of CCSVI:

I was an active participant with the Society until 3 years ago when I had to take my daughter who has MS to Poland for the CCSVI procedure without any help from the Society or government. She has received benefit from the procedure.

I used to support financially and through walks and bike rides but until the society supports ccsvi, all of my donations (and I donate a substantial amount every year) goes to MS Direct and CCSVI charities. I have asked anyone that knows that I have MS and who makes charitable donations to stop supporting the MS Society. I do not believe the MS Society has patient's best interests at heart and I don't believe they listen to what patients really want.

My wife is in denial with her diagnosis and is upset at the MS society for blocking the ccsvi trials.

Other reasons offered by a low number of respondents (fewer than 50 respondents):

- **Lack of relevant services**: MSSOC does not offer relevant services, there is no local MSSOC office, there are no services where I live, I am not interested in the services offered by the MSSOC, the local Chapter has closed, I live in an isolated community.

- **Some comment that the** time and location of programs are not suitable, in particular for working people, or that the location is not easily accessible. A handful notes that programs offered are too expensive.

- **Lack of awareness**: respondents say they are not aware of services offered, or are not aware that MSSOC offers services. A few note they were just diagnosed. A handful said that they were under the impression that you have to be a member to receive services from MSSOC.

- **Poor services**: a small number of respondents (under 50) commented on the poor quality of services received, their calls were not answered or returned, negative experience with services, cut in funding to clients, staff not available during work hours, no receipts for donations, lack of knowledge, administrative processes overwhelming to get services.

- **Lack of trust in MSSOC** – these comments could be related to CCSVI however the connection is not explicit. Comments include loss of faith and trust in MSSOC, MS Society not being focussed.
on the person with MS, not advocating on behalf of people w MS, MS Society “does not represent me”. Some comment that MSSOC operations and administration costs are too high. A handful of respondents reference the renewal initiative. Other feedback speaks about the MSSOC being part of a “big pharma conspiracy”, and the MSSOC not being supportive of alternative therapies (such as diet, cannabis). A handful of respondents noted that they after not being able to continue to volunteer or fundraise for the MSSOC they felt pressured by the Society to fundraise or volunteer. Others just commented they will not be able to fundraise this year.

- **I am not ready**: denial, fear about learning about the worst case scenario, fear of being treated badly, fear about seeing people who are very disabled, introverts, lack of desire, “it depresses me”.

  I find that the more I talk about the disease, the more real it becomes. If I stay away from everything, I can pretend it doesn’t exist.

  Denial, pride, mixed messages from popular media regarding interviews with MS patients who may not have been completely informed.

  I have visited your website and subscribe to your Facebook feeds. My sister and I also plan on doing this MS Walk this April. I haven’t actually engaged directly with the MS Society yet because I’m afraid of what I might find out. I’m so worried for my Mom and am fearful that I’ll learn more than I need to know which may result in more stress or worry. I am also fearful of meeting people with advanced MS knowing that this may be what happens to my Mom over the coming years

- **Lack of time**: too busy, “trying to have a life”

- **Health issues get in the way**: both MS and non-MS
4.3. Who is the MS Society serving and who are the people affected by MS who do not use the programs and services of the MS Society?

Demographics – ALL RESPONDENTS

(n=5497 respondents)

Gender

![Gender chart showing percentages of male, female, and other responses.]

Age range

![Age range chart showing percentages of different age groups.]

Age range and gender: 55 years old and over men 44% vs. women 31%
Employment status

Gender and employment status: More men (22%) than women are retired (14%), which is consistent with the older age of men respondents.

Use of Internet
Self-assessed quality of life in the past year

Relationship to MS

Gender and relationship to MS
- More women (75%) than men (65%) have a confirmed diagnosis of MS
Use of client services from MSSOC

n=4354 respondents
Please indicate which, if any, of the following ways you have engaged with the MS Society in the past year?

<table>
<thead>
<tr>
<th>Type of MS and use of client services from MSSOC:</th>
<th>RRMS</th>
<th>Progressive MS</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am a member of the MS Society</td>
<td>75%</td>
<td>94%</td>
<td>61%</td>
</tr>
<tr>
<td>I called the MS Society to ask for information or support</td>
<td>29%</td>
<td>41%</td>
<td>26%</td>
</tr>
<tr>
<td>I received financial help or equipment (on loan or purchased) or special services, such as snow removal from the MS Society.</td>
<td>19.5%</td>
<td>7%</td>
<td>9%</td>
</tr>
<tr>
<td>I went to MS Society presentations, workshops, or conferences (in person, online or on the phone).</td>
<td>29%</td>
<td>41%</td>
<td>26%</td>
</tr>
<tr>
<td>I was part of an MS Society exercise, recreation, or social program (such as, yoga, swimming, Tai Chi or holiday dinner)</td>
<td>13%</td>
<td>25%</td>
<td>13%</td>
</tr>
<tr>
<td>I was part of an MS Society support, self-help or peer support group</td>
<td>16%</td>
<td>26%</td>
<td>15%</td>
</tr>
<tr>
<td>I was part of MS Walk</td>
<td>41%</td>
<td>29%</td>
<td>35%</td>
</tr>
<tr>
<td>I donated to the MS Society</td>
<td>62%</td>
<td>61%</td>
<td>53%</td>
</tr>
</tbody>
</table>
Province / Division

Urban / Rural
Demographics – RESPONDENTS WITH A DIAGNOSIS OF MS OR CIS

(n= 3323 respondents)

Gender

<table>
<thead>
<tr>
<th>Gender and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>16%</td>
<td>31%</td>
</tr>
<tr>
<td>Women</td>
<td>84%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Age range

<table>
<thead>
<tr>
<th>Age range and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>55 years old and over</td>
<td>20%</td>
<td>54%</td>
</tr>
<tr>
<td>35 to 54 years old</td>
<td>61%</td>
<td>43%</td>
</tr>
<tr>
<td>18 to 34 years old</td>
<td>19%</td>
<td>2%</td>
</tr>
</tbody>
</table>
### Employment status

#### Employment status and type of MS

<table>
<thead>
<tr>
<th></th>
<th>RRMS (%)</th>
<th>Progressive MS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I work full-time</td>
<td>43%</td>
<td>10%</td>
</tr>
<tr>
<td>I receive long-term disability</td>
<td>24%</td>
<td>55%</td>
</tr>
<tr>
<td>I am retired</td>
<td>8%</td>
<td>24%</td>
</tr>
</tbody>
</table>

#### Employment status and age range

<table>
<thead>
<tr>
<th>Age Range</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
</tr>
</thead>
<tbody>
<tr>
<td>I work full time or part time</td>
<td>19%</td>
<td>33%</td>
<td>34%</td>
<td>12%</td>
</tr>
<tr>
<td>I receive long term disability or short term disability</td>
<td>4%</td>
<td>18%</td>
<td>38%</td>
<td>38%</td>
</tr>
</tbody>
</table>

### Self-assessed quality of life in the past year

#### Self-assessed QOL and type of MS

<table>
<thead>
<tr>
<th>QOL</th>
<th>RRMS (%)</th>
<th>Progressive MS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>11%</td>
<td>3%</td>
</tr>
<tr>
<td>Very good</td>
<td>30%</td>
<td>18%</td>
</tr>
<tr>
<td>Fair</td>
<td>18%</td>
<td>33%</td>
</tr>
<tr>
<td>Poor</td>
<td>4%</td>
<td>10%</td>
</tr>
</tbody>
</table>
### Years since diagnosis

<table>
<thead>
<tr>
<th>Years since diagnosis</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 5 years</td>
<td>30%</td>
<td>11%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>27%</td>
<td>18%</td>
</tr>
<tr>
<td>More than 20 years</td>
<td>14%</td>
<td>39%</td>
</tr>
</tbody>
</table>

### Type of MS

<table>
<thead>
<tr>
<th>Type of MS</th>
<th>n=3301 respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinically Isolated Syndrome (CIS)</td>
<td>1.8%</td>
</tr>
<tr>
<td>Relapsing-remitting</td>
<td>55.4%</td>
</tr>
<tr>
<td>Secondary-progressive</td>
<td>19.1%</td>
</tr>
<tr>
<td>Primary-progressive</td>
<td>9.3%</td>
</tr>
<tr>
<td>Progressive-relapsing</td>
<td>2.8%</td>
</tr>
<tr>
<td>Not sure</td>
<td>8.1%</td>
</tr>
<tr>
<td>Other (please describe)</td>
<td>3.6%</td>
</tr>
</tbody>
</table>

### Type of MS and gender

<table>
<thead>
<tr>
<th>Type of MS and gender</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>RRMS</td>
<td>56%</td>
<td>42%</td>
</tr>
<tr>
<td>Primary progressive</td>
<td>9%</td>
<td>19%</td>
</tr>
</tbody>
</table>
### Living arrangement

<table>
<thead>
<tr>
<th>Living arrangement</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I live with others (spouse or partner, friends or family) at home.</td>
<td>84%</td>
<td>76%</td>
</tr>
<tr>
<td>I live in supportive housing that provides some health care as well as services like meals or housekeeping.</td>
<td>0.8%</td>
<td>0.6%</td>
</tr>
<tr>
<td>I live in a long-term care facility.</td>
<td>1.7%</td>
<td></td>
</tr>
<tr>
<td>Other (please describe)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**n=3236 respondents**

### Living arrangement and type of MS

<table>
<thead>
<tr>
<th>Living arrangement and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I live with others</td>
<td>84%</td>
<td>76%</td>
</tr>
</tbody>
</table>

### Unpaid or paid caregiver support received at home

<table>
<thead>
<tr>
<th>Unpaid or paid caregiver support received at home</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>77.4%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>22.6%</td>
<td></td>
</tr>
</tbody>
</table>

**n=3126 respondents**

### Unpaid caregiver support and type of MS

<table>
<thead>
<tr>
<th>Unpaid caregiver support and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15%</td>
<td>39%</td>
</tr>
</tbody>
</table>
Level of care received

![Bar chart showing the percentage of respondents who receive enough care (78.6%) and those who need more care (21.4%).]

<table>
<thead>
<tr>
<th>Level of care received and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I receive enough care</td>
<td>84%</td>
<td>75%</td>
</tr>
</tbody>
</table>

Level of care needed – for those who do not receive care from an unpaid or paid caregiver

![Bar chart showing the percentage of respondents who do not need care (90.3%) and those who need care (9.7%).]

<table>
<thead>
<tr>
<th>Level of care needed and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need this kind of care</td>
<td>6%</td>
<td>20%</td>
</tr>
</tbody>
</table>
Mobility requirements

Mobility requirements and gender

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Male - Never</th>
<th>Female - Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need to use a wheelchair</td>
<td>65%</td>
<td>75%</td>
</tr>
<tr>
<td>I need to use a scooter</td>
<td>74%</td>
<td>83%</td>
</tr>
</tbody>
</table>

Mobility requirements and type of MS

<table>
<thead>
<tr>
<th>Requirement</th>
<th>RRMS -Never</th>
<th>Progressive MS - never</th>
</tr>
</thead>
<tbody>
<tr>
<td>I require help from another person to remain mobile.</td>
<td>65%</td>
<td>24%</td>
</tr>
<tr>
<td>I need to use a cane.</td>
<td>66%</td>
<td>40%</td>
</tr>
<tr>
<td>I need to use a walker.</td>
<td>88%</td>
<td>50%</td>
</tr>
<tr>
<td>I need to use a wheelchair.</td>
<td>88%</td>
<td>41%</td>
</tr>
<tr>
<td>I need to use a scooter.</td>
<td>88%</td>
<td>59%</td>
</tr>
</tbody>
</table>
MS symptoms with most impact on day-to-day life in the past year

<table>
<thead>
<tr>
<th>Symptoms and type of MS</th>
<th>RRMS</th>
<th>Progressive MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>81.2%</td>
<td>67.5%</td>
</tr>
<tr>
<td>Problems with walking, balance and coordination</td>
<td>45.7%</td>
<td>73.4%</td>
</tr>
<tr>
<td>Vision problems</td>
<td>21.1%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Bladder problems</td>
<td>26.9%</td>
<td>49.3%</td>
</tr>
<tr>
<td>Bowel problems</td>
<td>11.4%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Feeling numb or tingling</td>
<td>41.5%</td>
<td>26.5%</td>
</tr>
<tr>
<td>Not thinking clearly (cognitive problems)</td>
<td>33.3%</td>
<td>20.3%</td>
</tr>
<tr>
<td>Spasticity</td>
<td>15.7%</td>
<td>40.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptoms and gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems with walking, balance and coordination</td>
<td>66.3%</td>
<td>51.8%</td>
</tr>
<tr>
<td>Pain</td>
<td>24.0%</td>
<td>32.2%</td>
</tr>
<tr>
<td>Spasticity</td>
<td>32.5%</td>
<td>21.5%</td>
</tr>
<tr>
<td>Sexual problems</td>
<td>22.7%</td>
<td>10.9%</td>
</tr>
</tbody>
</table>
Professionals seen because of MS or probable MS in the past year

- Neurologist: 87.9%
- Family doctor: 75.8%
- Nurse: 25.3%
- Physiotherapist: 24.6%
- Occupational therapist: 16.1%
- Speech and language pathologist: 7.2%
- Nutritional or dietitian: 4.8%
- Physiatrist: 12.0%
- Massage therapist or chiropractor: 28.3%
- Naturopath or homeopath: 20.9%
- Ophthalmologist or optician: 2.6%
- Orthotist: 6.6%
- Urologist: 7.7%
- Psychiatrist, psychologist or therapist: 7.1%
- Sex therapist: 13.4%
- Vascular surgeon: 3.1%
- Radiologist: 5.4%
- Lawyer: 6.6%
- Financial planner: 0.3%
- Social worker: 3.2%
- Other (please describe): 13.4%
Province / MSSOC division

<table>
<thead>
<tr>
<th>Province / MSSOC division</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC &amp; Yukon</td>
<td>16%</td>
</tr>
<tr>
<td>Alberta &amp; NWT</td>
<td>11%</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>6%</td>
</tr>
<tr>
<td>Manitoba</td>
<td>5%</td>
</tr>
<tr>
<td>Ontario</td>
<td>32%</td>
</tr>
<tr>
<td>Quebec</td>
<td>23%</td>
</tr>
<tr>
<td>Atlantic</td>
<td>6%</td>
</tr>
</tbody>
</table>

n=3194 respondents

Rural / Urban area

<table>
<thead>
<tr>
<th>Area</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural Areas</td>
<td>15%</td>
</tr>
<tr>
<td>Urban areas</td>
<td>85%</td>
</tr>
</tbody>
</table>

n=3194 respondents
Demographics – RESPONDENTS AWAITING A DIAGNOSIS OF MS

(n=91 respondents)

Gender

Age range
Employment status

- I work full-time: 50.5%
- I work part-time: 9.9%
- I am a student: 8.8%
- I do not have a paid job: 2.2%
- I receive long-term disability: 16.5%
- I receive short-term disability: 6.6%
- I am retired: 2.2%
- Other (please describe): 7.7%

Self-assessed quality of life in the past year

- Excellent: 11.1%
- Very good: 18.9%
- Good: 33.3%
- Fair: 25.6%
- Poor: 11.1%
Years seeking a diagnosis from health care professionals

<table>
<thead>
<tr>
<th>Years seeking a diagnosis</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>29.9%</td>
<td>21.8%</td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>16.1%</td>
<td>14.0%</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>13.8%</td>
<td>14.0%</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>18.4%</td>
<td>14.0%</td>
</tr>
</tbody>
</table>

Diagnosis and gender

<table>
<thead>
<tr>
<th>Years seeking a diagnosis</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>44%</td>
<td>28%</td>
</tr>
<tr>
<td>3-5 years</td>
<td>0%</td>
<td>17%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>0%</td>
<td>15%</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>33%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Living arrangement

<table>
<thead>
<tr>
<th>Living arrangement</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>I live by myself at home.</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>I live with others (spouse or partner, friends or family) at home.</td>
<td>21.3%</td>
<td>0%</td>
</tr>
<tr>
<td>I live in supportive housing that provides some health care as well as services like meals or housekeeping.</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>I live in a long-term care facility.</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Other (please describe)</td>
<td>1.1%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Paid / Unpaid caregiving support received at home

Level of care received
Level of care needed for those who do not receive care from unpaid or paid caregiver

<table>
<thead>
<tr>
<th>I do not need care.</th>
<th>I need this kind of care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>93.8%</td>
<td>6.3%</td>
</tr>
</tbody>
</table>

Mobility requirements

- I require help from another person to remain mobile.
- I need to use a cane.
- I need to use a walker.
- I need to use a wheelchair.
- I need to use a scooter.

- All of the time
- Most of the time
- Some of the time
- Never

n=90 respondents

n=88 respondents
Symptoms that impact on your day-to-day life in the past year

- Fatigue: 75.9%
- Problems with walking, balance and coordination: 50.6%
- Vision problems: 32.2%
- Bowel problems: 24.1%
- Feeling numb or tingling: 12.6%
- Pain: 55.2%
- Not thinking clearly (cognitive problems): 46.0%
- Spasticity: 39.1%
- Depression: 23.0%
- Sexual problems: 26.4%
- Feeling dizzy: 13.8%
- Other (please describe): 27.6%
- Other: 4.6%

n=87 respondents
Professionals seen because of MS or probable MS

- Neurologist: 78.0%
- Family doctor: 88.8%
- Nurse: 14.6%
- Physiotherapist: 19.1%
- Occupational therapist: 11.2%
- Speech and language pathologist: 7.9%
- Nutritionist or dietician: 4.5%
- Psychiatrist: 12.4%
- Physiatrist: 38.2%
- Fitness professional or exercise therapist: 14.6%
- Acupuncturist: 22.5%
- Massage therapist or chiropractor: 2.2%
- Naturopath or homeopath: 6.7%
- Ophthalmologist or optician: 13.5%
- Orthotist: 0.0%
- Physiotherapist or chiropractor: 3.4%
- Other (please describe): 7.9%
- Social worker: 3.4%
- Financial planner: 22.5%
- Vascular surgeon: 3.4%
- Lawyer: 1.1%
- Radiologist: 1.1%
- Psychiatrist, psychologist or therapist: 3.4%
- Sex therapist: 0.0%
- Orthotist: 10%
- Orthotist: 20%
- Orthotist: 30%
- Orthotist: 40%
- Orthotist: 50%
- Orthotist: 60%
- Orthotist: 70%
- Orthotist: 80%
- Orthotist: 90%
- Orthotist: 100%
Province / MSSOC Division

- BC & Yukon: 10%
- Alberta & NWT: 17%
- Saskatchewan: 5%
- Manitoba: 5%
- Ontario: 34%
- Quebec: 17%
- Atlantic: 11%

n=87 respondents

Rural / Urban area

- Rural Areas: 28%
- Urban Areas: 72%

n=87 respondents
Demographics – CAREGIVERS

(N= 171 respondents)

Gender

- Male: 36.3%
- Female: 63.7%
- Transsexual, transgender, two-spirited: 0.0%

Age range

- <18: 0%
- 18-24: 2%
- 25-34: 8%
- 35-44: 10%
- 45-54: 23%
- 55-64: 35%
- 65+: 22%
Employment status

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I work full-time</td>
<td>42.1%</td>
</tr>
<tr>
<td>I work part-time</td>
<td>11.7%</td>
</tr>
<tr>
<td>I am a student</td>
<td>2.9%</td>
</tr>
<tr>
<td>I do not have a paid job</td>
<td>2.9%</td>
</tr>
<tr>
<td>I receive long-term disability</td>
<td>3.5%</td>
</tr>
<tr>
<td>I receive short-term disability</td>
<td>0.6%</td>
</tr>
<tr>
<td>I am retired</td>
<td>31.6%</td>
</tr>
<tr>
<td>Other (please describe)</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

n=171 respondents

Self-assessed quality of life in the past year

<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>12.5%</td>
</tr>
<tr>
<td>Very good</td>
<td>23.8%</td>
</tr>
<tr>
<td>Good</td>
<td>29.8%</td>
</tr>
<tr>
<td>Fair</td>
<td>28.6%</td>
</tr>
<tr>
<td>Poor</td>
<td>5.4%</td>
</tr>
</tbody>
</table>

n=168 respondents
Professionals seen for support as caregiver

- Family doctor: 51.0%
- Nurse: 14.2%
- Physiotherapist: 11.0%
- Occupational therapist: 12.3%
- Nutritionist or dietician: 4.5%
- Psychiatrist: 1.3%
- Occupational therapist or dietician: 11.6%
- Massage therapist or chiropractor: 23.9%
- Psychiatrist, psychologist or therapist: 13.5%
- Sex therapist: 0.6%
- Financial planner: 4.5%
- Social worker: 12.3%
- Does not apply to me: 15.5%
- Other (please describe): 18.7%
Demographics – CLOSE TO OR FAMILY MEMBERS OF A PERSON WITH MS

(n=998 respondents)

Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>n=992 respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>29.9%</td>
</tr>
<tr>
<td>Female</td>
<td>70.0%</td>
</tr>
<tr>
<td>Transsexual, transgender, two-spirited</td>
<td>0.1%</td>
</tr>
</tbody>
</table>

Age range

<table>
<thead>
<tr>
<th>Age Range</th>
<th>n=962 respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;18</td>
<td>1%</td>
</tr>
<tr>
<td>18-24</td>
<td>4%</td>
</tr>
<tr>
<td>25-34</td>
<td>17%</td>
</tr>
<tr>
<td>35-44</td>
<td>18%</td>
</tr>
<tr>
<td>45-54</td>
<td>21%</td>
</tr>
<tr>
<td>55-64</td>
<td>23%</td>
</tr>
<tr>
<td>65+</td>
<td>16%</td>
</tr>
</tbody>
</table>
Employment status

- I work full-time: 57.7%
- I work part-time: 13.5%
- I am a student: 4.7%
- I do not have a paid job: 2.3%
- I receive long-term disability: 2.0%
- I receive short-term disability: 0.2%
- I am retired: 19.9%
- Other (please describe): 4.4%

n=997 respondents

Self-assessed quality of life in the past year

- Excellent: 26.5%
- Very good: 40.5%
- Good: 23.7%
- Fair: 7.3%
- Poor: 2.0%

n=990 respondents
Province / MSSOC Division

- BC & Yukon: 15%
- Alberta & NWT: 17%
- Saskatchewan: 6%
- Manitoba: 7%
- Ontario: 38%
- Québec: 10%
- Atlantic: 7%

n=968 respondents

Rural / Urban

- Rural Areas: 14%
- Urban areas: 86%

n=968 respondents
Demographic profile by self-reported engagement with the MS Society and client services use

**Respondents' Use of Client Services**

<table>
<thead>
<tr>
<th>Use Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substantial</td>
<td>8%</td>
</tr>
<tr>
<td>Considerable</td>
<td>26%</td>
</tr>
<tr>
<td>Moderate</td>
<td>11%</td>
</tr>
<tr>
<td>Some use</td>
<td>30%</td>
</tr>
<tr>
<td>No use</td>
<td>26%</td>
</tr>
</tbody>
</table>

n=4354 respondents

**Comparative demographics by level of use of client services**

**Gender**

<table>
<thead>
<tr>
<th>Use Level</th>
<th>Male</th>
<th>Female</th>
<th>Other</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substantial use</td>
<td>23%</td>
<td>77%</td>
<td>0%</td>
<td>77%</td>
</tr>
<tr>
<td>Considerable use</td>
<td>25%</td>
<td>75%</td>
<td>0%</td>
<td>75%</td>
</tr>
<tr>
<td>Moderate use</td>
<td>20%</td>
<td>80%</td>
<td>0%</td>
<td>80%</td>
</tr>
<tr>
<td>Some use</td>
<td>22%</td>
<td>77%</td>
<td>0%</td>
<td>77%</td>
</tr>
<tr>
<td>No use</td>
<td>24%</td>
<td>76%</td>
<td>0%</td>
<td>76%</td>
</tr>
<tr>
<td>ALL</td>
<td>24%</td>
<td>76%</td>
<td>0%</td>
<td>76%</td>
</tr>
</tbody>
</table>
Employment status

- I work full-time
- I work part-time
- I am a student
- I do not have a paid job
- I receive long-term disability
- I receive short-term disability
- I am retired

<table>
<thead>
<tr>
<th>Substantial use</th>
<th>Considerable use</th>
<th>Moderate use</th>
<th>Some use</th>
<th>No use</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>19%</td>
<td>21%</td>
<td>12%</td>
<td>14%</td>
<td>14%</td>
<td>16%</td>
</tr>
<tr>
<td>37%</td>
<td>32%</td>
<td>51%</td>
<td>5%</td>
<td>5%</td>
<td>24%</td>
</tr>
<tr>
<td>3%</td>
<td>6%</td>
<td>3%</td>
<td>12%</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>10%</td>
<td>9%</td>
<td>3%</td>
<td>12%</td>
<td>12%</td>
<td>3%</td>
</tr>
<tr>
<td>2%</td>
<td>2%</td>
<td>3%</td>
<td>3%</td>
<td>5%</td>
<td>11%</td>
</tr>
<tr>
<td>14%</td>
<td>26%</td>
<td>35%</td>
<td>46%</td>
<td>48%</td>
<td>40%</td>
</tr>
<tr>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
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<tr>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>19%</td>
<td>21%</td>
<td>12%</td>
<td>14%</td>
<td>14%</td>
<td>16%</td>
</tr>
</tbody>
</table>

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Self-assessed QOL

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substantial use</td>
<td>12%</td>
<td>4%</td>
<td>9%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Considerable use</td>
<td>34%</td>
<td>20%</td>
<td>24%</td>
<td>17%</td>
<td>16%</td>
</tr>
<tr>
<td>Moderate use</td>
<td>29%</td>
<td>39%</td>
<td>36%</td>
<td>33%</td>
<td>26%</td>
</tr>
<tr>
<td>Some use</td>
<td>17%</td>
<td>28%</td>
<td>23%</td>
<td>33%</td>
<td>30%</td>
</tr>
<tr>
<td>No use</td>
<td>8%</td>
<td>8%</td>
<td>8%</td>
<td>13%</td>
<td>20%</td>
</tr>
<tr>
<td>ALL</td>
<td>5%</td>
<td>9%</td>
<td>5%</td>
<td>5%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Relationship to MS

<table>
<thead>
<tr>
<th></th>
<th>I have MS</th>
<th>Family / Friend</th>
<th>Awaiting Diagnosis</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substantial use</td>
<td>87%</td>
<td>81%</td>
<td>76%</td>
<td>70%</td>
</tr>
<tr>
<td>Considerable use</td>
<td>6%</td>
<td>4%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Moderate use</td>
<td>15%</td>
<td>16%</td>
<td>24%</td>
<td>33%</td>
</tr>
<tr>
<td>Some use</td>
<td>16%</td>
<td>24%</td>
<td>33%</td>
<td>33%</td>
</tr>
<tr>
<td>No use</td>
<td>7%</td>
<td>3%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>ALL</td>
<td>4%</td>
<td>2%</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>
RRMS vs. Progressive MS

Living arrangements
Receive care from paid/unpaid caregiver

Level of care received

Level of care needed
## Engagement with the MS Society of Canada in the last year

<table>
<thead>
<tr>
<th>Activity</th>
<th>Substantial use</th>
<th>Considerable use</th>
<th>Moderate use</th>
<th>Some use</th>
<th>No use</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have not been in touch with the MS Society in the past year</td>
<td>29%</td>
<td>4%</td>
<td>8%</td>
<td>37%</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>3%</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
<td>3%</td>
</tr>
<tr>
<td>2. I gave money to the MS Society</td>
<td>49%</td>
<td>62%</td>
<td>48%</td>
<td>54%</td>
<td>43%</td>
<td>52%</td>
</tr>
<tr>
<td>3. I volunteered for the MS Society in a non-fundraising capacity</td>
<td>13%</td>
<td>18%</td>
<td>3%</td>
<td>1%</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>4. I volunteered for the MS Society at a fundraising event</td>
<td>23%</td>
<td>26%</td>
<td>9%</td>
<td>5%</td>
<td>5%</td>
<td>12%</td>
</tr>
<tr>
<td>5. I was involved in other MS Society fundraising events</td>
<td>27%</td>
<td>25%</td>
<td>15%</td>
<td>11%</td>
<td>8%</td>
<td>15%</td>
</tr>
<tr>
<td>6. I was part of MS Bike</td>
<td>6%</td>
<td>7%</td>
<td>4%</td>
<td>5%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>7. I was part of MS Walk</td>
<td>35%</td>
<td>40%</td>
<td>31%</td>
<td>27%</td>
<td>25%</td>
<td>31%</td>
</tr>
<tr>
<td>8. I was part of an MS Society support, self-help or peer support group</td>
<td>32%</td>
<td>40%</td>
<td>0%</td>
<td>13%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I was part of an MS Society exercise, recreation, or social program</td>
<td>28%</td>
<td>36%</td>
<td>0%</td>
<td>11%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(such as, yoga, swimming, Tai Chi or holiday dinner)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>10. I went to MS Society presentations, workshops, or conferences</td>
<td>45%</td>
<td>74%</td>
<td>0%</td>
<td>22%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(in person, online or on the phone).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I received financial help or equipment (on loan or purchased) or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>special services, such as snow removal from the MS Society.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I received in-person information or support from the MS Society</td>
<td>41%</td>
<td>30%</td>
<td>36%</td>
<td>0%</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>13. I called the MS Society to ask for information or support</td>
<td>63%</td>
<td>35%</td>
<td>82%</td>
<td>0%</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>14. I received information in print form or from the MS Society's</td>
<td>79%</td>
<td>79%</td>
<td>71%</td>
<td>100%</td>
<td>0%</td>
<td>64%</td>
</tr>
<tr>
<td>website</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I am a member of the MS Society</td>
<td>86%</td>
<td>80%</td>
<td>55%</td>
<td>47%</td>
<td>24%</td>
<td>53%</td>
</tr>
</tbody>
</table>
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 for taking time to complete this survey about the needs of Canadians affected by MS. Results of this survey will help us improve our programs, services and our government relations work.

The survey will take you about 20 to 25 minutes to complete. You must complete the whole survey in one sitting. In addition, you cannot go back and review or change existing responses.

Doing the survey is voluntary.

All of your answers will be kept completely private.

We will not ask you to provide your name, address or phone number.

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

If you cannot complete the survey on the computer or in one sitting, please call us at 18002687582 or go to mslistening.ca to print out a paper copy.

You will see the results

Stay tuned to MS Canada and our website (mslistening.ca) for more information on what people affected by MS have to say about their day to day lives with MS.

Thank you in advance for sharing your voice. Your time and participation are greatly valued.

Please take the survey if one of the following is true for you:

- I have a diagnosis of Multiple Sclerosis (MS) or Clinically Isolated Syndrome (CIS).
- 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)
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.

You must finish the survey and click SUBMIT for your answers to be counted.

When you are ready to complete the survey, please click NEXT.

1. I am...
   - Male
   - Female
   - Transsexual, transgender, two-spirited

2. In what year were you born?

3. What is your employment status?
   - I work fulltime
   - I work part time
   - I am a student
   - I do not have a paid job
   - I receive long term disability
   - I receive short term disability
   - I am retired
   - Other (please describe)

4. Please describe your use of the internet:
   - I use the Internet on a daily basis
   - I use the Internet a few times a week
   - I use the Internet a few times a month or less
   - I do not have regular access to the Internet
   - I do not know how to use the Internet
   - I cannot use the Internet
   - Other (please describe)

5. In general, would you say that YOUR quality of life in the past year was....
   - Excellent
   - Very good
   - Good
   - Fair
   - Poor
   - Other

6. 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 about having MS in your life?
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)
- MS Clinics
- Other registered health professionals (such as naturopaths or chiropractors)
- Exercise professionals or exercise therapists
- Friends or family
- Face-to-face support groups or online groups for people with MS
- Product, health or disease websites
- MS Society of Canada staff and volunteers
- The MS Society of Canada online or print resources
- MS Society of Canada Facebook page or Twitter feed
- Online news stories or printed newspapers
- Magazines and books
- TV or radio
- None
- Other (please describe)

8. The Multiple Sclerosis International Federation (MSIF) has identified factors that help improve the quality of life of people affected by multiple sclerosis. We are interested in your opinion. As someone dealing with MS, which of these have been important in your day-to-day life in the past year?

Please choose all that apply.

- Being able to be part of the community where I live
- Being able to make decisions about treating and managing MS
- Having access to medical care
- Getting services that allow the person with MS to be as independent as possible (i.e., allow someone to remain at home for as long as possible)
- Being able to find information and services that encourage physical, emotional, mental and/or spiritual wellness
- Having support for family members and caregivers
- Having access to transportation that allows a person with MS to get around easily
- Getting support in the workplace
- Getting financial help
- Accessing education despite challenges of MS
- Being able to enter and exit buildings easily, both public (e.g., schools or government buildings), and private (e.g., homes or apartments)

9. 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
- Does not apply to me

- I am able to be part of community life as much as I want to.
• I have access to a broad range of information and advice about MS.
• I have access to information and advice about exercise, nutrition, and ways to manage stress.
• Community buildings such as government offices, hospitals, clinics, and schools (at all levels) are accessible.
• I am retired from work but I feel fulfilled by volunteer work, hobbies or domestic life.
• Our children (under the age of 18) have caregiving responsibilities.
• I find it difficult to get financial assistance for MS related issues.

10. What was the most important MS related concern or problem that YOU needed help with in the last year?

11. Which of the following supports did you try for the concern or problem you identified above and how helpful were they in solving it?
   - Tried, very helpful
   - Tried, somewhat helpful
   - Tried, not at all helpful
   - Did not try this service or support

   • Government programs such as subsidies, financial assistance or training programs
   • Programs and services in my area run by charities or agencies other than the MS Society
   • Personal networks (friends and family who provide help)
   • Personal financial resources
   • Health care professionals outside of MS clinics
   • MS clinics
   • MS Society of Canada staff and volunteers
   • MS Society of Canada online or print resources
   • Support at work or support to find work
   • Unpaid caregiver (close friend or family that sometimes or always provides care to a person with MS)
   • Paid caregiver
   • Self-help, support groups, or online groups that offer support
   • Religious or spiritual groups that provide support, such as a church, temple or meditation group.
   • Respite care or short-term care (temporary help)
   • Long-term care facility
   • Accessible transportation
   • Mobility aids
   • Other (please describe)

12. Were there particular barriers that prevented you from solving the concern or problem that you identified above? Please choose all that apply.
   • 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 money for needed supports or services
   • I had a lack of support from family and friends
   • I had a lack of support at work
   • I had problems accessing the Internet or other technology I needed
- I had problems coping with MS in my life (such as denial, caregiving stress, or not being able to ask for help that I need)
- I did not know where to go for help (information problems)
- Language was a problem
- I had problems that are not related to MS
- I had difficulty contacting a doctor
- I had difficulty getting an appointment
- My MS symptoms got in the way
- I had problems moving around (such as transportation challenges or needing mobility aids)
- None of the above
- There were no barriers
- Other (please describe)

13. Which ONE of the following categories BEST describes you?

- I have a diagnosis of Multiple Sclerosis (MS) or Clinically Isolated Syndrome (CIS).
- I have a close relationship with someone with MS or CIS (family member, spouse or partner or 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).

14. How many years have you had Multiple Sclerosis?

- 1 to 5 years
- 6 to 10 years
- 11 to 20 years
- More than 20 years

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

- Clinically Isolated Syndrome (CIS)
- Relapsing remitting
- Secondary progressive
- Primary progressive
- Progressive relapsing
- Not sure
- Other (please describe)

16. 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
- Does not apply to me

- I help to decide on medical treatments or other aspects of living with MS that affect my life.
- I have access to treatments, programs and services whether I can pay for them or not.
- I have access to disease modifying treatments, medicine to manage symptoms and rehabilitation services (such as physiotherapy) approved in Canada.
- 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).
- I feel that my healthcare team cares about my wellbeing, and does not just focus on treating my disease.
- My family doctor is knowledgeable about MS.
- My long-term care facility provides activities and supports that engage and interest me.
- The people who are paid to care for me are knowledgeable about MS.
- Transportation services where I live allow me to travel around, as I need to.
- My workplace makes changes so that I can still work despite my MS.
- My disability benefits (public or private) allow me to maintain a standard of living that is good enough.
- My health care provider(s) offer me routine medical care, like flu shots, pap smears, or other tests that are not related to my MS.
- My school accommodates my MS so I can continue with my education.

17. Please indicate whether the statements below are true for you:
   - True
   - Not true
   - Does not apply to me

   - I received the support I needed from my health care professional(s) when I first learned that I had MS.
   - I was referred to the MS Society at the time of my diagnosis.
   - I feel that I have the support I need to stay in my home as long as possible.
   - Other people my age live in the same long-term care facility where I live.
   - My car has changes made to it so I can still drive it.
   - My home has been adapted to make it easier to live with MS.

18. How long have you been seeking a diagnosis from health care professionals?

   - Less than one year
   - 1 to 2 years
   - 3 to 5 years
   - 6 to 10 years
   - More than ten years

19. 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)

20. Do you receive care at home from an unpaid or paid caregiver?
21. You said that you receive care at home or in supportive housing or a long term care facility. Which of the following is true for you?

- I receive enough care to meet my needs.
- I need more care than I currently receive.

22. You said that you do not receive care from an unpaid or paid caregiver. Which of the following is true for you?

- I do not need care.
- I need this kind of care.

23. How often have you needed the following supports to stay mobile in the past year?

- All of the time
- Most of the time
- Some of the time
- Never

- I require help from another person to remain mobile.
- I need to use a cane.
- I need to use a walker.
- I need to use a wheelchair.
- I need to use a scooter.
- Other (please describe)

24. What 3 symptoms have had the most impact on your day-to-day life in the past year?

- Fatigue
- Problems with walking, balance and coordination
- Vision problems
- Bladder problems
- Bowel problems
- Feeling numb or tingling
- Pain
- Not thinking clearly (cognitive problems)
- Spasticity
- Depression
- Sexual problems
- Feeling dizzy
- Other (please describe)

25. Which of the following professionals have you seen because of MS or possible MS in the past year? Please choose all that apply.

- Neurologist
- Family doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Speech and language pathologist
- Nutritionist or dietician
- Physiatrist
- Fitness professional or exercise therapist
- Massage therapist or chiropractor
- Acupuncturist
- Naturopath or homeopath
- Ophthalmologist or optician
- Orthotist
- Urologist
- Psychiatrist, psychologist or therapist
- Sex therapist
- Vascular surgeon
- Radiologist
- Lawyer
- Financial planner
- Social worker
- Other (please describe)

26. In the past year, did you rely on financial help outside of your own personal resources to help with issues linked to MS?

- No
- Yes
- If yes, please describe below

27. 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
- Does not apply to me

- I can find the support I need as a caregiver or family member.
- I have access to respite services that allow me to take breaks from caregiving.
- As a caregiver, I have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving.
- I feel that I have someone to talk to when I am feeling tired or when negative feelings arise.
- My boss gives me time off, as needed, so I can care for the person with MS in my life.

28. Which of the following professionals have you seen for support in your role as a caregiver to someone with MS in the past year? (Remember this is support for you as a caregiver, not the person you are caring for).
• Family doctor
• Nurse
• Physiotherapist
• Occupational therapist
• Nutritionist or dietician
• Psychiatrist
• Fitness professional or exercise therapist,
• Massage therapist or chiropractor
• Psychiatrist, psychologist or therapist
• Sex therapist
• Lawyer
• Financial planner
• Social worker
• Does not apply to me
• Other (please describe)

29. The mission of the MS Society of Canada is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life. We want to know how you think the MS Society of Canada could best invest in our mission. To help you answer this question, imagine that you gave $100 to the MS Society. Please tell us how you want the MS Society to spend this $100. Put numbers ONLY in the boxes below and make sure the amount adds up to 100.

• Research to prevent MS, stop MS, restore damage caused by MS, or help people live well with MS
• Programs, Services and Governmental Relations in support of: Recreational, social and wellness programs; Financial assistance; Information and supportive counseling; Support and self-help groups; Education; Governmental relations and social action; and Individual advocacy

30. Please indicate which, if any, of the following ways you have engaged with the MS Society in the past year?

• I am a member of the MS Society
• I received information in print form or from the MS Society’s website
• I called the MS Society to ask for information or support
• I received in person information or support from the MS Society
• I received financial help or equipment (on loan or purchased) or special services, such as snow removal 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 exercise, recreation, or social program (such as, yoga, swimming, Tai Chi or holiday dinner)
• I was part of an MS Society support, self-help or peer support group
• I was part of MS Walk
• I was part 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 gave money to the MS Society
• Other
- I have not been in touch with the MS Society in the past year
- If you have NOT been in touch with the MS Society in the past year, please explain why:

31. This survey is intended to understand the quality of life of people affected by MS. Did we miss anything or do you have any further comments? What do you think is the most important thing that would help you to improve your quality of life today?

32. What are the first three digits of your postal code? For instance, if your home postal code is M4W 3R8, the first three digits would be M (letter), 4 (number), W (letter). (We will use this to help us understand whether Canadians from all regions of the country are doing this survey. We will not be able to identify you).

- First digit
- Second digit
- Third digit

For example M4W

You have finished the survey! Thank you for your time. When you click SUBMIT, we will receive your survey and you will go directly to the MS Society’s website. Thank you!