Summary Report:

Key Findings
Special Acknowledgements:

The Listening to People Affected by MS Initiative was an important and critical undertaking by the MS Society of Canada that began with the formation of an Advisory Group to the National VP Programs and Services in April 2012.

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.

The advisory group members were as follows:
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This initiative would not have been possible without the critical input and participation of thousands of people affected by MS who provided us with meaningful feedback and insight on quality of life issues.

We are also indebted to the time commitment and passion of the advisory group members made up of volunteers and staff from across the country.

Throughout the process we received ongoing feedback and advice from client services directors across the country and also from client services staff and volunteers on the ground in communities across Canada.

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**Executive Summary**

The Listening to People Affected by MS initiative sought input from a large number of Canadians who are affected by MS through a web-based survey, online poll, environmental scan and focus groups. A broad range of people were consulted through the project including those diagnosed with MS/CIS (Clinically Isolated Syndrome), people waiting for a diagnosis of MS, informal caregivers of a person with MS and family members and close friends of people with MS. The overall goal of the evaluation was to increase the MS Society’s understanding of current quality of life (QOL) needs, priorities, gaps and barriers experienced by these groups. The main themes across all four components of the evaluation are consistent and provide insight into these QOL issues.

When asked to describe what a good QOL means to them, participants from across the country speak about the same things. Maintaining independence and autonomy, and not being a burden on family and friends is critical. Having the freedom to make lifestyle choices, and being able to do the things one wants, when one wants and how one wants is important. Participating in the community, through social and recreational activities, employment, volunteer work or other pursuits is also vital. Having the financial freedom to make choices, access treatments and remain active and mobile is essential.

Participants also talk about how important it is to regularly reset and redefine one’s expectations. Living with MS requires an ever-changing definition of QOL and a resetting of priorities to match one’s current abilities. People told us that having MS itself can be a barrier to a good QOL, as coping with the disease and dealing with its symptoms are a challenge. Despite this, the participants in this initiative report a relatively good QOL, and convey a sense of hope and optimism for the future.

Delving deeper into QOL, the results of the initiative revealed that there are several important areas that are key priorities for people affected by MS. While there are commonalities in these priorities between those diagnosed with MS and those who provide informal care or are close to someone with MS, there are also key differences. All participants speak about the importance of access to medical care, involvement in decision-making about treatment and disease management, financial support, and support for caregivers and family members. However, while those with MS also prioritize the importance of information and services to encourage physical, mental, emotional and spiritual wellness, caregivers focus on the practical issues such as services to allow for independence and access to transportation and buildings.

For many people, access to medical care and being involved in decision-making regarding treatment are the most important QOL priorities. However, we heard repeatedly through the initiative that navigating the health care system in Canada is challenging. Accessing doctors, specialists, tests, treatment and services in a timely and convenient manner is difficult for many. Finding information about programs and services is also consistently problematic. Participants repeatedly indicate that there is a significant need for a navigation service for people with MS to help them sort through the maze of information, services and programs, be it financial support, wellness programs or health care services, and to help them find those best suited to their QOL needs.

The importance of maintaining independence and staying at home as long as possible is also an important QOL priority. People with MS want to live at home and not be a burden on family and friends. They want to be active participants in their communities. However, we heard that accessing services to maintain this independence can be difficult. Home care services and assistance with personal care vary significantly by region, have long wait times, and often limited access. Sometimes these services are not even provided at all. For those who are unable to remain at home, finding a good QOL is also significantly challenging. There are few age-appropriate long-term care facilities for people with MS and...
life is very difficult for those living in facilities that do not provide the mental, recreational and social stimulation required to maintain good physical, mental, emotional and social health.

Additionally, finding accessible buildings and transportation services to allow people to function independently and participate in their communities is also a challenge for some Canadians. There are many gaps in daily transportation services in cities and regions across the country. In many cities across Canada these systems are fraught with issues such as inaccessibility for those with mobility restrictions, inconvenient booking requirements (i.e. having to book days or weeks in advance), limited service availability, constant delays in service provision, and limited hours of operation. Accessible buildings also pose a challenge for many. Although Canada overall does very well in considering accessibility issues in the design of new buildings, many buildings continue to be inaccessible to people with mobility restrictions and seemingly small issues such as lack of door-opening buttons, placement of towel dispensers and the location of accessible doors provide significant barriers to active participation in community activities.

Access to health promotion information and services also emerged as an important QOL priority, particularly for those diagnosed with MS. Participants speak about the importance of maintaining an active lifestyle through participation in programs to improve physical, mental, emotional and spiritual wellness. Participation in these programs is limited by a lack of information about what is available, lack of government support in this area, financial constraints, MS symptoms including fatigue and reduced mobility, and programs not suited to those with MS.

Given the chronic and potentially debilitating nature of MS combined with the fact that many people with MS are unable to work, the economic barriers presented by this disease are also significant. Participants prioritized getting adequate financial help as important to QOL. Many people with MS ultimately have to rely on income replacement programs or other financial support services to survive. These programs do not provide a sufficient income and are difficult to access for many who need them.

Finally, both people with MS and their close family and friends believe that supports for family members and caregivers are an important QOL priority. People with MS do not want to be a burden on their families and they worry about how living with MS affects the QOL of their whole family in a negative way. There is no structured support system in place specifically for caregivers nationally or provincially. Many caregivers are unable to find the supports they need both for themselves or to help them care for their loved one with MS. Respite care services are limited and caregivers face similar system navigation challenges to find information and support related to QOL.

Canadians affected by MS look to the MS Society of Canada as an important leader. Levels of engagement with the MS Society are high, programs and services are offered across the country and the organization is currently an important and valued source of information for people affected by MS; thus, positioning the organization to play an important role in improving and advocating for the overall quality of life of Canadians affected by MS.
Background

In 2012, the MS Society of Canada launched an initiative to obtain the perspectives of Canadians affected by MS. Through the counsel of an Advisory Group combined with input from Society staff, a multi-pronged evaluation (including a web-based survey, online poll, environmental scan and focus groups) was designed to gather information and seek input from Canadians affected by MS. The overall goal of the initiative is to increase the MS Society’s understanding of current quality of life (QOL) needs, priorities, gaps and barriers experienced by Canadians affected by MS. The evaluation did not, however, focus on programs and services currently offered by the MS Society of Canada to improve QOL.

In general, quality of life refers to the physical, mental and social well-being of an individual. In a healthcare context, it moves beyond a disease-focused approach to a more complete view of an individual’s experiences and needs, with focus on issues such as independence and empowerment, access to healthcare, employment, education and other factors that contribute to a person’s sense of well-being and participation in life. Within this framework, the Multiple Sclerosis International Federation (MSIF) researched and developed ten principles to improve QOL of people with MS. Although the principles include health care, they reach beyond medical care to a broad range of other domains including employment, housing, education and accessibility. The principles are designed to guide the development and evaluation of services and programs for people with MS. Accordingly, the MS Society of Canada used these principles in the development of all aspects of this evaluation initiative.

The MS Society of Canada will use the information gathered to inform its mission-related decision-making. Specifically, the results of this initiative will enable the MS Society of Canada to:

1. Understand the characteristics and 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 QOL 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; and
3. Develop recommendations with respect to what the organization is able to do within the confines of its mission and directions set by Momentum and Renewal, either directly through programs and services or indirectly through advocacy, in order to enable Canadians affected by MS to have their QOL needs met.

The initiative considered a broad range of people for consultation. Anyone meeting the following criteria was included in the initiative: 1) those diagnosed with MS/CIS; 2) persons awaiting a diagnosis with respect to MS; 3) informal caregivers of a person with MS; and 4) family members or close friends of people with MS.

Methodology

There were four distinct components of this evaluation: 1) an online poll administered through a market research company; 2) an environmental scan; 3) a web-based survey administered by the MS Society; and 4) focus groups. Each component is described briefly below. All of the data from each component of the initiative has been analyzed and summarized in this report. For more detailed information and the specific results for each prong, please refer to the full report that has been produced for each one.
1. **Online Market Research Poll**
   An online poll was conducted by Leger Marketing from November 13-18, 2012. The sample for this survey came from Leger Marketing’s central database (referred to as a panel) of Canadians who have consented to participate in surveys. Leger Marketing has profiled panel members by disease (e.g. MS) to allow for targeted recruitment. Canadians who met the criteria (as noted previously) were invited via email to complete the survey online. A total of 542 respondents completed the survey: 67% diagnosed with MS or CIS, 17% with a close relationship to someone with MS, 3% waiting for a diagnosis of MS and 13% caregivers of someone with MS. A probability sample of this size would yield a margin of error of +/- 4.2%, 19 times out of 20.

2. **Environmental Scan**
   An environmental scan was conducted to examine Canadian legislation and regulations that impact QOL issues for people affected by MS. A variety of data collection methodologies were utilized including document reviews (internal and external), web searches, web-site reviews and analysis, and key informant interviews. Documents were identified through broad-based and key-word Internet searches, the MS Society web-site and archives, internal organization reports, personal referral and community resource databases. Other environmental scans were accessed to source additional references. A total of 17 key informant interviews were conducted with staff, volunteers, health professionals and people affected by MS.

3. **Web-based Survey**
   A web-based survey was conducted from November 26, 2012 to January 19, 2013 on the MS Society’s web site. Respondents included Canadians affected by MS (as defined previously) who were recruited through community outreach, Facebook and Twitter postings, MS Society division newsletters, direct email invitations, and other Society promotional vehicles. Hard copies of surveys were also available to be completed and returned by mail. A total of 5497 Canadians participated in the survey: 72% diagnosed with MS or CIS, 2% awaiting a diagnosis of MS, 22% with a close relationship to someone with MS, and 4% caregivers of someone with MS. A probability sample of this size would yield a margin of error of +/- 4.2%, 19 times out of 20.

4. **Focus groups**
   Eight focus groups were conducted (one in each division) across Canada: one with caregivers, six with people diagnosed with MS and one with young adults affected by MS. A total of 68 participants were recruited locally through division and chapter offices using a variety of methods including word of mouth, posters and flyers in MS clinics and chapter offices, and direct requests. Care was taken to ensure a wide range of demographic representation so that each group was balanced for gender, age, type of MS, length of time living with MS, cultural backgrounds and degree of disease progression.

The initial purpose of the online poll was to contact people affected by MS who did not have a relationship of any kind with the MS Society of Canada. We were surprised to find only 15% of the survey and 8% of the poll respondents reported that they have not been in touch the MS Society in the past year. And given that the web-based survey respondents were self-selected, there is a possibility our results may not be representative of all persons affected by MS. However, the large sample size, and consistency across all four components of the initiative provide us with greater confidence that the results reflect the views of the Canadians affected by MS.

This report provides an overview of the findings from all four components of the initiative. The results from each component were collated, compared and summarized for this report. The key findings of the poll and survey were compared, triangulated, and summarized together with the results from the focus
groups. Additionally, the gaps identified in the environmental scan were compared with those identified from the poll, survey and focus groups and have also been summarized in this report. Appendix A provides a visual overview of the analysis approach taken for the Listening Initiative. Appendix B provides a summary of the results of each component for every QOL priority.

Results

Demographic Profile
Over 60001 people affected by MS were consulted through the four components of this initiative with the bulk participating through the online poll and the web-based survey. The demographics of the online market research poll and web-based survey samples are different in a few areas. The survey respondents are slightly younger: the average age of the survey respondents is 50 years and 52 years for the poll respondents. A greater proportion of the survey respondents are in the workforce while more of the poll respondents are on long-term disability and are retired. However, across the two samples, almost half of the respondents work full or part-time (or 42% of survey respondents with MS), less than a quarter are retired and just over a quarter are on long or short-term disability. This reflects findings from other studies that a small proportion (20-45%) of people with MS remains employed following diagnosis (Pompeii et al., 2005; Fraser, Clemons & Bennett, 2002). Approximately three quarters (75% for survey; 69% for poll) are female, and the majority (72.5% for survey; 67% for poll) has been diagnosed with MS. There are slightly more caregivers in the poll sample. Of those diagnosed with MS, about half are diagnosed with relapsing-remitting MS and a third indicates a diagnosis of a progressive form of MS. An equal number of respondents with MS have lived with the disease for up to 5 years, 6 to 10 years, or more than 20 years. The greatest number has lived with MS for 11 to 20 years. Almost all respondents live in a private residence either alone or with family; a small minority lives in long term care or in supportive housing. Respondents are primarily from urban areas.

Figure 1. Demographic profile of on-line poll and web-based survey respondents.

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>Poll Respondents</th>
<th>Survey Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>31% male; 69% female</td>
<td>24% male; 76% female</td>
</tr>
<tr>
<td>Age</td>
<td>Average age = 52 years</td>
<td>Average age = 50 years</td>
</tr>
<tr>
<td></td>
<td>18-34 yrs = 9%</td>
<td>18-34 yrs = 15%</td>
</tr>
<tr>
<td></td>
<td>35-44 yrs = 15%</td>
<td>35-44 yrs = 21%</td>
</tr>
<tr>
<td></td>
<td>45-64 yrs = 62%</td>
<td>45-64 yrs = 53%</td>
</tr>
<tr>
<td></td>
<td>65+ yrs = 14%</td>
<td>65+ yrs = 10%</td>
</tr>
<tr>
<td>Employment Status</td>
<td>36% employed</td>
<td>42% employed</td>
</tr>
<tr>
<td></td>
<td>29% receive LTD/STD</td>
<td>25% receive LTD/STD</td>
</tr>
<tr>
<td></td>
<td>23% retired</td>
<td>16% retired</td>
</tr>
<tr>
<td>Relationship to MS</td>
<td>67% diagnosed with MS/CIS</td>
<td>72% diagnosed with MS/CIS</td>
</tr>
<tr>
<td></td>
<td>17% family/friends</td>
<td>22% family/friends</td>
</tr>
<tr>
<td></td>
<td>13% caregivers</td>
<td>4% caregivers</td>
</tr>
<tr>
<td>Type of MS</td>
<td>46% RRMS</td>
<td>55% RRMS</td>
</tr>
<tr>
<td></td>
<td>37% progressive (all types)</td>
<td>31% progressive (all types)</td>
</tr>
<tr>
<td>Years Since Diagnosis</td>
<td>1-5 yrs = 20%</td>
<td>1-5 yrs = 24%</td>
</tr>
<tr>
<td></td>
<td>6-10 yrs = 17%</td>
<td>6-10 yrs = 23%</td>
</tr>
<tr>
<td></td>
<td>11-20 yrs = 38%</td>
<td>11-20 yrs = 30%</td>
</tr>
<tr>
<td></td>
<td>20+ yrs = 23%</td>
<td>20+ yrs = 23%</td>
</tr>
</tbody>
</table>

1 Most of these are unique; however, a small proportion may have participated in more than one component of the initiative. For instance, a person may have completed the web-based survey and participated in a focus group.
Quality of Life
The focus group participants were asked to describe what a good QOL means to them. The themes from these discussions were identical across the country and reflect the Multiple Sclerosis International Federation (MSIF) QOL principles. The participants speak about the importance of maintaining independence and autonomy; not wanting to be a burden to family and friends; having the freedom to make lifestyle choices and to participate in community life; and feeling ‘normal’. Additionally, having the financial freedom to make choices, access treatments, and remain active and mobile is essential. Finally, the recognition that expectations and goals need to change over time was also seen as vital to maintaining a positive quality of life.

The survey respondents were asked what worries them most about having MS in their life. The responses to this question were consistent across all demographic variables and client groups (i.e. those diagnosed with MS, caregivers and those close to someone with MS) and reflect findings from other research (Finlayson, 2004). The greatest worries for people affected by MS include the impact that MS has on the entire family, what the future will bring, increased levels of disability, overall QOL and the loss of independence. Being a burden to one’s family is a major worry for people diagnosed with MS. Many speak about the loss of QOL for the whole family as a result of MS. Respondents also worry about the unpredictability and the uncertainty of the future as well as the progression of their disease over time. Concerns about loss of mobility, losing vision and the cognitive impact of the disease are also issues for people affected by MS. Additional worries include the financial impact of the disease and the impact of caregiving on loved ones.

“I am mostly worried about my future. 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 and the impact all of this on my loved ones.”

Despite these worries, the respondents generally report a high QOL, with three quarters of poll and survey respondents reporting that their QOL is good or better. This finding is not surprising as other studies have found that, while physical functioning can decline and be severely and negatively affected by chronic disease and age, mental health remains relatively high and stable (Hopman et al., 2009; Mavaddat et al., 2011). Accordingly, overall health-related QOL remains similarly positive and stable for those with chronic diseases.

Caregivers report approximately the same QOL as those diagnosed with MS. On the other hand, those who have a close relationship to someone with MS report a significantly better QOL: they are twice as likely as caregivers and those diagnosed to report an excellent QOL. Figure 2 shows the self-reported QOL ratings for the survey respondents.
**MS-Related Symptoms and Quality of Life**

The respondents with MS in the poll and survey report a variety of MS-related symptoms with fatigue being the single greatest challenge: the greatest number of respondents indicated fatigue as one of the most problematic symptoms that has affected their daily QOL. Mobility, balance and walking problems affect approximately half of respondents, and are a particular concern for older respondents. Physical symptoms such as numbness and tingling affect the daily QOL for more than one third of the respondents. Other problematic symptoms include pain, bladder problems and cognitive issues. The focus group respondents noted that the ‘invisible’ symptoms (e.g. fatigue, pain, cognitive problems, etc.) of MS are very problematic as they are not visible to others, yet bring daily challenges that have a significant impact on QOL. Figure 3 provides the survey findings to the question “What three MS symptoms have had the greatest impact on your day-to-day QOL in the past year?”. 
Analysis of the survey data found that respondents who indicated that they need mobility supports, even just occasionally, report a lower QOL. Furthermore, those who indicated they require help from another person to remain mobile also report a lower QOL. This reflects findings from other research that mobility impairment may contribute to declines in QOL in MS patients (Coleman et al., 2013). Overall, it appears that the symptoms of MS themselves are the greatest obstacle impeding people’s ability to meet their most urgent QOL needs. One in five poll respondents’ most urgent MS-related needs are associated with issues of balance, walking and general mobility. The survey respondents were asked to identify the most important or urgent MS-related needs or problem they needed help with over the past year. The greatest need identified is the management of MS symptoms such as dealing with fatigue, chronic pain, depression, issues with balance and mobility and generally relapse management. This is reflected in the focus group discussions when participants were asked if they could have anything, what they would most like that would improve their QOL and the responses were resoundingly consistent: a cure for MS.

**Quality of Life Priorities**

Poll and survey respondents were asked about their long-term and short-term priorities regarding their QOL. With respect to the long-term priorities, respondents diagnosed with MS prioritize the following:

- access to medical care;
- being able to make decisions about treatment and managing MS;
- having support for family members and caregivers;
- being able to find information and services that encourage physical, emotional, mental and/or spiritual wellness;
- getting financial support related to disability; and
- getting services that allow them to be as independent as possible.

There are important differences between the priorities of respondents with relapsing-remitting MS and those with progressive forms of MS. Both groups identify access to medical care as their top priority; however, those with progressive MS place greater importance on services for independence, accessing
buildings and being part of their communities. Additionally, there are differences in the priorities between those with MS, caregivers and people close to someone with MS. People with MS indicate their main QOL priorities are access to medical care; being able to make decisions regarding treating and managing MS; support for family members and caregivers; being able to find information and services that encourage physical, emotional, mental and/or spiritual wellness; and being able to be part of the community where I live. In contrast, caregivers prioritize more practical concerns: getting services that allow the person with MS to be as independent as possible; having support for family members and caregivers; access to medical care; being able to enter and exit buildings easily, both public and private (e.g. accessible buildings); and getting financial help. Those close to someone with MS (i.e. family/friends) prioritize similar issues as caregivers with a few differences. They prioritize services for independence, support for family and caregivers and access to medical care. However, they also prioritize finding information and services that encourage physical, emotional, mental and/or spiritual wellness and being able to make decisions about treating and managing MS.

Figure 4. QOL priorities broken down by client group i.e. Persons with MS, caregivers, family/friends (taken from web-based survey findings)

When the survey respondents were asked about the priorities that would improve their quality of life today or in the short-term, the greatest priority is finding a cure for MS or repairing the damage and reversing the effects of the disease. Secondary to this, respondents once again indicate that financial support (i.e. to cover cost of care, retirement, home renovations, medications and treatment), access to medical care and treatment/medications (and improved quality of care), information (regarding MS, treatment, and supports/services) and information and access to supports and services for people with MS and their family/caregivers are important priorities.

The desire to find the cure for MS was reinforced by the survey respondents’ perspective on the investment of the MS Society’s resources. When asked to imagine that they had donated $100 to the MS Society and to explain how they would allocate the money between two categories: research and programs, services and government relations, respondents would allocate, on average, $60 to research and $40 to programs, services and government relations. Half of the respondents would allocate the
majority to research, just over one third would allocate the funds equally between the two categories, and 14% would allocate the majority to programs, services and government relations.

Gap Analysis: Unmet QOL Needs
Several key areas of unmet QOL needs emerged from all four components of the evaluation. Five key areas of need were identified: 1) health care; 2) financial support; 3) accessible buildings and transportation; 4) employment supports; 5) support for caregivers.

1. Health Care
There are several key areas of unmet need within the scope of health care. The first relates to navigating the health care system and accessing quality medical care services. Survey and focus group respondents report challenges finding new doctors and neurologists, and getting timely referrals and access to medical tests. They describe the need to self-advocate and to speak up, ask questions, demand services, call around and push for what they need or want. Every focus group suggested that a toll-free hotline that provides some type of system navigation or caseworker-type support would be greatly valued and would improve their quality of life. The participants suggested this service could provide information, referrals, advice or input on quality of life programs/services that might be valuable. Although some participants indicate they have received information from their local chapter of the MS Society, they still express a need for greater support. They discuss the need for assistance with system navigation and experts who can help determine what they need, and then help them find programs and services to meet that need.

“I want one-stop shopping. So many services are offered by different organizations but I want to contact one person to find out about it all.”

Access to information, services and treatments for MS is a gap for a proportion of people in Canada. One fifth of survey respondents do not have access to information and advice about MS. Just over one quarter indicate that they do not have access to disease-modifying treatments, symptom management medications and rehabilitation services approved in Canada and almost one third do not have access to treatments, programs and services whether they can pay for them or not. Given the chronic and debilitating nature of this disease combined with the fact that many people with MS are unable to work, the economic barriers to accessing these therapies can be difficult to overcome. The scan found that not all people with MS in Canada have access to the same programs and services through the MS Clinics or healthcare professionals. Services available vary significantly by region and many are not available in rural areas. Additionally, prescription drug coverage for disease modifying therapies and symptom management medications for MS is not universal across the country resulting in uneven access to and compensation for these treatments.

“With the physical changes I was experiencing, I was looking for a physiotherapist. I couldn’t get pointed to one, even when I called the MS Society.”

Satisfaction with the quality of care is not very high. Only 61% of survey respondents feel their doctor is knowledgeable about MS all or most of the time. Additionally, almost one third feel that their healthcare team does not care about their well-being and 22% indicate they did not receive the support they needed from their health care professionals when they first learned they had MS. The focus group participants and survey respondents commented on the poor quality of care they often receive:
neurologists do not take enough time to give advice; long waits for appointments; finding qualified physiotherapists with knowledge of MS; failing to help them understand if certain symptoms are MS-related; and poor medical support, particularly for those with progressive types of MS.

“I felt like I had to babysit my doctors, remind them about things. You have to be an advocate for yourself always.”

Access to age-appropriate long-term care facilities is another area of unmet need. For a small proportion of people with MS, limited housing and care choices combined with a reduced income and need for specialized care may result in younger adults having to reside in institutional care facilities. The scan found that the majority of long-term care facilities are not well-suited to younger adults who are busy and engaged in employment, volunteer work, social and recreational programs. There are often limited opportunities in these facilities for them to participate in these activities and to remain engaged in their communities. Although residents of long-term care facilities were under-represented in this initiative, only one-third of survey respondents agree that other people their age live in the same long-term care facility where they live and even fewer indicate that their long-term care facility provides activities and supports that engage and interest them. This sentiment was echoed in the focus group discussions where participants identified the lack of availability of age-appropriate long-term care facilities as a significant gap in the health care system. The scan indicated that this lack of age-appropriate care often results in depression, anxiety and longer-term mental health issues. Broader MS research supports these findings. Studies have found that while residents with MS are typically younger at admission than most nursing home residents they are often more physically dependent but more cognitively intact (Buchanan et al., 2001; Buchanan et al., 2002; Buchanan et al, 2003). This research concluded that nursing homes for residents with MS should provide services and programs including mental health care that address the specific needs of these younger residents.

“There is no facility for younger adults in the entire province where you could be looked after appropriately.”

Home care services in Canada are also not meeting the needs of people affected by MS. Although 83% of respondents indicate they feel they have the support they need to stay in their homes, only 22% of the survey respondents diagnosed with MS report receiving care at home from a paid or unpaid caregiver and respondents note that accessing special assistance for personal care (including dressing, bathing, transferring between bed and wheelchairs, personal care and grooming) as well as for help around the house (including home cleaning, yard work, laundry, meal preparation, groceries, etc.) is a significant challenge. This need is felt particularly strongly by caregivers, with over one third of the poll caregiver respondents indicating this is a significant need. Similarly, the scan revealed gaps in the current home care system. Home care services across Canada vary considerably by region, have long wait times, and limited access. Furthermore, home care programs tend to focus on the provision of acute care services, leaving people with chronic diseases and long-term needs for care without assistance. Many of the services required by people with MS, such as homemaking, dressing, and bathing are often not provided. Many of the focus group participants who are receiving home care talk about the poor quality of service they receive and express great frustration with the difficulties in having their needs met through the current home care system.
Health promotion information and services emerged as an important QOL priority for people affected by MS. Focus group participants spoke about the importance of exercising in maintaining their physical and mental health. Research supports the cardiovascular, muscular strength and endurance benefits of exercise for people with MS and promising evidence is emerging that exercise may reduce depression and fatigue, and have positive effects on cognitive status, QOL and disease progression (Smith, 2012; Motl and Snook, 2008; Heesen et al., 2006). However, there appears to be a gap in the current system with respect to health promotion information and programs. The environmental scan indicated that the federal and provincial governments provide minimal leadership and no direct services/programming regarding health promotion and MS. The focus group participants discussed the challenges of finding and accessing fitness and other health promotion programs that are suitable to their needs as someone living with MS. They also discussed the financial constraints that limit their ability to participate in health promotion programs. Timing of programs is also an issue. Fatigue is a significant barrier to participation for people diagnosed with MS. Additionally, almost one third (31%) of the survey respondents indicates they do not have access to information and advice about exercise, nutrition, and ways to manage stress.

2. Financial Support
Respondents identified maintaining employment, accessing financial support and managing the high costs of this disease as a challenge. This is consistent with research that shows multiple sclerosis seriously affects the economic life of those diagnosed, even within a few years of onset (Pfleger et al., 2010). The survey and focus group participants note the challenges of paying for medication, services, equipment, treatment and transportation. Many indicate that they need more money and have difficulty navigating the system to find financial support, be it for medications, income replacement, or claiming tax deductions related to disability. Almost one third (30%) of survey respondents indicate that they have relied on financial help outside of their own personal resources to help with issues linked to MS over the past year. For those with progressive MS, this number is even higher and many have had to rely on federal income supports. Over half of the survey respondents answered questions about disability entitlements. Of these respondents, only half (51%) indicate that their disability benefits (public or private) allow them to maintain a standard of living that is good enough and 42% indicate they find it difficult to get financial assistance for MS related issues. These gaps are confirmed by the findings of the environmental scan. Federal and provincial income support programs do not recognize or accommodate the needs of people with episodic diseases for flexible work options and income support.

Qualifying for these programs is challenging for people with MS due to the episodic nature of the disease. Complicated application processes, requirements for numerous verified medical forms, and strict eligibility criteria pose significant problems for respondents. Additionally, part-time employment is not well supported and subsidies provided are inadequate. Taken together, it seems clear that the current income replacement subsidies are not sufficient to allow a person to live a good QOL.
“You can’t live off of the CPP-D amount. And you can’t really work because they take the little they are giving you away if they find out you are earning money somewhere else. So you get stuck in a bad cycle that you can’t get out of.”

3. Accessibility
Despite Canada’s Charter of Rights that prevents discrimination on the basis of disability, a proportion of people affected by MS still do not have access to transportation and buildings (both public and private). Almost 40% of survey respondents do not have access to equipment and technology that they can afford and that helps them maintain their independence (such as mobility aids and modifications to their car and home). While the majority of survey respondents indicated that transportation issues do not apply to them, for those to whom it does apply to, there are significant unmet needs. For instance, 40% of survey respondents to whom the statement applies, indicate that transportation services where they live do not allow them to travel around as they need to. Additionally, 27% of the survey respondents to whom it applies indicate that their car has been modified so they can still drive it.

Clearly, for those with mobility limitations, accessible transportation can be a problem. The scan found that while all of the larger cities across Canada provide accessible transit options, in many cases these options are limited and do not always meet the needs of people with disabilities. Not all public transit vehicles are accessible to people with mobility restrictions. The convenience and accessibility of door-to-door accessible transit services vary greatly across Canada. These services require reservations, sometimes days or weeks in advance. Services are limited to certain hours, are often delayed (resulting in long wait times for pick-ups and returns), and may be restricted to only those requiring travel to medical appointments, leaving out those trying to get to employment, volunteer work or other community activities. Application processes can be time-consuming and require additional medical documentation. Travel between regions is challenging as very few transit systems work together to provide seamless travel between municipalities. The focus group participants shared many stories about the lack of accessible transit systems.

“You have to plan very far ahead to book the handi transit. And you have to call at inconvenient times and try several times before you can get through. It often isn’t worth the bother. But then I don’t get out. So what do you do?”

Accessible buildings, particularly for programs and services such as restaurants, fitness programs, and recreation centres, is another area that presents gaps for Canadians affected by MS. This issue was discussed by the focus group participants who indicated that many of these programs/services are not available to them because the buildings are not fully accessible. The scan found that many buildings and spaces are not accessible to people with disabilities. Building codes govern this accessibility through minimum standards that are not highly specific so many issues ‘fall through the cracks’ such as the height of sinks, towel and soap dispensers, and the location of wheelchair accessible doors and ramps which may not be convenient. Additionally, these codes only apply to new buildings and larger renovations, leaving many existing structures inaccessible. Considerations such as the use of interlocking brick, uneven walkways, and poorly designed stores create daily challenges for those with restricted mobility. All of these issues have a significant impact on a person’s daily life, their ability to get around and stay active in their community; ultimately, having a negative impact on their QOL.
“These architects do not really know what accessible means. It is about more than the size of the stall in the bathroom”.

4. Employment Supports
MS is most often diagnosed during peak years of employment and many people with MS have to leave the workforce because their symptoms make maintaining employment a challenge (Pompeii et al., 2005). In fact, survey respondents with MS who receive long term disability or short term disability are more likely to be aged 44 to 64 years old and therefore still in their prime working years. The scan found that accommodations for people with MS in workplaces across Canada vary greatly. Only half (54%) of the survey respondents to whom it applies, indicate their workplace makes accommodations so that they can still work despite MS. Only 42% of caregivers and those close to someone with MS (to whom this applies) indicate that their boss gives them time off, as needed, so they can care for the person with MS in their life. The focus groups reflect these findings. There were mixed reviews regarding employers accommodating the needs of people with MS. Some told stories of employers who were very accommodating and made many adaptations while others had the opposite experience. Similarly, some caregivers spoke about very understanding employers accommodating the need for time off to provide care while others did not have very understanding or accommodating employers.

“My employer was understanding but a little bit intimidated – they didn’t know what to do. I went in prepared to ask for what I needed. This is where the MS Society can help us.”

Research indicates that people with MS who are working report being healthier, more financially secure, more socially active and experiencing better QOL than those who are unemployed (Sweetland et al., 2012) thus maintaining employment is particularly important. However, vocational training programs in Canada do not appear to be meeting the needs of people diagnosed with MS. Among survey respondents, for those who tried this type of program, 37% indicate that support at work or support to find work was not at all helpful. The scan found that the orientation of these programs tends to be towards re-training and re-employment as opposed to workplace accommodation, making them less suitable for many people with MS. Additionally, most of these programs are linked with income replacement programs so many people with MS are unable to access them. Other issues such as a lack of awareness of these programs, lack of qualified staff and long waiting lists also limit the ability of these services to assist a large proportion of people affected by MS. The comments from the focus group participants suggest that employment counseling is a critical gap in the current system. Participants feel that counseling is required to help people with MS find employment that will work in light of their disease symptoms and to help employers find alternative work arrangements that are suitable for everyone. Support and advice are required in disclosing an MS diagnosis, particularly in terms of when and how. For younger people diagnosed with MS the need for counselling is more important as many are still in school and will be seeking employment, feeling unsure about what type of work to look for and how to talk to potential employers without fear of discrimination because of their diagnosis.

“A lot of companies want to hire disabled people. But how do you find them? We need a job developer who understands MS to help people find jobs.”
5. **Support for Caregivers**

Although support for family members and caregivers is clearly an important priority to the participants, caregivers do not appear to be well supported. Less than half (45%) of the survey respondents and even fewer (23%) of caregiver respondents indicate they can find the support they need as a caregiver or family member of someone with MS. Similarly, only 21% of survey respondents who are caregivers or close to someone with MS indicate they have access to professional help and evaluations to deal with the physical and emotional stress linked to caregiving and 77% do not have access to respite services that allow them to take breaks from caregiving. This gap in services was also clearly identified in the environmental scan. The scan revealed that there is no structured support system in place specifically for caregivers nationally or provincially. Any available programs and services are community-based and offered by charities and other non-profit organizations. Caregivers face numerous issues: those forced to leave work to care for a loved one lose not only their income but also contributions to CPP; employers are not required to continue employment benefits for those taking a caregiver leave; navigating the maze of services available is challenging and most services must be paid for out-of-pocket – a challenge for those already struggling financially. Across the country, respite care services are limited and difficult to access, either in-home or in facilities or day programs. These gaps were echoed in the focus groups from both caregivers and those diagnosed with MS. Both groups feel that caregivers need to find a balance between providing care, advocacy and support, and meeting their own needs and taking care of themselves. They also talk about the lack of quality and readily available respite care services, both for overnight stays but also daily or hourly services to allow caregivers a break and time to address their own needs. Survey respondents echoed this finding with 37% of those who have tried respite or short-term care programs indicating that these programs were not helpful.

“When you have MS, the whole family has MS.”
**Barriers to Meeting Needs**

Poll and survey respondents were asked about the particular barriers that have prevented them from meeting their most urgent or recent MS-related needs or problems. The main barriers are: the lack of financial support; problems coping with MS in my life; and MS symptoms getting in the way. Poll respondents also note the lack of government support, which is a particular concern for caregivers. The focus groups confirm these findings as the issues of financial support and having MS itself were major points of discussion among the participants.

**Figure 5. Barriers to meeting needs (taken from on-line poll findings).**

What prevented you from meeting your most urgent MS-related needs in the last year?

- **MS symptoms getting in the way**: 44%
- **Ability to pay for what is needed**: 32%
- **Lack of governmental support**: 31%
- **Struggle coping with MS in my life**: 26%

Additionally, almost one fifth (19%) of the survey respondents indicated that they did not know where to go for help. This was even more strongly noted by the focus group participants who talked a lot about the challenges of finding the right information at the right time and not knowing where to go. There is a feeling among the participants that, although there is a lot of information out there, finding it can be challenging. They feel you have to seek out what you need, that the information is not all in one easily accessible place. The participants talked about having to advocate for yourself, to use word of mouth to learn about programs and services and the amount of time they have to spend finding the specific information they need. When the focus group participants were asked what they would most like to have to improve their quality of life, after the cure for MS, the second most popular response was an MS hotline that would provide information, advice, referral and system navigation all at one place. They would like one place to call that would meet all their information and support needs, including programming to improve QOL.

> “I would like a system navigator. Someone to guide me in dealing with the health care system and obtaining access to services.”
**The MS Society**

The survey and poll respondents were asked where they obtain their information about MS. The results are resoundingly clear: health care professionals are the top source (61% of survey and 52% of poll respondents) followed by the MS Society of Canada website (45% of survey; 43% of poll respondents). In addition to the MSSC website, MS Society staff or volunteers are a source of information for 17% of survey and 11% of poll respondents. MS clinics are the third most frequent (34% of survey; 32% of poll respondents) source of information and an equal proportion indicate that online news stories are important sources of information about MS.

![Figure 6. Sources of information about MS (taken from web-based survey findings).](image)

The poll also asked respondents to indicate which sources of support have been most effective in meeting their needs and the results show that personal networks and health care professionals inside and outside of MS clinics are perceived as the most effective sources of support. The MS Society of Canada ranks as the fifth most effective source after unpaid caregivers. Those with the highest use of MS Society programs and services are more likely to highlight the MS Society of Canada as an effective source of information.

The overall level of involvement with the MS Society of Canada is quite high among Canadians affected by MS. Two thirds of the poll and survey respondents have visited the MS Society web site and many have donated (63% of poll; 52% of survey respondents). The majority of the poll and survey respondents indicate that they have not needed any programs or services over the past year. While a third of the caregivers from the poll echo this sentiment, the same proportion indicates that the MS Society programs and services do not meet their needs. Additionally, one quarter of the poll respondents but fewer survey respondents indicate that they were unaware that the MS Society offered programs and services of relevance to them. This was supported by some of the focus group participants who were surprised to hear about the availability of some MS Society programs and services. There were also a small proportion of respondents who indicate dissatisfaction with the MS Society.
**Use of MS Society Client Services**

Poll and survey respondents were categorized into levels of client services (CS) usage based on a screening question which asked to identify any MS Society programs and services they had used within the past year. The levels of CS use categories range from no use to maximum use of programs and services. According to the survey and poll results, the greatest proportion of respondents falls into the low use category (about one third) with the least number reporting maximum use of services. Figure 7 below provides the breakdowns by each category from the poll and survey samples.

**Figure 7. Proportion of respondents in each Use of Client Services category (from on-line poll and web-based survey findings).**

The profile of each usage group varies (based on survey results) and is described below with the definition of each level:

- **No Use of CS** - Respondents indicated that, while they had not used client programs and services within the last year, they still had a relationship with the MS Society as they may have participated in any of the following activities: MS Walk/Bike, other fundraising events, volunteered or made a donation. This is a young group (average age 50 years) who report the highest QOL. Most (60%) are employed either part or full-time. The group includes the greatest number of respondents who are close to someone with MS. Those living with MS in this group are more likely to have been diagnosed with relapsing-remitting MS in the last 5 years and live at home with others. The majority do not receive care from a caregiver although one-fifth (22%) indicated the need for this type of care. This group is most likely to report they have not been in touch with the MS Society in the past year.

- **Some Use of CS** - Respondents may have participated in any of the activities noted previously (i.e. participation in MS Walk/Bike, other fundraising events, volunteer, made a donation) plus they also accessed information from the MS Society via print and/or online newsletters or publications and/or they visited the Society’s website for information.
This group has a similar demographic profile to the previous group: younger (average age 49 years), employed, and reporting a higher QOL. Most (70%) have MS and almost one quarter are family members or close to someone with MS. Those with MS in this group are more likely to have been diagnosed with relapsing-remitting MS in the last 5 years, with about one quarter reporting progressive MS. The majority does not receive care from a caregiver and report the lowest need for this type of care. This 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 client services).

- **Moderate Use of CS** - Respondents fell into this category if they may have answered yes to involvement with the previous activities as well as if they contacted the MS Society for information/support/referrals and/or received in-person information/support/referrals.

Similar to the previous groups, this group is younger (average age 49 years). However, less than half are employed and one third receive LTD or STD. They reported a slightly lower QOL than the previous group. Three quarters of the respondents in this group have MS and there are more caregivers. For those with MS, most have relapsing-remitting with one-third reporting progressive MS. Over half have lived with MS for 1-10 years and the majority does not receive care at home. Almost half (45%) reported a need for more care (they are either not receiving care or not receiving enough care). This group is more likely than the respondents reporting no use or some use of client services to be a member of the MS Society.

- **Considerable Use of CS** - Respondents may have participated in any of the previous activities as well as attended an MS Society presentation, workshop or conference (in person, online or on the phone), participated in an MS Society exercise/recreation/social program (e.g. yoga, holiday dinner, swimming, Tai Chi), and/or attended an MS Society support/self-help group or peer support.

This is an older group (average age is 54 years) with the greatest number of retirees (23%). However, many are still in the workforce or receiving LTD: 36% are employed and 36% receive LTD. They report a good or very good QOL but are less likely to report an excellent QOL. The majority has MS with an increasing number indicating a progressive form and has a larger number who have lived with MS for over 20 years. One quarter receives care and they are the largest group to indicate that they receive enough care. This group is more likely than the previous groups to be members of the MS Society and have donated money to the MS Society in the past year. They are also more likely to have volunteered in a non-fundraising capacity, be involved in other MSSSOC fundraising events and have participated in the MS Walk. They are as likely as the substantial users to have volunteered at a MSSOC fundraising event.

- **Substantial Use of CS** - Respondents in this category participated in any of the previous activities and received financial assistance or equipment provision (loan or purchase), or special services (snow removal) from the MS Society.

Similar to the previous group, this group is older (average age 53 years) and fewer are still working: less than one quarter is employed and one quarter is retired. They have the greatest number of people receiving LTD/STD at 53%. This group has the greatest number of people with MS and has one of the largest proportions of caregivers. They report the lowest QOL of all the groups. Those with MS have lived with the disease the longest and over half indicated they have a progressive form. Although two-thirds report living with others, over one quarter indicated that they live alone. Half receive care and half indicated the need for more care (they are either not receiving care or not receiving enough care). Similar to the previous group (substantial users), they are highly involved in the MS Society in a number of ways. They volunteer for the MS Society in a fundraising and/or non-fundraising capacity and
participate in other client services programs such as exercise programs, presentations or workshops and peer support groups.

**Figure 8. Summary of the demographic profile of the Use of Client Services Categories (taken from web-based survey findings)**

<table>
<thead>
<tr>
<th>Demographic</th>
<th>No Use</th>
<th>Some Use</th>
<th>Moderate Use</th>
<th>Considerable Use</th>
<th>Substantial Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age</td>
<td>50 years</td>
<td>49 years</td>
<td>48 years</td>
<td>54 years</td>
<td>53 years</td>
</tr>
<tr>
<td>QOL (self-report)</td>
<td>Highest QOL</td>
<td>High QOL</td>
<td>Good QOL</td>
<td>Good QOL</td>
<td>Lowest QOL</td>
</tr>
<tr>
<td>Employment Status</td>
<td>Employed</td>
<td>Employed</td>
<td>Employed/LTD</td>
<td>Retired</td>
<td>disability</td>
</tr>
<tr>
<td>Client Category</td>
<td>Family/friends</td>
<td>70% MS</td>
<td>&gt;caregivers</td>
<td>MS</td>
<td>MS &amp; caregivers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>25% family/friend</td>
<td>RRMS</td>
<td>Progressive</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RRMS 1/3 progressive</td>
<td>Progressive</td>
<td></td>
</tr>
<tr>
<td>Type of MS</td>
<td>RRMS</td>
<td>RRMS</td>
<td>RRMS 1/3 progressive</td>
<td>Progressive</td>
<td></td>
</tr>
<tr>
<td>Years with MS</td>
<td>&lt; 5 years</td>
<td>&lt; 5 years</td>
<td>1-10 years</td>
<td>20+ years</td>
<td>20+ years</td>
</tr>
<tr>
<td>Living Arrangement</td>
<td>live with others</td>
<td>live with others</td>
<td>live with others</td>
<td>live with others</td>
<td>&gt;live alone</td>
</tr>
<tr>
<td>Care at Home?</td>
<td>no care</td>
<td>no care</td>
<td>no care</td>
<td>25% report care</td>
<td>50% report care</td>
</tr>
<tr>
<td>Need more care?</td>
<td>22% need care</td>
<td>no need</td>
<td>no care</td>
<td>enough care</td>
<td>50% need care</td>
</tr>
<tr>
<td>Donation/Volunteer</td>
<td>None</td>
<td>None</td>
<td>MSSCOC member</td>
<td>Donors &amp; volunteers</td>
<td>volunteers</td>
</tr>
</tbody>
</table>

**In Summary**

The Listening to People Affected by MS Initiative sought input from a large number of Canadians affected by MS. It identified key priorities, needs, gaps and barriers relating to maintaining a positive QOL. Priorities include access to medical care and involvement in decision-making about treatment and medications. Support for family members, being able to access financial support and services to maintain independence are also important priorities. Finding programs and information about physical, emotional, mental and spiritual health are also essential, particularly for those diagnosed with MS. Many needs and gaps in programs and services were also identified in the areas health care, financial support, accessibility, employment supports and support for caregivers. Having MS itself is a barrier to QOL, as coping with the disease and dealing with its symptoms are a significant challenge for people. Additionally, the lack of available information and knowing where to look for information along with accessing financial support to deal with disability were also identified as problematic. Despite these concerns, the overall feelings of hopefulness, optimism and positivity about the future is also strongly evident among the participants. Although MS has a significant impact on their lives, people affected by this disease are able to maintain and improve their quality of life.
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Appendix A: Analytical Framework

Listening to People Affected by MS: Analytical Framework

- Online Poll
  - Are the findings similar between the poll and the survey?
- Web-based Survey
  - How do the gaps identified in the scan align with the findings of the poll, survey and focus groups?
- Focus Groups
  - Are the qualitative & quantitative findings consistent?
- Environmental Scan

QOL Priorities, needs & gaps
## Appendix B: QOL Principles and Initiative Results

<table>
<thead>
<tr>
<th>MSIF Principle</th>
<th>On-line Poll</th>
<th>Web-based Survey</th>
<th>Environmental Scan</th>
<th>Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence &amp; Empowerment</td>
<td>• decision-making re treatment is 3rd priority for PwMS &amp; family/friends</td>
<td>• ranked as 4th most important QOL priority</td>
<td>• not all PwMS are able to be full participants in their communities due to accessibility issues such as the unavailability of accessible transportation or buildings that are not fully accessible</td>
<td>• participants defined this as important component of QOL</td>
</tr>
<tr>
<td></td>
<td>People with MS are empowered as full participants in their communities and in decision-making about the management and treatment of the disease.</td>
<td>• 63% of PwMS say being able to make decisions about treating &amp; managing MS is QOL priority (2nd most important priority after access to medical care)</td>
<td>• these issues prevent PwMS from travelling outside their home, working, acquiring an education and doing other things that people without disabilities do</td>
<td>• one of the biggest barriers for participants is finding information about programs and services to help improve QOL; this is a significant concern for all participants</td>
</tr>
<tr>
<td></td>
<td>• participation in community is not high priority for any client groups</td>
<td>• 48% of PwMS say being part of the community where I live is a QOL priority</td>
<td>• these issues prevent PwMS from travelling outside their home, working, acquiring an education and doing other things that people without disabilities do</td>
<td>• participants often do not feel empowered to access information when needed</td>
</tr>
<tr>
<td></td>
<td>• both of these are less important to caregivers and family/friends</td>
<td>• 48% of PwMS say being part of the community where I live is a QOL priority</td>
<td>• additional issues including lack of adequate financial support may also prevent full participation in one’s community for PwMS</td>
<td>• many participants do not have access to treatment, programs and services due to their inability to pay and, in many rural areas, due to a lack of availability</td>
</tr>
<tr>
<td></td>
<td>• PwMS fear their loss of independence, having to depend on others &amp; becoming a burden on family/friends</td>
<td>• 88% of respondents help to decide on medical treatments or other aspects of living with MS that affect their life all or most of the time</td>
<td>• not all PwMS have access to treatments, programs and services due to their inability to pay for these things or due to the lack of availability of services in their communities (this is particularly an issue for those living in rural areas)</td>
<td>• some PwMS, particularly those with progressive forms, are unable to fully participate in their communities due to limited or no availability of accessible transportation or buildings that are not accessible</td>
</tr>
<tr>
<td></td>
<td>• 21% do not have access to info &amp; advice about MS</td>
<td>• 88% of respondents help to decide on medical treatments or other aspects of living with MS that affect their life all or most of the time</td>
<td>• 33% are not able to be part of community life as much as they want; and 48% of caregivers are not</td>
<td>• additional issues including lack of adequate financial support may also prevent full participation in one’s community for PwMS</td>
</tr>
</tbody>
</table>
Appendix B: QOL Principles and Initiative Results

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<th>Focus Group</th>
</tr>
</thead>
</table>
| **Medical Care**               | People with MS have access to medical care, treatments and therapies appropriate to their needs. | • most important QOL priority for PwMS & family/friends  
  • 76% of PwMS have seen a neurologist in past year  
  • 62% of PwMS have seen a GP in past year (re MS)  
  • 45% of caregivers have seen GP for support related to caregiving | • most important QOL priority for PwMS & 3rd most important for caregivers  
  • 68% of respondents indicate access to medical care is a QOL priority  
  • 87% of PwMS have seen a neurologist in past year  
  • 76% have seen a family doctor (MS-related)  
  • 20-30% have seen other health professionals e.g. OT, PT, RMT, chiropractor, nurse, ophthalmologist  
  • 22% did not receive support they needed from HCP when they first learned they had MS  
  • 27% do not have access to DMT, medicine to manage symptoms & rehab services (18% of RRM & 41% of progressive MS)  
  • 31% feel their healthcare team does not care about well-being  
  • 63% were referred to MSSOC at time of diagnosis  
  • 39% say GP is not knowledgeable about MS | • not all PwMS across the country have equal access to programs and services through the MS clinics or other HCP; services vary significantly by region  
  • many necessary services are not available in rural regions including specialists, MRI services, PT, OT, psychosocial support and complementary therapies  
  • prescription drug coverage for DMTs and symptom management drugs for MS is not universal across the country resulting in uneven access and compensation for these treatments/meds  
  • there are typically delays in coverage by the provincial formularies after Health Canada approval of new treatments | • participants noted a lack of rehabilitation programs and qualified physiotherapists with knowledge of MS is an issue  
  • some experience challenges in accessing DMTs, other medications and treatments  
  • concern expressed re quality of care in some MS clinics – long wait times for tests & appointments, poor interactions with medical staff, etc.  
  • participants believe you have to be a strong advocate to obtain health care services that you need in a timely manner  
  • concerns expressed about the challenges of navigating the health care system |

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2 HCP = health care professional
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<td><strong>Continuing (long-term or social) Care</strong></td>
<td>*services to ensure independence (or ability to live at home) is 5&lt;sup&gt;th&lt;/sup&gt; priority for PwMS but 3&lt;sup&gt;rd&lt;/sup&gt; priority for caregivers and family/friends *need for caregivers *having more help or domestic support is the 2&lt;sup&gt;nd&lt;/sup&gt; most important thing that would improve QOL for caregivers *lack of government support is cited as one of the top 3 barriers to meeting urgent needs</td>
<td>*46% identify this as a QOL priority *most important priority for caregivers (74%) *83% feel they have the support they need to stay in their homes as long as possible *56% indicate the people who are paid to care for them are knowledgeable about MS *34% to whom it applies agree that other people their age live in the same LTC facility&lt;sup&gt;3&lt;/sup&gt; *22% of PwMS receive at home from a paid or unpaid caregiver *21% of those receiving care at home, indicate they need more care *10% of those not receiving care at home indicate they do need this kind of care</td>
<td>*home care services vary significantly across the country and within provinces; regional operation of these services results in varying provision between regions so that some PwMS are able to access services they require while others in the same province are not *home care services tend to focus on acute care for those released from hospital, while those with chronic diseases are often not able to access the home care they require *homemaking services are very limited or not available, user fees may be charged in some regions, long wait times are common *for a small % of PwMS, limited housing &amp; care choices combined with reduced income may result in younger adults having to reside in institutional care *the lack of age-appropriate care often result in depression, anxiety &amp; longer-term mental health issues</td>
<td>*participants cited concerns re lack of appropriate home care services *complaints of long wait times to be assessed for eligibility *complaints that needed services are not available, particularly homemaking services *issues with quality of services were noted including shortages of staff, lack of consistency in staff providing care, poorly trained staff, providers not showing up when supposed to *complaints about the variability of services provided across provinces &amp; regions; one person in a region may get needed services while another in the same province but different region cannot access the same needed service *lack of age-appropriate LTC facilities is a concern for many who worry about their future or friends who are in LTC that are unhappy</td>
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<sup>3</sup> This question only applied to a small number of respondents (84) so results should be interpreted with caution.
## Appendix B: QOL Principles and Initiative Results

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<td><strong>Health Promotion &amp; Disease Prevention</strong>&lt;br&gt;People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle.</td>
<td>•Info &amp; services that promotion physical, emotional, mental and spiritual wellness are a priority for almost one third of PwMS and one quarter of family/friends and caregivers •It is more important to females diagnosed with MS •5% of PwMS identify staying in shape/healthy eating habits as an urgent need</td>
<td>•50% of respondents say this is a QOL priority •3rd most important QOL priority; more important for PwMS •80% say HCP offers them routine medical care like flu shots, pap smears &amp; other tests •31% do not have access to information and advice about exercise, nutrition &amp; ways to manage stress</td>
<td>•There is little government leadership regarding health promotion programs for PwMS •Service provision falls to community-based organizations</td>
<td>•Strong theme that exercise is the most important activity to slow the progression of MS and to maintain good mental health •Concerns were expressed re availability of affordable, quality exercise facilities that meet the needs of PwMS •Concerns expressed re accessing information on programs that can improve QOL; they indicated that navigating the maze of information to find programs/services to improve QOL is difficult</td>
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<tr>
<td><strong>Support for Family Members</strong>&lt;br&gt;Family members and caregivers receive information and support to mitigate the effects of MS.</td>
<td>•Support for family and caregivers is fourth most important priority overall •It is the second most important priority for caregivers (49% rank as important) •Caregivers urgently need</td>
<td>•2nd most important QOL priority overall •Most important priority for caregivers &amp; family/friends •2nd most important for PwMS •One of the greatest worries for PwMS and caregivers is</td>
<td>•No structured support system in place federally or provincially •Federal leadership is required to address the many issues faced by caregivers •Caregivers forced to leave</td>
<td>•Lack of available and quality respite care is an issue for participants across the country •Very few options are available for overnight and daily respite care •This issue was identified by</td>
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<td>help around the house &amp; report they cannot keep up on their own</td>
<td>the impact of disease on caregivers’ health and QOL</td>
<td>work to care for a PwMS lost their income but also lose contributions to CPP</td>
<td>caregivers and PwMS are concerned that their caregivers will burn out</td>
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<tr>
<td>lack of government support is cited as a barrier by 45% of caregivers</td>
<td>•55% of caregivers cannot find support they need as a caregiver or family member</td>
<td>•employers are not required to continue employment benefits for those taking caregiver leave</td>
<td>caregivers discussed the challenges and negative effects of caregiving but did not seem interested in participating in support groups</td>
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<tr>
<td>paid caregivers are less popular among PwMS but 24% of caregivers have used this source in the past year</td>
<td>•58% feel they have someone to talk to when tired or have negative feelings</td>
<td>•the Caregiver Tax Credit is a positive support but it is non-refundable so does not provide support to low income families</td>
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<tr>
<td>only 2% of PwMS and 10% of caregivers indicate respite care is an effective source of support</td>
<td>•26% indicate children (&lt;18) have caregiving responsibilities</td>
<td>•very few provinces provide direct support to caregivers</td>
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<td></td>
<td>•77% do not have access to respite services</td>
<td>•navigating the maze of community services available can be difficult and many programs require adequate income to pay for services</td>
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<td></td>
<td>•21% have access to professional help &amp; evaluations to deal with physical and emotional stress of caregiving</td>
<td>•there is a significant lack of respite care programs across the country to allow caregivers a break</td>
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<tr>
<td>Transportation</td>
<td>•accessible transportation is ranked as a priority by 15% of respondents</td>
<td>•28% identified transportation as a QOL priority</td>
<td>•accessible transportation is a significant barrier for many participants</td>
<td></td>
</tr>
<tr>
<td>People with MS have access to their communities through accessible public transportation and assistive technology for personal automobiles.</td>
<td>•it appears to be a higher priority for caregivers and males diagnosed with MS (1/5 ranked as a priority)</td>
<td>•40% (to whom it applies) indicate transportation services where they live allow them to travel around as they need to</td>
<td>many issues with public transit were noted including lack of accessible vehicles and significant issues with accessible transit system</td>
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<td></td>
<td>•modifying vehicles/finding accessible transportation is an urgent need for 3% of PwMS and 5% of caregivers</td>
<td>•27% (to whom it applies) say their car has changes made to it so they can still drive it</td>
<td>including difficulty booking rides, unreliability of service, limited availability of service, challenges when crossing regions with</td>
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<td>family/friends and 20% of caregivers</td>
<td></td>
<td>scooters • the convenience &amp; accessibility of door-to-door accessible transit services vary greatly across Canada • these services require advance reservations, sometimes days or weeks in advance; services are limited and sometimes prioritized for medical appointments leaving out those trying to get to work or other appointments; application processes can be time-consuming and inconvenient • rural areas are underserviced • travel between regions is challenging as very few transit systems work together to provide seamless travel between municipalities &amp; they often have different application processes &amp; requirements</td>
<td>different providers • lack of accessible transit can be a barrier to participating in community life for some PwMS</td>
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**Employment & 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.

*employment supports do not rank highly among respondents: it is a priority for 12% of PwMS, 2% of caregivers and 10% of family/friends *urban PwMS are more likely to say this has been a priority in the last 12 months (13% vs 5% in rural) • 20% identified this as an important QOL priority • 55% (to whom it applies) are retired from work but feel fulfilled by volunteer work, hobbies or domestic life • those who are fulfilled by volunteer work, hobbies or domestic life are more likely • many PwMS leave the workforce because their symptoms make maintaining employment a challenge • accommodations in workplaces across Canada vary greatly • there appears to be work to be done to ensure • wide range in experiences with employers – some report very accommodating employers while others report the opposite • appears to be a need for employment counselling in terms of when and how to disclose a diagnosis • also counselling re what |
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<td>only 2% of caregivers and 7% of PwMS made effective use of employment supports</td>
<td>to report a high quality of life</td>
<td>equitable access to workplace accommodations</td>
<td>type of work to look for and what accommodations are successful for PwMS</td>
<td></td>
</tr>
<tr>
<td>• 54% (to whom it applies) say their workplace makes changes so they can still work despite MS</td>
<td>• 42% of caregivers and family/friends say their boss gives them time off, as needed, to care for the person with MS in their life</td>
<td>• vocational rehabilitation programs are available for people with disabilities in Canada</td>
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<tr>
<td>• 42% of caregivers and family/friends say their boss gives them time off, as needed, to care for the person with MS in their life</td>
<td></td>
<td>• the focus is on re-training and re-employment, making them less suitable for PwMS</td>
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<td></td>
<td></td>
<td>• most programs are linked with CPP-D and provincial income replacement programs so many PwMS do not qualify for them</td>
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<tr>
<td>Disability Entitlements &amp; Cash Assistance</td>
<td>• financial support is an important issue for all respondents</td>
<td>• income support is a major concern for PwMS</td>
<td>• having adequate finances was seen as very important to maintaining a good QOL</td>
<td></td>
</tr>
<tr>
<td>Disability entitlements and services are available to those in need, provide an adequate standard of living and have flexibility to allow for the disease variability that is characteristic of MS.</td>
<td>• having more money/financial support/better income is most important thing to improve QOL for all groups</td>
<td>• maintaining employment, financial security &amp; managing the high costs of the disease are a challenge</td>
<td>• challenges around qualifying for LTD and CCP-D were noted as significant problems</td>
<td></td>
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<tr>
<td>• it is the second most important priority for all</td>
<td>• 35% identified this as QOL priority</td>
<td>• current income support programs do not recognize or accommodate the needs of people with episodic diseases for flexible work options and income support</td>
<td>• income replacement programs do not provide sufficient funds to have a good QOL; they must be supplemented</td>
<td></td>
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<tr>
<td>• it is more important to caregivers; 54% cite financial assistance related to disability as QOL priority (compared to 1/3 of PwMS)</td>
<td>• 44% of caregivers say it is a priority</td>
<td>• qualifying for these programs is often challenging for PwMS due to the episodic nature of the disease</td>
<td>• value of MS Society financial support programs was noted by many</td>
<td></td>
</tr>
<tr>
<td>• problems with finances/needing more money is the top 5 urgent needs</td>
<td>• 51% to whom it applies say their disability benefits allow them to maintain a standard of living that is good enough</td>
<td>• part-time work is not well supported</td>
<td>• difficulty of determining tax credits that PwMS may qualify for was noted</td>
<td></td>
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<tr>
<td>• it is the second greatest urgent need noted by caregivers</td>
<td>• 42% to whom it applies say they find it difficult to get financial assistance for MS-related issues</td>
<td>• entitlement amounts are not sufficient</td>
<td>• complaints about gov’t disability supports programs were noted including RDSP – these programs do not provide enough financial</td>
<td></td>
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<tr>
<td>• 30% of PwMS relied on financial help outside their personal resources to help with issues related to MS in the past year</td>
<td>• 30% of PwMS relied on financial help outside their personal resources to help with issues related to MS in the past year</td>
<td>• tax credits are largely non-refundable (so don’t help</td>
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<tr>
<td>MS does not inhibit the education of people with MS, their families or careers.</td>
<td>•this does not appear to be a QOL priority for respondents who ranked it the least important priority</td>
<td>•this does not appear to be a QOL priority for many (11%)</td>
<td>•accommodations at public schools are available and typically the responsibility of parents to deal with individually with the school</td>
<td>•no issues reported</td>
</tr>
<tr>
<td><strong>Housing and Accessibility of Buildings in the Community</strong></td>
<td>•accessible buildings is a QOL priority for 20% of respondents</td>
<td>•this is not a top QOL priority overall</td>
<td>•building codes govern accessibility of buildings through minimum</td>
<td>•accessible buildings and spaces were a problem for some</td>
</tr>
<tr>
<td>Accessibility, both of public</td>
<td></td>
<td>•36% of PwMS and 54% of</td>
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those who need it most) & again do not recognize the episodic nature of MS so many PwMS do not qualify
•financial support for medical supplies & equipment is limited, varies by province and rarely meets the needs of PwMS
•grants for home renos & vehicle changes are available but funding is limited, there are long wait lists and the amount is typically not sufficient

Education
MS does not inhibit the education of people with MS, their families or careers.

•this does not appear to be a QOL priority for respondents who ranked it the least important priority

•53% (to whom it applies) indicate their school accommodates their MS so they can continue with their education; this was not a large number of respondents so this finding should be interpreted with caution

•accommodations at public schools are available and typically the responsibility of parents to deal with individually with the school
•students with disabilities face a wide array of challenges at post-secondary institutions including accessible facilities and housing
•many post-secondary institutions offer support programs to assist students with disabilities
•these programs vary significantly by institution as does access to the accommodations

•no issues reported
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<td>buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS.</td>
<td>• it is more important to men diagnosed with MS – 31% rank this as a QOL priority</td>
<td>caregivers identified this is a QOL priority</td>
<td>standards</td>
<td>• truly accessible buildings are an issue; in most cases the building codes only provide basic information and the design of spaces is not adequate for respectful and easy use of facilities</td>
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<td>• 25% indicate community buildings (e.g. gov’t offices, hospitals, clinics &amp; schools) are not accessible</td>
<td>• building codes only apply to new buildings or larger renovations</td>
<td>• complaints such as grocery carts too far from entrances, uneven pathways, towel and soap dispensers in washrooms at wrong height, etc. were noted as small things with a big impact on accessibility</td>
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<td>• 38% to whom it applies, indicate their home has not been adapted to make it easier to live with MS</td>
<td>• codes are not highly specific so many issues ‘fall through the cracks’ e.g. height of sinks, towel &amp; soap dispensers</td>
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<td>• code only enforced through building permit process which has limitations including lack of sufficient staff &amp; long wait times for permits &amp; inspections</td>
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<td>• weather conditions add further complications to accessible buildings through ice and snow build-up</td>
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