



MULTIPLE SCLEROSIS SOCIETY OF CANADA

CLIENT SERVICES NATIONWIDE SURVEY *EXECUTIVE SUMMARY*

Listening to the Voice of People Affected by MS

EXECUTIVE SUMMARY

On October 8, 2003 Kelly & Associates in conjunction with Campbell Research Associates was retained by National Client Services of the Multiple Sclerosis Society of Canada, to assist with a number of tasks related to the Society's study - "Client Services Review". A major component of this review was to undertake a survey of members of the MS Society of Canada in every division of the country, from coast to coast.

Approach

A nation-wide survey of members of the MS Society of Canada was planned and designed in consultation with Divisional Client Services Directors in late 2003-early 2004. A questionnaire instrument was developed in both French and English and using the *MS Canada* publication mailing list, the survey was distributed to 36,867 households. The survey was also made available on the internet via the MS Society's website. Survey targets were established with respect to each division and rural/urban representation. A total of 10,558 responses were received, for a response rate of 28.6 per cent of the mailing list - all respondent targets were exceeded. Just over 26 per cent of responses were completed on-line.

TARGETS AND RESPONSES

	BC	AB	SK	MB	ON	QU	AT	TOTAL
MAILED								
URBAN	4749	2631	1372	1526	12078	6174	1711	30241
MAILED								
RURAL	634	571	905	561	2015	1201	739	6626
TOTAL MAILED	5383	3202	2277	2087	14093	7375	2450	36867
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URBAN								
TARGET	904	501	261	292	2299	1175	326	5758
RURAL								
TARGET	121	109	172	108	384	229	141	1262
TOTAL TARGET	1025	609	433	400	2683	1404	466	7020
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URBAN								
RESPONSES	1113	803	372	360	3195	1869	631	8343
RURAL								
RESPONSES	181	148	207	133	624	437	233	1963
TOTAL RESPONSES	1294	951	579	493	3819	2306	864	10306

Based on the division, rural and urban response rates, weightings were applied to the data in all of the SPSS analysis runs to produce results that represented the division, rural and urban distribution of the survey sample (i.e., the mailing list). Frequencies were carried out for all questions at the nation-wide, division and rural/urban levels both nation-wide and within divisions. Crosstabulations were also performed for gender, age, primary client category and type of MS, for those who indicated that they have this, with the kinds of MS Society services respondents indicated that they have used or received.

Overview of Survey Results

Survey findings are presented in the main report on a nation-wide and individual division basis. A standard approach to reporting survey findings is used for each jurisdiction and includes findings related to:

- profile of respondents;
- primary client category;
- living arrangements;
- use of MS Society of Canada services, and;
- respondent suggestions for services that would enhance quality of life.

The survey and reporting of findings were not designed to compare between divisions, or between divisions and nation-wide results. The following section extracts key results from the entire respondent group nation-wide. For individual division level result, recourse should be had to the main report.

Profile of Respondents

Just over 80 per cent of all respondents gave an urban postal code. The majority of individuals are from Ontario and Quebec which closely mirrors the population to whom *MS Canada* is mailed. Most respondents received their copy of the questionnaire in their mailed issue of *MS Canada* while less than eight per cent reported seeing it on the MS Society web-site. Eighty per cent of respondents are members of the MS Society.

Over three-quarters of those responding are female. Sixty-eight per cent are over the age of 44 years with the single largest age group being the 45-54 years category.

Primary Client Category

By far the greatest proportion of survey respondents have a confirmed diagnosis of MS followed by those who have a close relationship with a person with multiple sclerosis. Other primary client groups appear in the survey in much smaller proportions – 3.4 per cent for those having a relationship a person with MS and being a caregiver, 1.8 per cent for those waiting for a diagnosis with respect to MS and .7 per cent for those who are a caregiver to a person with MS.

Living Arrangements

Living arrangements were asked only of the group having a confirmed diagnosis. Almost all live in a private residence with only a small minority residing in a care facility. Of the former group, 17.1% live alone. However, this is twice as likely to be the case for urban respondents than for rural respondents.

Use of MS Society of Canada Services

Eighty-eight per cent of those surveyed have received information services, supports and/or other forms of assistance from, or taken part in, programs with the MS Society at some point. This participation rate did not differ between the rural and urban respondents. Crosstabulations of having ever used MS Society services were carried out with respondent gender, age and primary client category.

The service received by most respondents is the *MS Canada* newsletter, which is not surprising given that the distribution list was the basis for the survey sample.

Next to the *MS Canada* newsletter the services most used are (in descending order):

- information booklets/pamphlets – 65.0%;
- a chapter newsletter – 61.0%; urban respondents reported this to a greater extent than rural respondents (63.1% versus 51.1%) probably due to the greater presence of chapters in urban areas;
- the division newsletter – 59.1%;
- the local chapter telephone number for information and/or support – 50.3%; again this is more likely to have been used by urban respondents than by rural respondents (51.7% versus 43.7%) also probably related to the location of chapters;
- MS Society website – 40.2%; less used by rural respondents than by urban respondents (35.4% versus 41.2%);
- research updates – 39.4%;
- in-person information and/or support from the local chapter – 37.6%; a lower percentage of rural than urban respondents (32.1% versus 38.8%);
- support/self-help groups – 31.8%;
- social events – 30.3%; less used by rural respondents than urban respondents (25.4% versus 31.3%);
- presentations (2-3 hours) – 28.8%; rural respondents are less likely than urban to have received these (24.5% versus 29.8%).

There is no difference by gender for each of the services (although there are approximately three times as many females as males in the respondent group and, hence, services have more female clients than male clients).

Respondents were asked to indicate the five services that they had used which were most important in terms of the benefit to their quality of life. In order of priority, the following were identified:

- the top first, second, third and fourth choices were the *MS Canada* newsletter (10.8%, 8.9%, 8.4% and 8.5% respectively,);
- the top fifth choice was social events (9.2%);
- other choices which are among the top five mentions for first, second, third, fourth and fifth priority included:
 - support/self-help groups
 - equipment provision
 - information booklets/pamphlets
 - newly diagnosed programs/services
 - research updates
 - exercise/recreation programs
 - chapter newsletter
 - MS Society web site.

The choice of priorities was crosstabulated with gender, age, primary client category and type of MS. The key results are:

- a higher proportion of males than of females ranked “equipment provision” as their number one priority in terms of the benefit to them (although females outnumber males and therefore more females gave this as their first priority);
- the 20-44-year age group listed “MS Society web site” as their top choice in comparison with 45-64 years and 65 and over;
- the 45-64 year category were more likely to say that “support/self-help groups” are their first choice;
- those with a confirmed diagnosis of MS and persons who have a relationship with and are a caregiver to a person with MS indicated “equipment provision” as their first priority in greater proportions than other primary client groups;
- individuals with secondary/primary/relapsing progressive MS, more than those with relapsing-remitting or benign MS, ranked “equipment provision” at the top of their priorities in terms of benefits;
- a smaller percentage of those with benign MS listed financial assistance in first place though a high percentage of these respondents put newly diagnosed programs or services first.

Suggestions that Would Enhance Quality of Life

Over one-quarter of all respondents said that there are other programs, services, supports or forms of assistance that the MS Society could provide that would help enhance their quality of life. They were asked to list up to five suggestions in order of priority. Most respondents listed answers similar to those listed in a previous question which were services offered by the MS Society. Few respondents identified “new” or “additional” services.

The most mentioned services in each of the five priority categories are:

- first priority: financial assistance;
- second priority: financial assistance and physiotherapy/medical help;
- third priority: physiotherapy/medical help;
- fourth priority: financial assistance;
- fifth priority: home care assistance;
- other suggestions among the top five in each priority category are:
 - exercise programs
 - research updates
 - government/public awareness
 - counselling/supportive listening
 - information booklets/pamphlets
 - on-line conferences/chats
- social events.

OBSERVATIONS ON THE SURVEY DATA

The conduct of this survey and the subsequent findings presented in this report suggest a number of general observations about both the implications of these findings and further steps which the MS Society may consider taking.

- There is strong evidence of the overall importance of the communication and education role of the MS Society. The provision of credible, accurate and up-to-date information about MS and MS research was stressed by respondents. This finding suggests that Society should consider examining this aspect of its programming in greater detail in order to ensure that respondents' confidence in the high standard of information continues to be maintained.
- Follow-up of the survey results regarding the impact of MS Society services on the quality of life of the Society's primary clients would most usefully be done through focus groups.
- The high value placed on financial assistance provided by the MS Society by a range of respondent groups could be further explored, especially to address the questions of specifically what types of clients are benefiting and how are they benefiting.
- The MS Society may be able to better address the needs of its primary clients by implementing a program of periodic and systematic evaluation of those services that clients use and value most, e.g., information and education which are given a high priority. The results obtained will enable the Society to improve or change these services to optimize their benefits for clients.
- The responses to survey question 14 regarding "other" services that respondents would like to receive may indicate either that individuals are not aware of the range of services and programs offered by the Society or that these services and

programs are not being provided to the extent necessary to meet the needs. This is also an issue that could be more fully examined through focus groups with clients.

- The list of most valued services varies from Division to Division across the country. In addition to the fact that the types of services provided also vary, this may be due as well to different practices and delivery processes for the same services. If so, there may be potential “best practice” models that all Divisions could share and benefit from. Here again is an area that deserves further exploration.