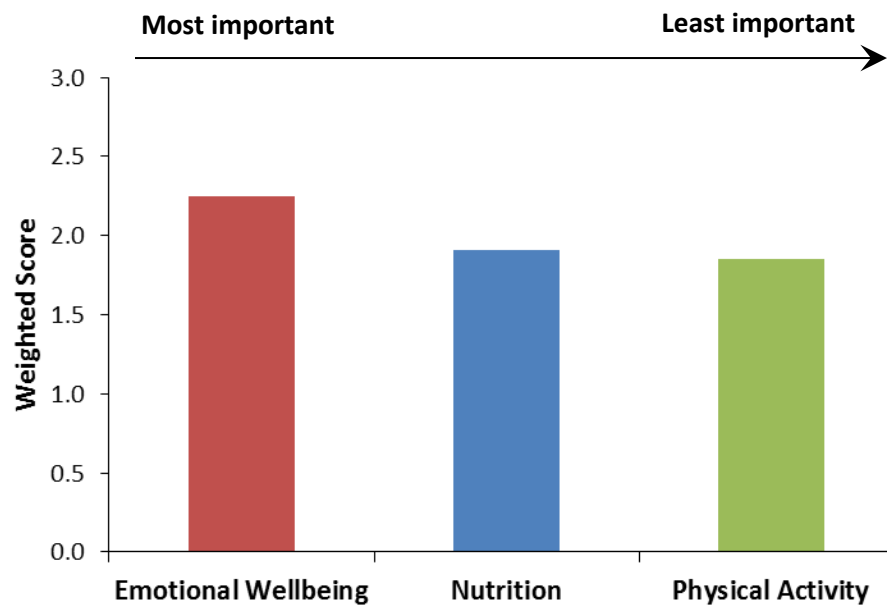




## MS Wellness Survey: Detailed Results

A total of 1,032 respondents from across Canada completed the survey. A sample set of this size yields a margin of error of  $\pm 3.0\%$ , 19 times out of 20. Group data that captures the responses to each question are summarized below.

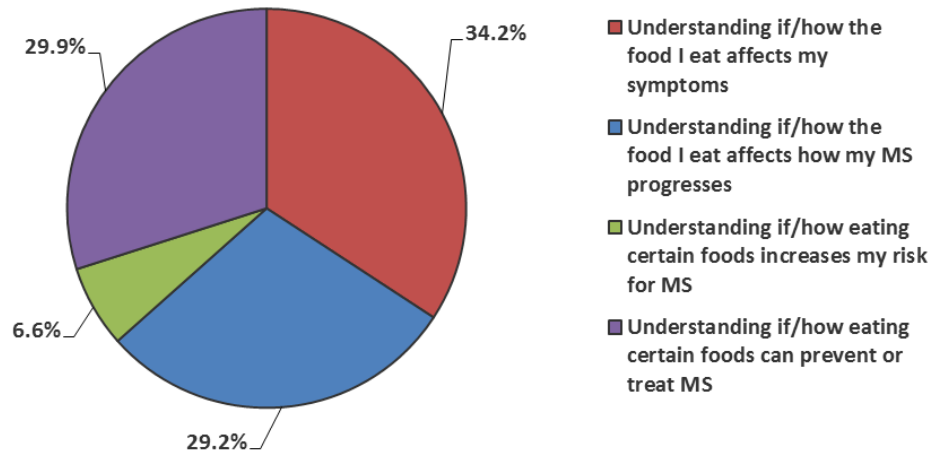
### What areas of wellness are most important to you?



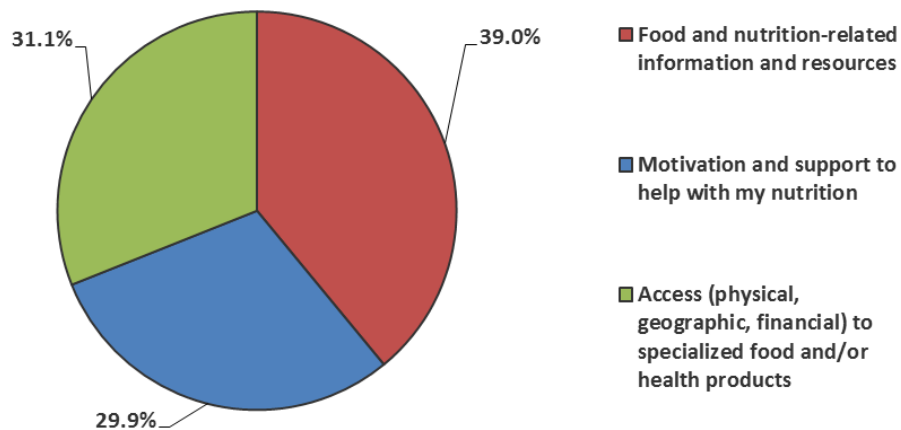
Wellness Area	Most important		Least important	Weighted Score
	1	2	3	
Emotional Wellbeing	52.1%	21.1%	26.8%	2.25
Nutrition	24.30%	42.00%	33.70%	1.91
Physical Activity	24.2%	36.7%	39.1%	1.85

**Note:** Respondents were asked to rank their preferences from 1 to 3, where 1 = most important and 3 = least important. Scores are presented as weighted averages.

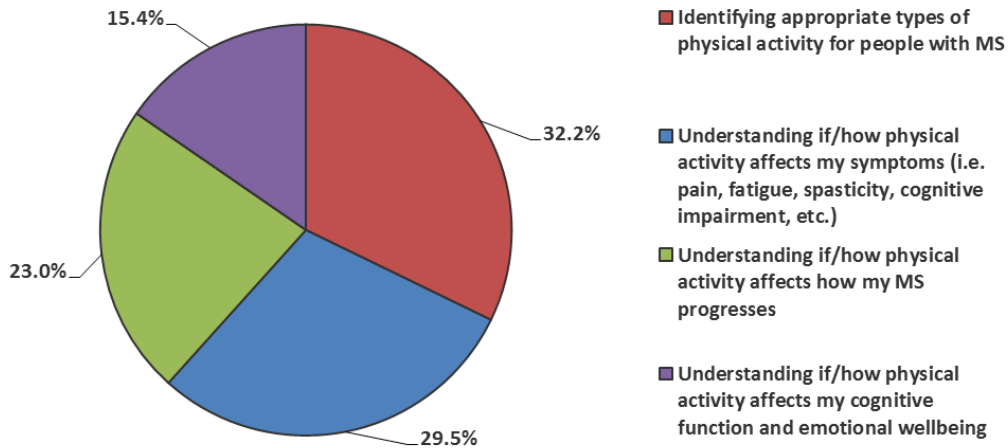
## What kind of research would you most like to see in the area of nutrition and MS?



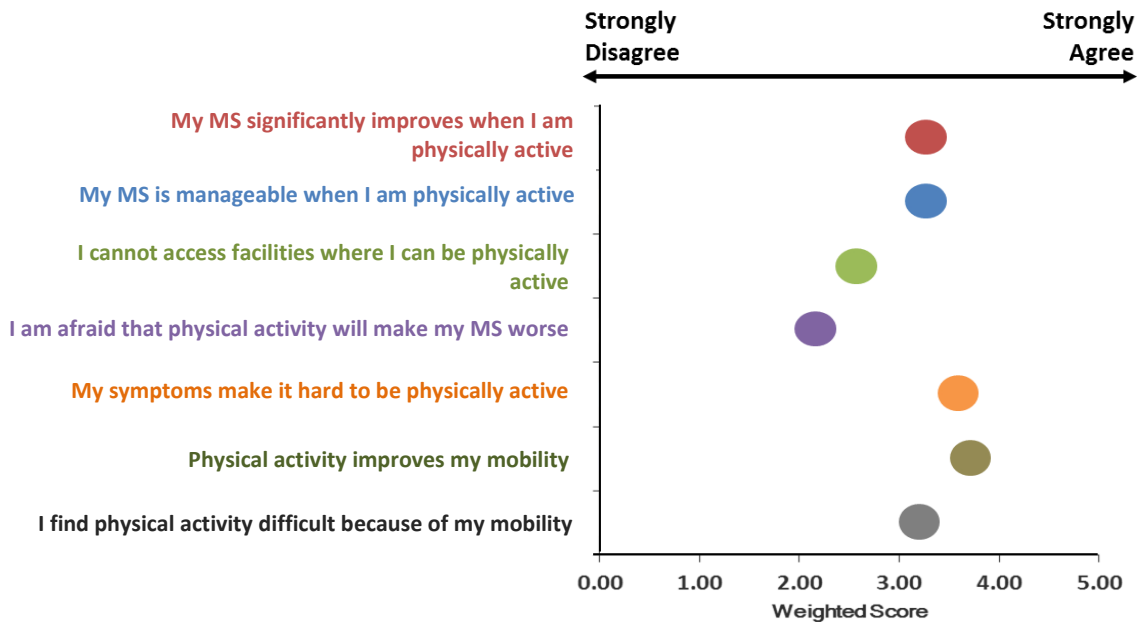
## Which of the following would help you live better in terms of nutrition?



## What kind of research would you most like to see in the area of physical activity and MS?

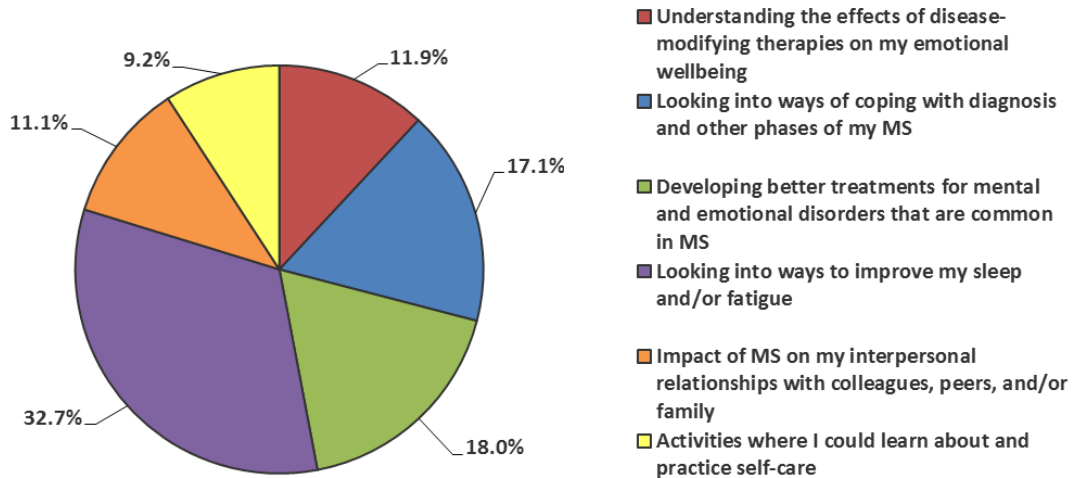


## How do you relate to the following statements?

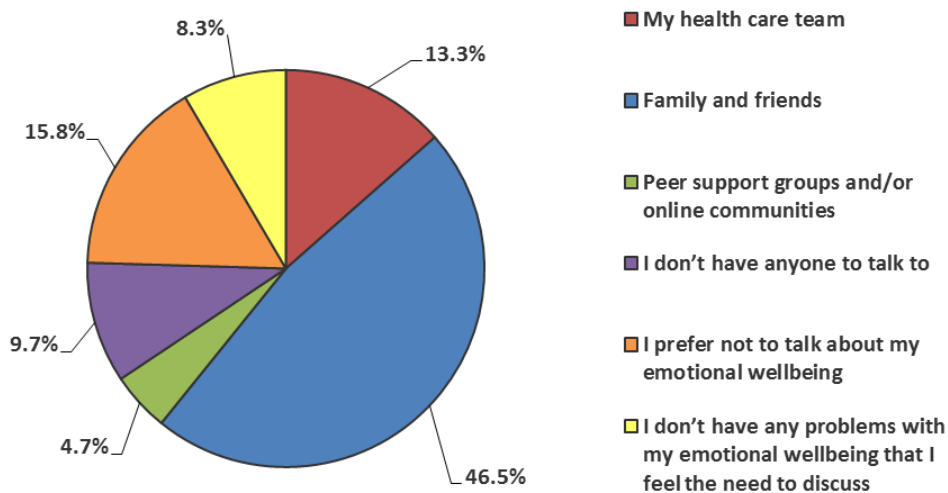


**Note:** Respondents were asked to rank their preferences as strongly disagree (1), disagree (2), neutral (3), agree (4) and strongly agree (5). Scores are presented as weighted averages.

## What kind of research would you most like to see in the area of emotional wellbeing and MS?



## Who/which of the following do you turn to most often to discuss your emotional wellbeing?



## Researcher for a Day

Survey respondents were asked to imagine they were a “researcher for a day”, where they were given the opportunity to create their own studies, inventions, applications and programs that they felt would address a number of priorities, challenges and needs in wellness. Respondents were asked the following question:

*Imagine you are a researcher and an expert in wellness. You are in charge of creating an invention or conducting a research study that will help people with MS live better. Tell us: What would it look like? What kind of research would you do? Who would your research involve? What would you hope to come of it? For example, perhaps you want to test how different types of physical activity – like walking, weight training or yoga – affect stress and anxiety in people living with MS. Or maybe you want to see whether community programs that provide weekly lunch get-togethers for people living with MS can reduce social isolation and improve nutritional health. Whatever your idea, don't be afraid to get creative and ask the research questions that are important to you!*

Overall, a number of trends were identified in this portion of the survey. Respondents were interested in research that would address the following gaps and priorities:

### Nutrition

- Accessible information about how specific foods, supplements/health products and diets affect disease course and symptoms.
- A resource (such as technological tools or programs/workshops) that provides meal plans, recipes and preparation advice appropriate for people living with MS to manage their symptoms, improve quality of life and build community with friends and family around food.
- Improved financial access to healthy, affordable, culturally-appropriate food.

### Physical Activity

- Personalized fitness trackers or other monitoring technologies and tools that are tailored to an individual's level of disability and symptoms.
- Tools and technologies that facilitate engagement in physical activity and managing recovery from activity, particularly fatigue and overheating.
- Increased access to exercise facilities and personal trainers who are sensitive to the unique needs of people living with MS.

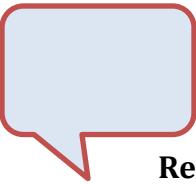
### Emotional Wellbeing

- Tools to manage stress and anxiety, cognitive issues such as memory, sleep and fatigue.

- Social groups and peer support programs, either at a grassroots level or through existing organizations, intended to alleviate isolation and build community around common challenges.
- Tools and solutions that allow people living with MS to build or maintain independence and facilitate meaningful participation in the community.
- Solutions to establish and maintain relationships with others and manage other people's perceptions of the disease.

### General

- Integrated multidisciplinary MS management programs that include neurologists, rehabilitation specialists, diet specialists, mental health professionals, and community service providers.
- Dismantling barriers to accessing proper wellness resources and programs; barriers include financial (low income), geographic (rural and underserved communities), societal (prejudices) and those caused by disability.
- Resources to help people affected by MS navigate through a large amount of detailed, oftentimes conflicting, information about integrating wellness strategies into their lifestyles.



## Researcher for a Day Highlights

The MS Society received a tremendous number of responses from people affected by MS. Several highlights of outstanding responses are provided below:

- “A wellness centre geared towards MS management. There would be physio-therapists, therapists, nutritionists, personal trainers etc. Everyone that could contribute to make living with MS a bit easier. This facility could monitor folks with MS over extended periods of time in many aspects of physical and mental health to gather all sorts of data to analyze and potentially find common factors to MS and its progression. Also, because many of these services are covered by health care, many folks could participate without putting a strain on funding. Honestly, I go to a wellness centre that has all but the therapist and it's great. They don't know loads about MS but it's a place I can go to decompress my aching body.”
- “Objective: to design a web based program which promotes all resources available locally for MS patients. This includes workshops, peer groups, medical assistance, financial help, nutritional tips, local resources for people who specialize in helping people with MS. Ex. Massage therapy. “
- “I would like to see a study that looks at how self-monitoring of physical activity and exercise can be applied to gauge progress of MS symptom on individuals. If it is possible to measure the relationship between physical activity and progression of the disease I would like to see a study of methods and devices for measurement leading toward development of personalized equipment that can be used to gauge disease progress. I think that having the ability to participate in measurement of your own symptoms would motivate and inspire individuals to exercise and participate in more physical activities.”
- “I want studies examining whether lifestyle changes, such as diet, affect the progression of MS. Does adopting certain dietary restrictions help me stay healthy longer (reduce/prevent relapses)? The research would involve people diagnosed with MS at differing stages (newly diagnosed with few symptoms, during relapse, when things start to progress). I would hope that scientifically validated information would be available about what lifestyle changes to make to prolong health functioning and decrease the progression of the disease. There isn't good research available on diet in particular.”
- “My research study would focus more on students who are struggling with the effects of cognitive difficulties. I would want to have bi weekly meetings (via in person, chat, webinar, social media) about the struggles of coming out or disclosing the challenges of accepting this type of "disability". I would like to know what has helped students to cope. What are some challenges they are faced with. How do they thrive in the face of adversity? How supportive is their school and/or community. I would hope that this study can help students accept the disease as it is and not be afraid to challenge the negative stigma attached to disability.”