

FAQ: Multiple Sclerosis Progression Cohort Study

Q – What is the Canadian Multiple Sclerosis (MS) Progression Cohort?

A – The Canadian MS Progression Cohort will allow researchers and clinicians to observe a large group of people living with multiple sclerosis (MS) from across Canada over a period of time, collect specific information that will allow them to identify features of progression in MS, and understand why and how progression occurs. This knowledge will help improve the diagnosis, treatment, potential prevention and long-term monitoring of progression in MS. The MS Progression Cohort will also serve as a rich source of information and an open resource for ongoing research by experts in the MS field and those who study other neurological diseases.

Q – What information will be gathered from the cohort?

A – Researchers will collect and analyze new information over time, but will also look at existing health data. They will develop a set of research questions about progression that pertains to three main research themes: mechanisms of progression (e.g. how does progression occur at the cellular level and what biological markers can be used to track progression?), treatments/real-world evidence (e.g. how do existing treatments for MS impact progression and what role does early diagnosis and self-management play?) and impact (what is the impact of progression on the health system, society, the economy, and the person's quality of life?). To answer these and other questions, the researchers will collect different types of information such as biological samples, imaging data, clinical data such as symptoms and treatment responses, and information about lifestyle, disability, healthcare costs, and other aspects of daily living and quality of life. By collecting this information, the researchers will create a comprehensive picture of how progression affects an individual physically, emotionally, economically and socially.

Q – How will a study like this impact those living with MS?

A – The results of this study could potentially impact how we treat MS, how we diagnose MS, how people live with MS, and how we talk about MS progression altogether – this is a significant pursuit of knowledge, one that could dramatically change the landscape about what we know about MS and MS progression.

This study will allow the person living with MS the opportunity to examine their own behaviours and make connections to others living with MS in hopes of finding common ground. MS affects each individual in unique and unpredictable ways making it crucial to study and understand each person's own experience over time. This study will provide those living with MS new opportunities for treating progressive MS and other neurodegenerative diseases, while addressing important public health matters such as access to treatment and impact of long-term disability on the health-care system.

Q – Why a Canadian MS Cohort study?

A – Canada has the highest rate of MS in the world. There are currently no nationwide studies of this kind being done in Canada. Given the tight-knit community of MS clinical and research experts across the country, the funding partners recognized a valuable opportunity to bring these experts together to collect and analyze data from people living with MS to understand disease progression. MS affects each individual in unique and unpredictable ways, making it crucial to study and understand each person's own experience over time. A pioneering and innovative study, the MS Progression Cohort will provide a means to compare biological, clinical and quality of life data from across the country, while building an open, centralized Canadian resource that can be used for research purposes.

This study will also strengthen the relationships between industry, non-profit, academia and government.

Q – How much money will go into funding this research project and who is supporting it?

A – Up to \$7.125 million is available to support the cohort, with potential to increase support from other partners as the project continues. Each funding partner is contributing more than \$2 million to the project. The MS Society is grateful to lead donors, PCL Construction and Bennett Jones LLP for their generous support at \$1.25 million and \$1 million, respectively, as well as to several individuals who made significant contributions. Funding partner Brain Canada receives financial support from Health Canada through the Canada Brain Research Fund.

Q – When will the MS Progression Cohort study begin?

A – The study will begin in early 2018.

Q – How long will the MS Progression Cohort be studied for?

A – The 5-year grant will allow the research team to develop and study the cohort with the potential for ongoing research and data collection beyond the 5-year funding term.

Q – Are there any other studies similar to this?

A – Although there are studies taking place in other countries that are similar to the MS Progression Cohort, this is the first study of its kind in Canada designed to answer fundamental questions related to progression in MS and serve as an open research tool for the MS community.

Q – How will the research team be selected?

A – The funding partners have released a request for applications (RFA) that invites interested research teams to apply for funding to design and implement the cohort. The RFA has two stages. First, up to \$250,000 will be awarded to one or more teams to plan and design the cohort. The teams will then be asked to submit a more fulsome application that outlines in detail

how they will identify and recruit participants, collect and analyze data, and ensure a coordinated research effort across the country. Selection of teams at both stages will be done through a rigorous independent review process involving international research and clinical experts and people affected by MS.