

Details, Facts, Key Messages, Quotes

Findings from the National Population Health Study of Neurological Conditions

What?

The \$15 million, four-year National Population Health Study of Neurological Conditions (the Study) represents Canada's first-ever population health study of neurological conditions. Undertaken between 2009 and 2013, the extensive research program of the study included three national surveys, 13 pan-Canadian research projects, the expansion of ongoing surveillance to include certain neurological conditions, and the development of a micro-simulation model to estimate impacts of neurological conditions over the next 20 years. [Mapping Connections: An Understanding of Neurological Conditions in Canada](#) is the final report synthesizing key findings from the Study.

Who?

The study was developed in partnership between the Government of Canada and Neurological Health Charities Canada (NHCC), a collaborative of 24 health charity organizations representing the voice of individuals and families impacted by neurological conditions across Canada. Approximately 177,000 Canadians with neurological conditions and their caregivers offered insight and personal experience into key areas of the Study. In addition, the study successfully engaged 130 researchers from 30 academic and non-academic institutions across Canada.

Why?

The study was designed to address the lack of information about neurological conditions in Canada. Findings are intended to inform Canadians and governing bodies about the impact neurological conditions have on affected individuals, families and the health care system, and inform future program and policy development.

Quick Facts

- Neurological conditions are estimated to affect more than 3.6 million Canadians, including more than half of individuals receiving home care or living in long-term care facilities.
- Canadian adults with a neurological condition were twice as likely to report activity limitations and symptoms consistent with depression compared with the general population.
- The prevalence of unemployment among those with a neurological condition was five times higher than in the general population (12 times higher with migraine removed from analysis).
- Caregiver distress was more than twice as high for those caring for individuals with neurological conditions.
- 35% of Canadians with a neurological condition reported receiving formal emotional support because of their condition.
- Individuals living with a neurological condition used more health services than Canadians with other chronic conditions, resulting in increased costs to individuals and the health care system.
- 35% of adults with a neurological condition reported that their family had experienced a financial crisis in the previous year, and close to one quarter of parents of children with neurological conditions reported financial issues.
- Over the next 20 years, Canada will see a significant increase in the number of people diagnosed with neurological conditions, as a result of the aging population.
- The number of Canadians living with dementia and Parkinson's disease is expected to almost double over the next 20 years, as are the total annual health costs for these conditions.

What does this mean for Canadians?

The study marks an unprecedented level of collaboration across fields, professions, jurisdictions, conditions, and interests. It provides information on neurological conditions within a Canadian context, including that neurological conditions, regardless of the specific diagnosis, present similar challenges for individuals, families, health care systems and the Canadian economy. Findings will help Canadians realize the scale, scope and financial burden of neurological conditions in Canada.

The study also highlighted remaining knowledge gaps, including those related to less prevalent conditions, childhood conditions, and specific population groups, such as Aboriginal people and new immigrants. More information is also needed on regional and jurisdictional differences related to the distribution, quality, and costs of health services for Canadians living with neurological conditions.

As the understanding of the impact and scope of neurological conditions in Canada increases, it is expected that governments, health care providers, community organizations and other partners will be better able to work together to develop and deliver policies, programs and services to meet the health and social needs of affected Canadians and their families.

For more information on the National Population Health Study of Neurological Conditions or neurological conditions, visit the NHCC website (www.mybrainmatters.ca) or the Public Health Agency of Canada website (www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php).

To download a copy of *Mapping Connections: An Understanding of Neurological Conditions in Canada*, visit <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>.

Key Messages

- NHCC applauds the Government of Canada's long-term support for neurological conditions, including the \$15 million investment in the National Population Health Study of Neurological Conditions, as well as the innovative approach to shared leadership it adopted for this study.
- The study, and its innovative partnership approach, significantly increased the momentum for collective action within the neurological community, opened doors for future collaborations and initiatives, and established neurological conditions as a priority public health issue for Canada.
- As the population grows and ages, Canadian communities and the health care system must be prepared to respond to the increased demand for caregiving from family and friends and the additional costs of care associated with the projected increase in number of people with neurological conditions.
- Home care programs and long-term care facilities must be prepared to support the increased number of Canadians projected to be living with severe disabilities related to their neurological conditions.
- Actions to facilitate innovations in care, prevention and treatment to reduce health care utilization by Canadians with neurological conditions could result in a substantial amount of health care resources being available to meet other needs.
- While gaps in information still exist, and more research and information is needed, the study provided evidence to support the future direction of activities related to neurological conditions, and identified better ways to meet and manage the health needs of individuals living with neurological conditions and their families.
- NHCC looks forward to building on the momentum fostered by the study by taking additional collective action with our partners in the neurological community to improve the quality of life for all persons with chronic neurological conditions, their families and caregivers.

Quotes

Note: quotes will be inserted throughout the mybrainmatters.ca website. Some quotes will also be included in the NHCC news release regarding the report release. Joyce Gordon is being quoted in multiple sources (Government of Canada news release, NHCC news release, mybrainmatters.ca website) and thus has multiple quotes listed here.

“We are proud to have partnered with the Government of Canada on this study. The study represents a new level of collaboration within the neurological community, and provides findings that have the potential to significantly improve the lives of Canadians living with neurological conditions, their families and caregivers.” [Joyce Gordon, Chair, Neurological Health Charities Canada, President & CEO, Parkinson Society Canada](#)

“NHCC applauds the Government of Canada for its investment and commitment to the collaborative partnership of the National Population Health Study of Neurological Conditions. In addition, we express our appreciation to the 177,000 Canadians affected by neurological conditions and the 130 researchers and clinicians who contributed to the study. This study marks a significant step forward in understanding neurological conditions in Canada and identifies areas where more work is required to improve the lives of all Canadians living with these conditions, their families and caregivers.” [Joyce Gordon, Chair, Neurological Health Charities Canada](#)

“The Canadian Epilepsy Alliance, a member of Neurological Health Charities Canada, is delighted by the release of ‘Mapping Connections’ in which Epilepsy was one of the priority conditions. This study will help provide greater understanding of the impacts that living with a neurological condition can have on people and families; identify gaps where more research is needed; and foster continuing partnerships, with the ultimate goal of improving the quality of life for Canadians affected by a neurological condition.” [Gail Dempsey, President, Canadian Epilepsy Alliance](#)

“The Dystonia Medical Research Foundation Canada is proud to have been a collaborative partner in Canada’s first-ever population health study of neurological conditions. We applaud the efforts of the thousands of volunteers across Canada who engaged in this study.” [Diane Gillespie, Executive Director, Dystonia Medical Research Foundation Canada](#)

“As a member of Neurological Health Charities Canada, the Alzheimer Society welcomes these new findings and applauds the Federal government for their ongoing commitment to address the challenges of neurological conditions. This report sheds more light on the widespread impact of such conditions, which include Alzheimer’s and dementia. More importantly, these numbers will guide our efforts in research and help us provide better support and services for Canadians and their families impacted by these diseases. The Alzheimer Society looks forward to working with its NHCC partners and government to put these numbers into action,” [Mimi Lowi-Young, CEO, Alzheimer Society of Canada](#)

“This study brought funding to research to enhance outcomes for persons with neurological conditions. The collective impact achieved through the partnerships and networks built through the study will be best advanced and achieve the greatest value from the Government of Canada’s investment by taking the critical next step – collective ACTION.” [Dr. Richard J. Riopelle; McGill University, Department of Neurology and Neurosurgery; Chair, Advocacy Committee, Canadian Neurological Sciences Federation; Chief Research Officer, Ontario Neurotrauma Foundation](#)

“As a member of the NHCC, the Heart and Stroke Foundation is looking forward to building on the results of the report to better combat neurological conditions, especially dementia, and other vascular disorders. This report will ultimately help Canadians, and health care providers by

advancing our understanding of the broad range of neurological disorders and how they are connected.” [Bobbe Wood, President, Heart and Stroke Foundation](#)

“Parkinson Society Canada is excited to share in today’s release of the report on The National Population Health Study of Neurological Conditions. We are incredibly proud of the contributions made by Canadians living with Parkinson’s disease and the role Parkinson Society Canada played in this outstanding achievement. This study gives us our first, evidence-based, overview of Parkinson’s disease and its impacts, for Canada, as well as clear indications of the gaps in care, data and research. Now, we need to address these gaps in order to improve the quality of life for people living with Parkinson’s.” [Joyce Gordon, President & CEO, Parkinson Society Canada](#)

“The National Population Health Study of Neurological Conditions is unique in that it represents a collaboration between so many groups and individuals (e.g. patients, advocacy groups, health care leaders, researchers and other key stakeholders). The information generated from this important study has paved the way to help us improve neurological care and to guide future research needs in Canada and beyond.” [Dr. Nathalie Jette and Dr. Tamara Pringsheim, NPHSNC researchers](#)

“The study will provide some much needed evidence of the challenges faced by Canadians like me and my family whose lives are impacted by neurological conditions” [person living with a neurological condition](#)

“I’m looking forward to the release of the study because it is my hope that with this new information we can begin as a nation to address some of the challenges my family experiences, as well as the millions of other Canadians who are impacted by neurological conditions” [caregiver of a person with a neurological condition](#)

“Thank you for your interest in learning more about the experience of Canadians like my family who have gone through the experience of caring for and living with a family member living with a debilitating and ultimately terminal neurological condition. Please join me and Neurological Health Charities Canada in ensuring that the quality of life of people living with neurological conditions in Canada is improved.” [Caregiver of a person with a neurological condition](#)