



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

National Population Health Study of Neurological Conditions

Frequently Asked Questions

Version 5: March 2015

If you have any questions about the National Population Health Study of Neurological Conditions (NPHSNC, or the Study), please do not hesitate to contact:

Neurological Health Charities Canada
Phone: 416-227-9700 ext. 3501
Email: info@mybrainmatters.ca

Members:

ALS Society of Canada
Alzheimer Society of Canada
Alzheimer Society of Ontario
Brain Injury Canada
Canadian Alliance of Brain Tumour Organizations
Canadian Epilepsy Alliance
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The National Population Health Study of Neurological Conditions

Frequently Asked Questions – Version 5

1) What is the National Population Health Study of Neurological Conditions (NPHSNC)?

The \$15 million, four-year National Population Health Study of Neurological Conditions (NPHSNC, or the Study) represents Canada's first-ever population health study of diseases, disorders and injuries of the nervous system ("brain conditions"). The Study investigated the human and economic impacts of brain conditions in Canada. Undertaken between 2009 and 2013, the extensive program of research included three national surveys, 13 pan-Canadian research projects, the expansion of ongoing surveillance to include certain brain conditions, and a microsimulation project to estimate the impacts of brain conditions between 2011 and 2031. [Mapping Connections: An Understanding of Neurological Conditions in Canada](#) is the final report synthesizing key findings from the Study.

2) Who was involved in the NPHSNC?

The Study was developed in partnership between the Government of Canada (Public Health Agency of Canada, Health Canada, Canadian Institutes of Health Research) and Neurological Health Charities Canada (NHCC), a coalition of health charity organizations representing the voice of individuals and families impacted by brain conditions across Canada. Approximately 177,000 Canadians with brain conditions and their caregivers offered insight and personal experience into key areas of the Study. In addition, the Study successfully engaged 130 researchers from across Canada.

3) What was the goal of the NPHSNC?

The NPHSNC was designed to address the lack of information about brain conditions in Canada, and to identify commonalities across conditions. The NPHSNC aimed to identify the scope (incidence and prevalence), quality of life and economic impacts, health service utilization and risk factors of brain conditions in Canada. Findings are intended to inform Canadians and governing bodies about the impact brain conditions have on affected individuals, families and the health care system, and inform future program and policy development.

4) Which brain conditions were included in the NPHSNC?

- Alzheimer's disease and other dementias
- Amyotrophic lateral sclerosis (ALS)
- Brain tumours
- Cerebral palsy
- Dystonia
- Epilepsy
- Huntington's disease
- Hydrocephalus
- Multiple sclerosis
- Muscular dystrophy
- Neurotrauma (traumatic brain injuries and spinal cord injuries)
- Parkinson's disease
- Spina bifida
- Tourette syndrome

The list above identifies the 14 brain conditions originally selected for inclusion in the NPHSNC. The Study also subsequently included some information on migraine, spinal cord tumour, Rett syndrome, and stroke.

5) How were the conditions chosen to be included in the NPHSNC?

Some researchers and other stakeholders have asked why other brain conditions, such as autism, were not included in the list of conditions for the NPHSNC. As NHCC member organizations were heavily involved in the NPHSNC, NHCC could not make commitments on behalf of organizations that were not members. In order to initiate the NPHSNC, brain conditions represented by organizations that were at the table when the agreement was signed were included. It would have been difficult, if not impossible, to add new conditions to the projects that were approved and underway as additional organizations joined NHCC.

It should be noted that NHCC is continuously gathering information on other work currently underway, which fills gaps in the brain condition spectrum. (*See also the information below on stroke, migraine and autism*)

6) Why was stroke not on the list of priority conditions?

Stroke has been identified as a priority area for the cardiovascular disease prevention and surveillance programs within the Public Health Agency of Canada (the Agency) for a number of years.

In terms of stroke surveillance initiatives, the Agency:

- 1) Published a report on cardiovascular diseases (2009), with a supplementary factsheet on stroke (2011). Please see the following websites to access the report: <http://www.phac-aspc.gc.ca/publicat/2009/cvd-avc/index-eng.php>, and factsheet: <http://www.phac-aspc.gc.ca/cd-mc/cvd-mcv/sh-fs-2011/index-eng.php>;

- 2) Included stroke in the Canadian Chronic Disease Surveillance System (routine surveillance system);
- 3) Regularly examines stroke statistics from ongoing surveys such as the Canadian Community Health Survey; and
- 4) Included stroke in the list of brain conditions surveyed in the Survey on Living with Neurological Conditions in Canada and the Survey of Neurological Conditions in Institutions in Canada.

7) Why was migraine not on the list of priority conditions?

Although migraine was not originally listed as a priority condition for this Study, questions related to the incidence, prevalence and impact of migraines were included in two of the Study's surveys:

- 1) Canadian Community Health Survey
- 2) Survey on Living with Neurological Conditions in Canada

8) Why was Autism Spectrum Disorder not on the list of priority conditions?

The Public Health Agency of Canada is collaborating with provincial and territorial governments, and stakeholders, to build the National Autism Spectrum Disorder (ASD) Surveillance System (NASS) in order to gain a comprehensive understanding of ASD across Canada. NASS will track the demographic profile of ASD, including key characteristics, patterns and trends, by collecting and analyzing administrative data from multiple provincial and territorial sectors such as health and education. NASS will first track ASD among children and youth with a view to expanding to adults with ASD and individuals with other developmental disorders.

Knowing how many of Canada's children and youth are impacted by ASD provides a better understanding of this population so policies, programs, services and research initiatives across the country can be implemented based on evidence.

The first collection of data is expected in 2015 with preliminary findings to be made available in 2016. For more information visit:

[http://healthy Canad ians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/autism-eng.php](http://healthy Canadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/autism-eng.php).

9) Were veterans, marginalized groups, ethnic populations and First Nations, Inuit and Métis populations included in the NPHSNC?

First Nations, Inuit and Métis populations:

One Study project specifically researched Aboriginal populations: *Understanding from Within: Developing community driven and culturally relevant models for understanding and responses to neurological conditions among Aboriginal peoples* (Principal Investigator: Carrie Bourassa). This project utilized a mixed methods approach to improve the understanding of how Aboriginal women conceptualize brain conditions, the impact on their families and communities, and the needed resources and supports to provide culturally safe and appropriate care. Since Aboriginal women have been documented to be at increased risk for developing brain conditions, associated with a disproportionate burden of ill-health (vs. non-Aboriginal women), there has been growing concern to conduct research in this field.

Other populations:

The NPHSNC included projects that focused on the role of risk factors (including demographics, ethnicity) in the development and/or progression of brain conditions. These included:

- The Canadian Longitudinal Study on Aging (Principal Investigator: Christina Wolfson)
- Systematic Review of Factors Influencing the Onset and Progression of Neurological Conditions (Principal Investigator: Daniel Krewski)
- Canadian Primary Care Sentinel Surveillance Network (CPCSSN): Neurological Conditions (Principal Investigator: Neil Drummond).

Though not part of the NPHSNC, efforts to build research capacity and advance clinical knowledge and practice related to the brain health of veterans are also already underway in Canada, including by the Canadian Institute for Military & Veteran Health Research (www.cimvhr.ca), and the Canadian Institutes of Health Research (www.cihr-isrc.gc.ca).

10) What was the criterion for selecting research projects within the NPHSNC?

The proposals submitted for funding under the NPHSNC were required to respect the following criteria, amongst others:

- Be national in scope to give a Canadian picture.
- Include a range of characteristics of Canadians – age, sex/gender, urban/rural, immigrant, official languages, north/south, community and institutional living, Aboriginal, etc.

All projects underwent both a relevance review and a scientific review prior to being selected for funding.

11)What was the governance model of the NPHSNC?

An Implementation Committee made up of representatives from the Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research, and Neurological Health Charities Canada provided oversight to the NPHSNC. A Scientific Advisory Committee provided the Implementation Committee with expert scientific advice and oversaw and evaluated the scientific elements of the Study. Various working groups, made up of NHCC and government representatives and researchers, also contributed to the success of the NPHSNC. The Health Canada Research Ethics Board reviewed projects that involved participants, and approval from the Chief Scientist was received in writing before their initiation.

12)How was the \$15 million spent?

The \$15 million dollars of the NPHSNC was approximately split as follows:

- \$1 million over four years to NHCC to cover personnel, travel, overhead, equipment, material and dissemination activities related to the Study;
- \$7 million over four years to fund the 13 research projects; and,
- \$7 million over four years to the Public Health Agency of Canada to cover personnel, evaluation, the development and execution of three surveys, progress meetings and the microsimulation project of the NPHSNC.

13)What is *Mapping Connections: An understanding of neurological conditions in Canada*, and how does it relate to the NPHSNC?

Mapping Connections: An understanding of neurological conditions in Canada is the final report produced from the research completed in the NPHSNC. A synthesis of the information and key messages from the 13 research projects, three national surveys and microsimulation project were all included in this document. This report is available for download at: <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>.

14) Who will use the *Mapping Connections* report?

To reduce the impact and burden of brain conditions in Canada, the information captured in the *Mapping Connections* report will be used by:

- Individuals, families and caregivers affected by brain conditions – to enhance understanding, support information sharing, and recognize the common impacts of brain conditions.
- Researchers – to identify gaps in brain research and build on existing work.
- Health care providers – to better understand the impact brain conditions have on the individuals, caregivers and families to whom they provide care.
- Health Charities – to support advocacy, education and research initiatives.
- Government agencies – to inform decision-making, public policy development, and program changes.
- Other stakeholders in the brain community (e.g. industry).

15) What was the process involved in developing *Mapping Connections*?

Final reports from the individual research components of the NPHSNC were submitted to the Public Health Agency of Canada in May 2013. An extensive process of review, synthesis and consultation ensued before the Honourable Rona Ambrose, Canada's Minister of Health, released the final report of the Study in September 2014.

Summary of Scientific Findings

The Scientific Advisory Committee of the NPHSNC prepared a summary report containing an overview and key findings of each of the individual research components of the Study, as well as the committee's overall impressions, highlights and gaps from the program of research.

Identification of Crosscutting Themes

A Synthesis Panel (*comprised of an external group of scientists, many of whom not otherwise affiliated with the NPHSNC*) identified key themes, highlights and gaps across multiple projects within each pillar of the Study (i.e. scope, risk, impact and health services), as well as across the pillars. The Synthesis Panel's summary report contained the scientific findings that informed the final report of the NPHSNC.

Stakeholder Consultation

The Synthesis Panel report was also used to inform the public of the outcomes of the NPHSNC. Formally, this dissemination occurred through a series of stakeholder consultations, including one in-person and four regional consultations (east, central, Quebec, west), as well as an online survey. Input was received from

individuals living with brain conditions, their families and caregivers; representatives of various NHCC organizations; governments; and health service organizations.

Integration of Scientific Findings and Stakeholder Insight

A Stakeholder Engagement Panel facilitated the integration of stakeholder insights into the report on scientific findings prepared by the Synthesis Panel. The Panel also contributed their insights as to how, through knowledge dissemination and translation, the Study findings could be used to improve the quality of life of persons affected by brain conditions.

Final Report – *Mapping Connections*

After final editing by the Implementation Committee and preparation for publication by the Public Health Agency of Canada, the Stakeholder Engagement Panel's synthesis report eventually become *Mapping Connections: An understanding of neurological conditions in Canada*, the final report of the NPHSNC.

16) What were some of the key findings of the NPHSNC?

Overall key messages

- Individuals living with a brain condition share many of the same functional impacts and needs, regardless of diagnosis.
- Brain conditions can compromise the quality of life of individuals, families and caregivers, due to negative impacts on mental health, general health and financial security.
- Canadians living with a brain condition typically use more health care services than those without a brain condition, or those with other chronic conditions.
- Services and supports provided by families and friends are an important component of care for people with brain conditions.
- As Canada's population grows and ages, more people will be living with brain conditions and experiencing severe disability.

Key messages from each of the pillars of the NPHSNC (impact, health services, scope and risk) can be found under Key Themes in each chapter of the *Mapping Connections* report, and at www.mybrainmatters.ca/en/highlights.

17) Are other resources, related to the NPHSNC or the *Mapping Connections* report available? How do I access them?

- Many of the researchers involved in the NPHSNC have published additional research reports related to their individual projects. They are available at: www.mybrainmatters.ca/en/projects.
- Knowledge products such as a postcard, brochure, YouTube video, video-graphic, and info-graphic related to the NPHSNC and *Mapping Connections* are available at: www.mybrainmatters.ca/en/highlights.
- Past editions of Brain Matters, the electronic newsletter distributed by Neurological Health Charities Canada, also provide extensive information about the NPHSNC and are available for download at: www.mybrainmatters.ca/en/brain-matters-newsletter.

18) How can smaller organizations gather information related to the scope (incidence and prevalence) of their conditions in Canada?

The chapter on the Scope of Neurological Conditions in *Mapping Connections* (Chapter three) provides information on how different methodologies are more effective than others for developing reliable estimates of incidence and prevalence for certain brain conditions. For example, the use of registries may be more effective for gathering information related to rare brain conditions. Registry development guidelines and a toolkit were also developed as part of the NPHSNC (refer to the Canadian Registry Network at <http://canadianregistrynetwork.org>).

19) How will the information from the NPHSNC be shared widely? For example, how will information from the administrative data projects of the Study be distributed to physicians to underscore the importance of good billing/record keeping to good research?

The *Mapping Connections* report and other materials are being broadly shared with as many stakeholders as possible. This includes engagement of various stakeholders, messaging using the NHCC website and social media (e.g. Facebook, Twitter), NHCC member organization websites and newsletters, the Public Health Agency of Canada website, distribution of various information products (including fact sheets to health providers), and other initiatives.

The following initiatives are underway to specifically engage physicians:

- The Canadian Primary Care Sentinel Surveillance Network (CPCSSN): Neurodegenerative Conditions was one of the projects funded by the NPHSNC. Information gathered through this project is being shared

specifically with physicians, through the project's information dissemination plan.

- NHCC is working on building relationships with the Canadian Medical Association.
- The Canadian Neurological Sciences Federation (CNSF), an NHCC member, is a federation of Societies representing medical professionals with a common focus on diseases, disorders and injuries of the nervous system. The CNSF has actively promoted both the progress and the results of the Study to its members.
- Many specialists in the brain field as well as general practitioners were also provided information relating to the NPHSNC and the *Mapping Connections* report through direct email or fax distribution.

20) Will the Government continue to work with NHCC on additional studies/gaps now that the Study has concluded?

Following the release and dissemination of *Mapping Connections*, the final report of the Study, the official partnership between NHCC and the Public Health Agency of Canada is complete. However, the Study provided a unique example of how organizations can work together with government to achieve extraordinary results, while leveraging the strengths of all organizations. Long-lasting, positive relationships have been built as a result of the Study, not only between NHCC and the Public Health Agency of Canada, but also within the brain community.

NHCC will continue its work in advocacy and awareness of brain conditions, and continue to press for action to fill knowledge gaps identified by the NPHSNC and to improve the quality of life of all persons affected by brain conditions in Canada.

The Public Health Agency of Canada's Canadian Chronic Disease Surveillance System will continue to track trends of certain brain conditions in the Canadian population on an ongoing basis (<http://www.phac-aspc.gc.ca/cd-mc/nc-mn/mc-fs-ec-fr-eng.php>) and update the Neurological Conditions section of the Canadian Best Practices Portal (<http://cbpp-pcpe.phac-aspc.gc.ca/chronic-diseases/neurological-conditions>).

21) How can I help?

Sharing information on brain conditions is the most important thing you can do to help. Please feel free to widely distribute the *Mapping Connections* report and all related products (listed in question 16) to your local Members of Parliament, colleagues, family members, friends and others within your network. Refer to Neurological Health Charities Canada's website (www.MyBrainMatters.ca), download the *Brain Matters* newsletters, Like MyBrainMatters on Facebook, and Follow NHCC on Twitter @MyBrainMatters.

RESEARCH PROJECTS of the NPHSNC

| Project | Principal Investigator | Institution | Area(s) of Focus |
|---|---|---|---|
| Neurological Conditions in British Columbia | Kim Reimer | British Columbia Ministry of Health | Incidence, prevalence and co-morbidities, Impact |
| Expansion of the Canadian Chronic Disease Surveillance System for National Surveillance of Neurological Conditions | Catherine Pelletier | Public Health Agency of Canada | Incidence, prevalence |
| Findings from the Canadian Community Health Survey (2010–2011) | Claudia Lagacé | Public Health Agency of Canada | Incidence, prevalence |
| Expansion of a Canadian Multi-Regional Population-Based Cerebral Palsy Registry | Michael Shevell Maryam Oskoui | McGill University McGill University | Incidence, prevalence and co-morbidities |
| Canadian Longitudinal Study on Aging: Neurological Conditions Initiative (CLSA-NCI) | Christina Wolfson Parminder Raina | McGill University McMaster University | Incidence, prevalence and co-morbidities, Impact, Risk |
| Canadian Primary Care Sentinel Surveillance Network – Neurodegenerative Conditions | Neil Drummond Richard Birtwhistle | University of Calgary Queen’s University | Incidence, prevalence and co-morbidities, Risk, Health Services |
| Use and Gaps in Health and Community Based Services for Neurological Populations: A Systems Analysis | Susan Jaglal | University of Toronto | Health Services |
| Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC) | John Hirdes Coleen Maxwell Nathalie Jetté | University of Waterloo University of Waterloo University of Calgary | Incidence, prevalence and co-morbidities, Impact, Health Services |
| The Everyday Experience of Living with and Managing a Neurological Condition (LINC) | Joan Versnel Tanya Packer | Dalhousie University Dalhousie University | Impact, Health Services |
| National Population Health Study of Neurological Conditions Microsimulation Component: Health and Economic Modelling of Neurological Conditions | Christina Bancej | Public Health Agency of Canada | Impact |
| Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal People | Carrie Bourassa | University of Regina | Impact, Health Services, Risk |
| Validation of Administrative Data Algorithms to Determine Population Prevalence and Incidence of Alzheimer’s Disease and Other Dementias, MS, Epilepsy and Parkinson’s Disease (Parkinsonism) | Karen Tu Liisa Jaakkimainen Debra Butt | University of Toronto University of Toronto University of Toronto | Incidence, prevalence and co-morbidities, Health Services, Impact |

| Project | Principal Investigator | Institution | Area(s) of Focus |
|---|---|---|--|
| Systematic Review of Factors Influencing the Onset of Neurological Conditions | Daniel Krewski | University of Ottawa | Risk |
| Systematic Review of Factors Influencing the Progression of Neurological Conditions | Daniel Krewski | University of Ottawa | Risk |
| Neurological Registry Best Practice Guidelines and Implementation Toolkit | Lawrence Korngut Nathalie Jetté Tamara Pringsheim | University of Calgary University of Calgary University of Calgary | Incidence, prevalence and co-morbidities |
| Survey on Living with Neurological Conditions in Canada (2011–2012) | Claudia Lagacé | Public Health Agency of Canada | Incidence, prevalence |
| Survey of Neurological Conditions in Institutions in Canada (2011–2012) | Claudia Lagacé | Public Health Agency of Canada | Incidence, prevalence |
| Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance | Nathalie Jetté Tamara Pringsheim | University of Calgary University of Calgary | Incidence, prevalence and co-morbidities |