

Objectives and Contributions of the Research Projects of the National Population Health Study of Neurological Conditions

This document provides a short summary of each of the individual research projects of the National Population Health Study of Neurological Conditions (the Study), including objectives and contributions to the Study.

The Study included three national surveys, 13 pan-Canadian research projects, the expansion of the national surveillance system to include certain neurological conditions, and a microsimulation project to estimate the impacts of neurological conditions between 2011 and 2031. The projects addressed the impacts, health service utilization, scope, and risk factors of selected neurological conditions.

Additional information is available in the Study's final report, [*Mapping Connections: An Understanding of Neurological Conditions in Canada*](#), as well as in related online resources, where available.

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Research Projects of the National Population Health Study of Neurological Conditions

NATIONAL SURVEYS

1. Findings from the Canadian Community Health Survey (2010-2011)

Principal Investigators:

Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Sulan Dai, Christina Bancej, Catherine Dickson, Jay Onysko, Public Health Agency of Canada

Objectives:

- i) To provide community-based prevalence estimates for neurological conditions by age and sex;
- ii) To examine the prevalence of neurological conditions by selected sociodemographic variables.

Contribution: This project added a neurological module to the Canadian Community Health Survey (CCHS) and provided a snapshot of the national prevalence of neurological conditions in Canadian communities. In addition, this project provided a better understanding of the advantages and disadvantages of using the CCHS survey methodology to estimate prevalence of neurological conditions at the national level, and insights to inform the development of valid surveillance approaches for neurological conditions in Canada.

Online Resources: CCHS Annual Component [2010](#) and [2011](#)

2. Survey on Living with Neurological Conditions in Canada (SLNCC)

Principal Investigators:

Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Sulan Dai, Christina Bancej, Catherine Dickson, Jay Onysko, Public Health Agency of Canada

Objectives: To describe the characteristics, general physical and mental well-being, and comorbid chronic conditions of Canadians living with a neurological condition; as well as the impact of neurological conditions on quality of life.

Contribution: This project provided an overview of the often diverse and debilitating impacts of neurological conditions on the lives of Canadians affected by these conditions, including their impacts on physical and mental health, daily activities, and work status, among others. Many common impacts were noted among affected Canadians, regardless of diagnosis. Findings can be used to inform programs and develop policies related to neurological conditions.

Online resources: [Survey on Living with Neurological Conditions in Canada](#)

3. Survey of Neurological Conditions in Institutions in Canada

Principal Investigators:

Claudia Lagacé, Asako Bienek, Catherine Pelletier, Ming-Dong Wang, Sulan Dai, Christina Bancej, Catherine Dickson, Jay Onysko, Public Health Agency of Canada

Objective: To provide prevalence estimates of neurological conditions in long-term care facilities in Canada.

Contribution: This survey provided a snapshot of the national prevalence of neurological conditions in Canadian long-term care facilities, which is essential to obtain a more comprehensive picture of the scope of these conditions in Canada. As neurological conditions can have serious and debilitating impacts, Canadians living with these conditions may have to transition into long-term care facilities. It estimated that 64.8% of residents in long-term care facilities had at least one of the targeted 16 neurological conditions.

Online resources: [Survey on Neurological Conditions in Institutions in Canada \(2011-2012\)](#)

PAN-CANADIAN RESEARCH PROJECTS

Collectively these pan-Canadian projects provided meaningful evidence on the impact, health service utilization, scope (incidence and prevalence), and risk factors associated with neurological conditions in Canada.

4. Neurological Conditions in British Columbia

Principal Investigator: **Kim Reimer**, British Columbia Ministry of Health

Objectives:

- i) To provide population-level estimates of incidence, prevalence, mortality, health care utilization and cost for neurological conditions in British Columbia; and,
- ii) To perform an extensive review of the diagnostic codes used to identify neurological conditions.

Contribution: This project identified the high use and direct costs of health services by individuals living with neurological conditions in British Columbia. Although these findings may not be fully representative of all provinces and territories, they provide useful information on a substantial proportion of the Canadian population and a baseline for comparison.

5. Expansion of a Canadian Multi-Regional Population-Based Cerebral Palsy Registry

Principal Investigators: **Michael Shevell, Maryam Oskoui**, McGill University

Objectives:

- i) To extend the existing cerebral palsy registry to additional regions and provinces;
- ii) To identify risk factors associated with cerebral palsy; and,
- iii) To acquire additional information on health service delivery to young children with cerebral palsy.

Contribution: This project identified key challenges related to registry expansion. Although restricted to cerebral palsy, the lessons learned can be extrapolated to registries for other conditions. This project also identified service gaps and regional disparities in health service delivery related to cerebral palsy.

Online Resources: [Canadian Cerebral Palsy Registry](#)

6. Canadian Longitudinal Study on Aging: Neurological Conditions Initiative (CLSA-NCI)

Principal Investigators:

Christina Wolfson, McGill University
Parminder Raina, McMaster University

Objectives:

- i) To design a comprehensive assessment to estimate the incidence and prevalence of four neurological conditions (dementia, neurological injury, epilepsy, Parkinson's disease);
- ii) To assess the impact of the conditions on health, the social care system and families; and,
- iii) To develop CLSA sub-studies to examine the risk and prognostic factors of the targeted neurological conditions.

Contribution: As a result of the CLSA-NCI, information specific to the four identified neurological conditions is being collected along with a variety of biological, medical, psychological, social, lifestyle and economic factors of peoples' lives. The information will be available for analysis to understand how, individually and in combination, the varying factors have an impact in both maintaining health and in the development of disease and disability as people age.

Online Resources: [Canadian Longitudinal Study on Aging](#)

7. The Canadian Primary Care Sentinel Surveillance Network: Neurological Disease

Principal Investigators:

Neil Drummond, University of Calgary

Richard Birtwhistle, Queen's University

Objectives:

- i) To develop a database with information on dementia, epilepsy and parkinsonism;
- ii) To study the epidemiology of the three conditions; and,
- iii) To study the clinical care of people with the three conditions in primary care settings.

Contribution: The Canadian Primary Care Sentinel Surveillance Network was expanded to include select neurological conditions. Evidence from this project suggests that the use of electronic medical records can be used for regular surveillance of neurological conditions in community-based primary care when appropriate guidelines are in place.

Online Resources: [Canadian Primary Care Sentinel Surveillance Network](#)

8. Use and Gaps in Health and Community-Based Services for Neurological Populations: A Systems Analysis

Principal Investigator: **Susan Jaglal**, University of Toronto

Objectives:

- i) To identify health and community based service needs and gaps and exemplary programs in the literature for individuals living with neurological conditions;
- ii) To explore, from the perspective of service providers, the health and community based service needs and gaps in the Canadian context from the perspective of service providers;
- iii) To describe the availability, access, use, coordination and integration of health and community services and needs and gaps among service providers; and,
- iv) To identify opportunities and successes that can be leveraged across the regions and nationally.

Contribution: This project analysed the health service utilization of persons with neurological conditions. Gaps were noted in areas such as mental health services for persons living with neurological conditions, and services for persons with rare neurological conditions. As well, Canadians living with a neurological condition typically use more health care services than those without a neurological condition, or those with other chronic conditions.

9. Innovations in Data, Evidence, and Applications for Persons With Neurological Conditions (ideasPNC)

Principal Investigators:

John Hirdes, Colleen Maxwell, University of Waterloo

Nathalie Jetté, University of Calgary

Objectives:

- i) To estimate the prevalence of 10 neurological conditions across the continuum of care;
- ii) To examine the costs associated with neurological conditions;
- iii) To examine the experience of caregivers;
- iv) To develop a detailed clinical profile of persons with neurological conditions in care settings;
- v) To evaluate the applicability to current planning approaches in various service settings for those with neurological conditions;
- vi) To examine access to, and utilization of, health and social services by persons with neurological conditions; and,
- vii) To identify approaches for performance measurement for organizations serving persons with neurological conditions.

Contribution: This project, described in *Mapping Connections* as “the interRAI Project”, provided a wealth of information on the impact of neurological conditions on individuals and caregivers in care facilities. It was determined that the use of existing data collection processes, like interRAI, could help address some of the gaps in research related to the impact of neurological conditions.

Online resources: [interRAI Canada - ideas PNC](#)

10. The Everyday Experience of Living With and Managing a Neurological Condition (LINC)

Principal Investigators: **Tanya Packer, Joan Versnell**, Dalhousie University

Objectives:

- i) To describe the impact of neurological conditions on the everyday life experiences of individuals, their families and caregivers;
- ii) To examine the complex inter-dependence between adults with a neurological condition and their families; and,
- iii) To describe the ability of health, social and community service agencies in supporting persons living with neurological conditions.

Contribution: Through surveys, phone conversations and personal interviews, the LINC project demonstrated that Canadians with neurological conditions have greater

limitations in daily activities and use more health services than Canadians with other chronic conditions. They rely extensively on paid and family support, and experience limitation at work, home and education. Many report that health care services do not meet their needs. The LINC Project provided unique information on the impact of neurological conditions on children and families and the quality of life of parents.

Online Resources: [LINC Project Videos and Fact Sheets](#)

11. Understanding from Within: Developing Community Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal Peoples

Principle Investigator: **Carrie Bourassa**, University of Regina

Objectives:

- i) To improve the understanding of how Aboriginal Canadians conceptualize neurological conditions and the impact on their families and communities;
- ii) To determine risk and protective factors for neurological conditions among the participants; and,
- iii) To assess the needed resources and supports to provide culturally appropriate care.

Contribution: This project identified several challenges met by First Nations and Metis individuals requiring health services for neurological conditions including lack of specialized care and transportation, as well as the need for improved navigation of the health system and better cultural competence among health care providers.

Online Resources: [Native Women's Association of Canada - Understanding From Within](#)

12. Validation of Administrative Data Algorithms to Determine Population Prevalence and Incidence of Alzheimer's disease and other dementias, Multiple Sclerosis, Epilepsy and Parkinson's Disease (Parkinsonism)

Principal Investigators:

Karen Tu, Liisa Jaakkimainen, Debra Butt, University of Toronto

Objectives:

- i) To perform an administrative data validation using primary care electronic medical records as a reference standard to determine the optimal administrative

- data algorithm to identify individuals with epilepsy, multiple sclerosis, Alzheimer's disease and other dementias and Parkinson's disease; and
- ii) To use the validated algorithms to examine incidence and prevalence for these conditions.

Contribution: This project completed the groundwork required to use administrative data in the surveillance of neurological conditions. Validated algorithms were used to support the addition of several neurological conditions to the Canadian Chronic Disease Surveillance System.

Online Resources: [Electronic Medical Record Administrative data Linked Database \(EMRALD\)](#)

13 & 14. Systematic Reviews of Factors Influencing the Onset and Progression of Neurological Conditions (2 projects)

Principal Investigator: **Daniel Krewski**, University of Ottawa

Objectives:

- i) To conduct a literature review of the risk factors for the development and progression of each of the priority neurological conditions in the Study; and,
- ii) To assess and summarize the available evidence on the determinants of neurological conditions and describe the strengths and weaknesses of the available literature.

Contribution: This project looked at the potentially modifiable risk factors for the onset and progression of neurological conditions such as cardiovascular risk factors, neurological injury, falls, chemical exposures and nutritional deficiencies. Existing data sources can be developed further to provide insight into factors that may increase the risk for developing a neurological condition.

15. Neurological Registry Best Practice Guidelines and Implementation Toolkit

Principal Investigators:

Lawrence Korngut, Nathalie Jetté, Tamara Pringsheim, University of Calgary

Objectives: To create guidelines and a toolkit for the development and implementation of registries of neurological conditions in Canada.

Contribution: This project developed comprehensive guidelines and a toolkit for the development, implementation and maintenance of registries of neurological conditions in Canada.

Online Resources: [Canadian Registry Network - Neurological Registry Guidelines](#)

16. Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance

Principal Investigators: **Nathalie Jetté, Tamara Pringsheim**, University of Calgary

Objectives:

- i) To perform systematic reviews of the incidence and prevalence of neurological conditions;
- ii) To summarize and make recommendations on the best ascertainment sources for surveillance of each condition; and,
- iii) To develop an inventory of existing neurological registries in Canada and other developed countries.

Contribution: This project produced new information related to the prevalence and incidence of neurological conditions in Canada, and outlined the most appropriate sources of ascertainment for the surveillance of various neurological conditions as well as gaps in knowledge. Findings also informed the inclusion of certain neurological conditions in the Canadian Canadian Chronic Disease Surveillance System.

NATIONAL SURVEILLANCE EXPANSION

17. Expansion of the Canadian Chronic Disease Surveillance System for National Surveillance of Neurological Conditions

Principal Investigators:

Catherine Pelletier, Asako Bienek, Sulan Dai, Jay Onysko, Chris Waters, Public Health Agency of Canada

Objectives:

- i) Among the 15 neurological conditions assessed, to determine which conditions can be appropriately tracked at the national level using health administrative databases; and,
- ii) To develop case definitions for Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, parkinsonism, and stroke to track prevalence and

incidence, and eventually all-cause mortality, comorbidities, and use of health care services among Canadians living with these conditions.

Contribution: Building on the evidence from other projects in the Study, this project determined which neurological conditions can be appropriately tracked at the national level using health administrative databases, and initiated the process of including Alzheimer’s disease and other dementias, epilepsy, multiple sclerosis and parkinsonism to the Canadian Chronic Disease Surveillance System for ongoing, national-level surveillance.

Online resources: [Public Health Agency of Canada - Surveillance](#)

MICROSIMULATION PROJECT

18. National Population Health Study of Neurological Conditions Microsimulation Component: Health and Economic Modelling of Neurological Conditions

Principal Investigators:

Christina Bancej, Anna J. Zycki, Ronald Wall, Trang Nguyen, Public Health Agency of Canada

Rochelle Garner, Philippe Fines, Douglas Manuel, Julie Bernier, Statistics Canada

Objective: To project the future burden, both in terms of dollars and impact on health, of seven neurological conditions over a 20-horizon (2011-2031) under status quo assumptions. The Statistics Canada Population Health Model (POHEM) platform was expanded to build microsimulation models for Alzheimer’s disease and other dementias, cerebral palsy, epilepsy, multiple sclerosis, Parkinson’s disease/parkinsonism, hospitalized traumatic neurological injury, and hospitalized traumatic spinal cord injury.

Contribution: This project developed population health microsimulation models for the seven neurological conditions studied. These models provide critical infrastructure for studying and projecting the health and economic impacts of these conditions over a 20-year horizon for incorporation into policy decisions. Findings of the project predict a significant increase in the number of people diagnosed and living with neurological conditions and shed light on the escalating costs of these conditions in their social, economic, and health dimensions.

Online Resources: [Statistics Canada - Microsimulation Health Models](#)