

National Population Health Study of Neurological Conditions in Canada

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Introduction

On June 5, 2009, the federal Minister of Health announced that the Government of Canada was committing \$15 million for a four-year national population health study of neurological conditions (NPHSNC). Designed to improve our understanding of neurological conditions and of their impacts on Canadians, the NPHSNC is being administered by the Public Health Agency of Canada (PHAC) and co-managed by Neurological Health Charities Canada (NHCC), a non-governmental organization representing 25 charities with a focus on neurology. Rather than a single study, the NPHSNC is an extensive research program comprising three national surveys and 13 pan-Canadian research projects, including some studies that look at the feasibility of ongoing surveillance of some neurological conditions and the development of a micro-simulation model. Results will inform future program and policy development. The NPHSNC team is made up of more than 125 researchers at 30 academic and non-academic institutions across Canada.

This paper provides a brief overview of the NPHSNC, summarizes the rationale for the study and presents its history, objectives and approaches.

Background

In 2006, the World Health Organization published *Neurological Disorders: Public Health Challenges*. This book warned of

the societal and health care consequences of the predicted increase in prevalence of neurological and other chronic disorders, coupled with disabilities resulting from the ageing of the global population and increasing life expectancy.¹

In 2007, the Canadian Institute for Health Information, the Canadian Neurological Sciences Federation and the Canadian Brain and Nerve Coalition jointly prepared *The Burden of Neurological Diseases, Disorders and Injuries in Canada*.² This report considered the impact of 11 common neurological conditions in Canada, including Alzheimer disease, amyotrophic lateral sclerosis (ALS), brain tumours, cerebral palsy, epilepsy, head injury, headaches, multiple sclerosis, Parkinson disease, spinal injuries and stroke. The total combined cost of these conditions was "...estimated to be \$8.8 billion, representing 6.7% of the total attributable cost of illness in Canada in 2000–2001."²

History of the NPHSNC

The growing impact of neurological conditions on Canadians and health care systems made it clear that more in-depth information was needed to inform future policy decisions. As a result, in 2008 a number of charitable organizations formed a coalition, NHCC, tasked with working to improve the quality of life of all people living with chronic brain conditions, disorders and injuries, as well as of their caregivers. NHCC does this by elevating brain health to the top of

government agendas and ensuring that research, prevention, treatments and supports for those living with chronic brain conditions are universally accessible.³ NHCC's role is "to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health."³

Although the individual member organizations represented by NHCC continued to fund their own psychosocial and/or clinical research projects, the information they gathered could not provide the practical steps necessary to prepare the entire country for the burgeoning population of older adults, in particular those affected by neurological conditions. In June 2008, members of NHCC met with representatives of the Government of Canada to discuss the paucity of epidemiological information on neurological conditions in this country.

In January 2009, PHAC established a Neurological Surveillance Advisory Committee. A nation-wide online survey in February 2009 asked respondents to prioritize research questions across eight themed areas: frequency and progression; access to professional care and services; risk factors; co-existing conditions; impact on individuals; management of the condition; unpaid caregiving; and paid caregiving. Of the 3000 people who responded, 34% identified themselves as living with a neurological condition, 35% as family members or unpaid caregivers, and 31%

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as members of the neurological workforce (service organization staff, health care professionals, researchers, paid caregivers). This input from stakeholders was shared with the approximately 40 neurological researchers at a technical workshop the following month. Hosted jointly by PHAC and NHCC, the purpose of the workshop was to introduce the notion of a national population-based study to the researchers and to prioritize research domains.

With consideration given to the survey results, workshop participants recommended that a study addressing neurological conditions be based on the following five areas of focus:

- the scope of brain conditions, specifically incidence, prevalence and comorbidities;
- the impact of neurological conditions on individuals, their caregivers and families;
- risk factors for onset and prognostic factors;
- best practices and gaps in health services; and
- registries.

In the fall of 2009, a broader group of researchers was formally invited to participate as members of one of five research project teams, later called Expert Advisory Groups. A chair for each group was identified, and in December 2009, a second technical workshop was held. The Expert Advisory Groups, each representing one of the five areas of focus, reorganized them and recommended the types of projects and methodology to be included in the study. “Registries” was subsumed under “scope,” leaving four main categories: scope (incidence, prevalence and comorbidities); risk factors; impact; and health services.

Taking into account both the population disease burden and key knowledge gaps, as well as the membership of NHCC at the time, the following priority conditions were chosen: ALS, Alzheimer disease and related dementia, brain tumours, cerebral palsy, dystonia, epilepsy, Huntington disease, hydrocephalus, neurotrauma (including brain and spinal cord injuries), multiple

sclerosis, muscular dystrophy, Parkinson disease, spina bifida, Tourette syndrome, stroke and migraine.

Following this meeting, PHAC and NHCC worked together to finalize the research plan and, in January 2010, PHAC and NHCC issued a call for letters of intent, receiving 42 responses from across Canada. Each letter of intent was reviewed to determine the fit of the proposed work with the needs of the broader study. From these, 12 teams were invited to submit full proposals by April 15, 2010. These projects underwent internal and external scientific review, and 10 were recommended for funding. Identified gaps in the received letters of intent resulted in reissuing the call for proposals in November of that year to further address the registries and health services components of the study through three additional projects.

Thus the NPHSNC was born.

Governance

An Implementation Committee made up of representatives from PHAC, Health Canada, CIHR and NHCC oversees the NPHSNC. A Scientific Advisory Committee provides the Implementation Committee with expert scientific advice and oversees and evaluates the scientific elements of the NPHSNC. Various working groups, made up of NHCC and government representatives and researchers, also contribute to the success of the NPHSNC. Projects that involved participants were reviewed by the Health Canada Research Ethics Board, and approval from the Chief Scientist was received in writing before their initiation.

Categories and projects

Each of the NPHSNC’s investigator-driven research projects fall under the aforementioned categories: scope, impact, risk factors and health services.

Scope

The scope category was developed to allow for a review of existing databases, tools and methods and to build capacity for national and patient-driven online registries of neu-

rological conditions. Included projects determined the incidence and prevalence of each of the priority neurological conditions in Canada and worldwide; used health administrative databases to assess co-existing health conditions, health service utilization and economic impact; and validated survey and/or administrative data in use. Other projects created an inventory of existing Canadian and international neurological registries; developed consensus guidelines on registry development and content; prepared a toolkit for the development and implementation of registries; and explored the feasibility of expanding existing registries by, for example, adding new conditions, expanding to other parts of the country, or adding new data.

Impact

Projects that assess the impact of neurological conditions on individuals and on their families and caregivers included a systematic literature review of the biopsychosocial and economic impact of neurological conditions and of the factors that influence the impact of these conditions. In addition, co-existing health conditions, self-management, and health and community services were assessed. Also documented and analyzed were the experiences of people living with neurological conditions both in the community and in institutions across Canada; these included approaches to self-management, challenges and coping strategies, use of and gaps in services, and suggestions for improvements. Lastly, an assessment of the quality of life of Canadians living with neurological conditions determined the influence of personal and community factors (such as accommodations, urban layout, etc.), health services and self-management.

Risk factors

A systematic review of the factors—biological, lifestyle, socio-economic, environmental and psychosocial—that influence the onset, prognostic factors and comorbidities of neurological conditions was conducted. This category also included projects that will add new knowledge on the risk of developing a neurological condition or of prognostic factors.

Best practices and gaps in health services

Projects in this category helped to identify the continuum of care needed for people living with neurological conditions and the best practice models of care that increase quality of life or slow its decline. In addition, an inventory of current health and related services across the country was created and exemplary services and gaps in current practices identified.

Additional NPHSNC components contributing to the “scope” and “impact” categories

Canadian Community Health Survey - Neurological Conditions Module

Pan-Canadian studies of the prevalence of neurological conditions were facilitated by adding questions about these to the 2010/2011 cycles of the Canadian Community Health Survey (CCHS). The aim of the CCHS - Neurological Conditions Module was to collect self-reported prevalence data on specific neurological conditions from individuals with these conditions as well as from other members of the 130 000 Canadian households surveyed. Unique to this module, CCHS methods were expanded on to include all household members, including children under the age of 12 years. The aim of this strategy was to increase the sample size and allow data collection on conditions that present in early childhood.

Survey on Living with Neurological Conditions in Canada (SLNCC)

A follow-up survey of the approximately 4500 individuals who reported neurological conditions in the CCHS Neurological Conditions Module focused on the impact of these conditions on quality of life, particularly family life.

Survey of Neurological Conditions in Institutions in Canada (SNCIC)

The CCHS does not include people living in institutions. Because many people with neurological conditions, particularly in more advanced stages, live in long-term residential care facilities and other institutions, in 2011/2012 Statistics Canada conducted a survey of a representative sample to measure the prevalence of selected neurological conditions in this population.

Expansion of the CCDSS

The PHAC's existing Canadian Chronic Disease Surveillance System (CCDSS), which uses data from provincial/territorial health administrative databases, will include selected neurological conditions. This surveillance system provides information on incidence of new diagnoses, prevalence of these conditions, health outcomes and use of related health services.

Microsimulation

A microsimulation model to project the future burden of priority neurological conditions over the next 5, 10, 15 and 20 years is being developed. This model projects the future incidence and prevalence of these conditions; quality of life of Canadians living with these conditions in terms of disability-adjusted life years and health-adjusted life expectancy (years lived in relative health); life expectancy; and need for, use of and treatment costs of health services.

Next steps

The NPHSNC is in its final year. Over the next several months, as the study's component projects are completed, NHCC and government agencies will undertake a synthesis process to engage stakeholders and disseminate information about the study. This synthesis process will include a meeting of research experts to compile major themes from the research data and significant stakeholder consultation. A “Synthesis Panel” will be struck, comprising experts in epidemiology, health economics, health care evaluation/administration, neurology and medical practice. Its task will be to review the final outputs from the various components and write a summary report. Additional input will be gathered through in-person consultations, online requests for information and feedback from key stakeholder groups. A “Stakeholder Engagement Panel,” comprising individuals in the broad community of neurological health charities who have a stake in the success of the NPHSNC and are familiar with one or more of the project focus areas, will then also be struck to review the report on the stakeholder consultations and make recommendations for integrating stakeholder insights in the report on findings. The culmination of all of this work will be a report, to be

submitted to the federal Minister of Health in March 2014.

NPHSNC's knowledge translation and dissemination strategy involves all partners, principal investigators, NHCC and the Government of Canada. Partners will work individually and collectively to ensure that the knowledge generated is disseminated broadly to Canadian stakeholders using a combination of knowledge translation strategies including, but not limited to, peer-reviewed publications, webinars, summary reports and fact sheets.

Conclusion

NPHSNC is collaboration between non-governmental organizations and government that will increase our knowledge about the scope, impact, risk factors and health services related to specific neurological conditions in Canada that can build the foundation for frameworks of intervention.

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