NATIONAL POPULATION HEALTH STUDY of NEUROLOGICAL CONDITIONS - Overview

The Honourable Leona Aglukkaq, Minister of Health for Canada, announced funding of $15 million to support a four-year National Population Health Study of Neurological Conditions on June 5, 2009. The first of its kind in Canada, this study is being jointly led by Neurological Health Charities Canada and the Public Health Agency of Canada (Chronic Disease Surveillance). Its purpose is to fill gaps in knowledge about the state of neurological conditions in Canada, and the experience of individuals with neurological conditions, their families, and caregivers.

In the words of Minister Aglukkaq, “this study will arm us with the knowledge we need to help alleviate some of the burden associated with these conditions (for individuals, families and society overall). It will allow both government and health charities to better develop and plan programs and health services.”

The study will provide key information to improve current knowledge about the:

- Incidence, prevalence, co-morbidities of neurological conditions
- Risk factors for the development of neurological conditions and prognostic factors
- Use of health services, gaps in services, and recommended improvements
- Impact of neurological conditions now and projected over the next 20 years

The National Population Study of Neurological Conditions includes several components – three national surveys, several pan-Canadian research projects and a micro-simulation model.

To date, the three survey projects are underway under the leadership of the Public Health Agency of Canada (PHAC) and ten research proposals have been recommended for funding by the Study’s Implementation Team. A second call for proposals was issued in November 2010 to fill gaps in the Health Services and Registries components.

Together, the surveys, micro-simulation modeling and research projects being undertaken by research teams across Canada, will shape our understanding of the current status of neurological conditions in Canada, related issues, and potential interventions and policy directions for the future.

THE PAN-CANADIAN RESEARCH PROJECTS

Collectively the projects described below will meet the objectives of the four pillars of the Study - impact, risk factors, health services, and incidence/prevalence.

The Everyday Experience of Living with and Managing a Neurological Condition (The LINC Study)

Principal Investigators:

Dr. Tanya Packer, Professor and Director, Dalhousie University, Occupational Therapy

Dr. Joan Versnel, Assistant Professor, Dalhousie University, Occupational Therapy
This research project seeks to understand the everyday lives of people with neurological conditions, who strive to work, go to school, raise families, and participate in the community. The support and resources that make everyday life possible and meaningful will be explored. Specifically, this research will describe:

- the impact of a neurological condition on the everyday life experiences of Canadians, including parents of children with neurological conditions;
- the complex inter-dependence between children and adults with a neurological condition and their families; and
- the ability of health, social and community services and agencies to support individuals and families to self-manage life with a neurological condition.

It is anticipated that the findings of this research project will inform service and policy development for people with neurological conditions across Canada.

**Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC)**

**Principal Investigators:**

**John P. Hirdes**, PhD, University of Waterloo and Homewood Research Institute

**Nathalie Jetté**, MD, University of Calgary

**Colleen J. Maxwell**, PhD, University of Calgary

The ideas PNC project will use clinical and administrative health care data from eight Canadian provinces and territories to explore the prevalence of neurological conditions across the continuum of care. The project will provide clinical profiles of persons with 12 different conditions. It will also examine caregiving issues, health service use, drug utilization, costs and quality of care. The evidence obtained from this study will help to improve health information systems and health services and support formal and informal caregivers for persons living with neurological conditions in Canada.

**Canadian Longitudinal Study of Aging: Neurological Conditions Initiative (CLSA-NCI)**

**Principal Investigators:**

**Dr. Christina Wolfson**, PhD, Professor, Department of Epidemiology, Biostatistics & Occupational Health and Department of Medicine, McGill University; Director, Neuroepidemiology Research Unit & Medical Scientist, Research Institute – McGill University Health Centre

**Dr. Parminder Raina**, PhD, Professor and Canada Research Chair in GeroScience; Raymond and Margaret Labarge Chair in Optimal Aging ; Director, Evidence-Based Practice Centre; Department of Clinical Epidemiology & Biostatistics, McMaster University
**Dr. Ron Postuma**, MD, MSc., Assistant Professor, Department of Neurology and Neurosurgery, McGill University

The Canadian Longitudinal Study on Aging (CLSA) is a national 20-year study of 50,000 adults aged 45-85 currently underway in Canada. In this study we propose to implant within the CLSA a research program to facilitate the conduct of population-based research projects in dementia, Parkinson’s disease, epilepsy and traumatic brain injury. The inclusion of a neurological focus within the CLSA will facilitate the conduct of studies related to prevalence and incidence; risk factors and prognostic factors; health services and impact of these conditions in the aging population.

**Neurological Conditions in British Columbia**

**Principal Investigators:**

**Kim Reimer**, Population Health Surveillance and Epidemiology, Population and Public Health, B.C. Ministry of Health

**Dr. Robert Fisk**, Population Health Surveillance and Epidemiology, Population and Public Health, B.C. Ministry of Health

Using data from administrative records (hospitalizations and physician services), this project will provide population-level measures of incidence, prevalence, comorbidity, mortality, health care service utilization and health care costs for selected neurological disorders and neurological conditions in BC. It will also provide data quality assessment work in the form of an extensive review of the diagnostic codes used to identify neurological conditions over time, an evaluation of alternative ways of defining neurological conditions in administrative data, and a comparison of findings with other sources, including surveys and published data. This work will contribute to the ongoing development and refinement of methodologies employing administrative datasets for chronic disease surveillance and the techniques and strategies for use will be shared with all jurisdictions through the Public Health Agency of Canada (PHAC). Work is underway: reviewing diagnostic codes, determining the best way to identify cases, and assessing incidence, prevalence, and mortality statistics in 2010/2011; analyzing comorbidities and utilization in 2011/2012; and conducting special analyses, such as reviewing prescriptions and performing detailed data quality assessments, and sharing with our academic partners and other jurisdictions in 2012/2013.

**Systematic Review of Factors Influencing the Onset and Progression of Neurological Conditions**

**Principal Investigators:**

**Dr. Daniel Krewski**, University of Ottawa

**Dr. Caroline Barakat-Haddad**, University of Toronto at Scarborough

**Dr. Tamara Pringsheim**, University of Calgary
The overall objectives of the project are to systematically assess and synthesize the world literature on risk factors for the development of priority neurological conditions, including biological, lifestyle, socioeconomic, environmental, and psychosocial factors, as well as co-morbid conditions and mechanisms of action. The research team will collate existing reviews, execute a literature search, quality assessment and data abstraction, synthesize previous studies, conduct quantitative meta-analyses, and link results to a Job-Environment-Exposure Matrix and microsimulation models in Canada. Results of the project will be a comprehensive, systematic review of risk and prognostic factors for the onset and progression of 14 neurological conditions in Canada; prioritization of risk factors, identification of data gaps and research needs, and guidance for policy-making.

Validation of Administrative Data Algorithms to determine Population Prevalence and Incidence of Alzheimer’s Disease, Dementia, Multiple Sclerosis, Epilepsy and Parkinson’s Disease

Principal Investigators:

Dr. Karen Tu, ICES/University of Toronto
Dr. Liisa Jaakkimainen, ICES/University of Toronto
Dr. Debra Butt, ICES/University of Toronto

This project is to perform an administrative data validation of Alzheimer’s disease, dementia, multiple sclerosis, epilepsy and Parkinson’s disease using a reference standard of primary care Electronic Medical Records (EMRs) as contained in the Electronic Medical Record Administrative data Linked Database (EMRALD). The result will be to determine the best combination of administrative data to identify patients with these conditions and the accuracy to which administrative data can capture people with these conditions. With this we will be able to provide estimates of prevalence and incidence for these conditions across Ontario and potentially across Canada.

Canadian Primary Care Sentinel Surveillance Network: CPCSSN Neurodegenerative Conditions

Principal Investigators:

Dr. Richard Birtwhistle, MD MSc FCFP, CPCSSN Chair, Professor of Family Medicine and Community Health and Epidemiology, Queen’s University
Dr. Neil Drummond, PhD, University of Calgary
Ms. Anita Lambert Lanning, BA MLS, CPCSSN Manager
Ms. Inese Grava Gubins, CFPC Director of Research
The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) derives deidentified clinical data from the electronic medical records of participating sentinel family physicians across Canada in order to study the epidemiology of chronic disease, (including prevalence, incidence, health care utilization, and determinants of outcomes) and to report findings in a timely and accessible manner. With support from the Public Health Agency of Canada Neurological Conditions Project CPCSSN has added dementia, Parkinson's disease and epilepsy to its suite of diseases of interest.

**Understanding from within: Developing community-driven and culturally relevant models for understanding and responses to dementia among Aboriginal peoples**

**Principal Investigators:**

Billie Allan, Native Women’s Association of Canada

Dr. Carrie Bourassa, First Nations University

The Native Women’s Association of Canada (NWAC) is undertaking this mixed methods study to improve understanding of how Aboriginal women conceptualize neurological conditions, the impact on their families and communities, and the needed resources and supports to provide culturally safe and appropriate care. The rationale for focusing on Aboriginal women specifically is two-fold: 1) Aboriginal women experience enhanced risk of developing neurological conditions associated with a disproportionate burden of ill-health (in comparison to non-Aboriginal women) and a greater lifespan than Aboriginal men; and 2) Aboriginal women represent the majority of caregivers in Aboriginal communities, whether they are formal or informal, paid or unpaid. Engaging Aboriginal women who are impacted by neurological conditions (as individuals living with a neurological condition, or as caregivers), the findings of this study will contribute towards advancing understanding of and culturally relevant responses to the neurological health needs of Aboriginal peoples in Canada.

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

**Principal Investigators:**

Dr. Nathalie Jetté, MD, MSc, FRCPC, University of Calgary

Dr. Tamara Pringsheim, MD, MSc, FRCPC, University of Calgary

Despite the significant impact of neurological conditions on patients, their families and society, our knowledge of how commonly they occur and who they affect remains limited. This study has three objectives: (1) Published international studies regarding how frequent 14 priority neurological conditions are and who they affect will be summarized; (2) An inventory of national and international neurological registries will be developed to guide future neurological registries in Canada; and (3) Recommendations regarding the best data sources to consider for future surveillance programs for neurological conditions in Canada will be created.
THE SURVEYS

The three surveys being developed as part of the study are: the addition of a neurological module to Canadian Community Health Survey (CCHS) 2010-2011, the Survey on Living with Neurological Conditions in Canada (SLNCC), and the Survey of Neurological Conditions in Institutions in Canada.

CANADIAN COMMUNITY HEALTH (CCHS) NEUROLOGICAL CONDITIONS HOUSEHOLD COMPONENT

The Canadian Community Health Survey (CCHS) is a survey of Canadians aged 12 and over who live in the community. The CCHS reaches approximately 65,000 Canadian households annually which are representative of the Canadian community-dwelling population. The CCHS collects information on health status, health care utilization and on factors that can improve or be a risk to one’s health. Federal and provincial departments of health and human resources, social service agencies, and other types of government agencies use CCHS data to monitor, plan, implement and evaluate programs to improve the health of Canadians. Researchers from various fields use the data to conduct research to improve health. Non-profit health organizations and the media use CCHS data to raise awareness about health, an issue of concern to all Canadians.

As part of the National Population Health Study on Neurological Conditions, a 3 minute module on neurological conditions was added to the CCHS for the years 2010 and 2011. These questions will reach approximately 130,000 Canadian households. This module asks respondents if they or anyone currently living in their household currently has or has had any of the following conditions: ALS, Alzheimer’s disease and related dementia, brain injury, brain tumour, cerebral palsy, dystonia, epilepsy, Huntington’s disease, hydrocephalus, migraine, multiple sclerosis, muscular dystrophy, Parkinson’s disease, spina bifida, spinal cord injury, spinal cord tumour, stroke and Tourette’s syndrome. Asking the questions of both the respondent about both them and about all members of their household will increase the sample size so as be able to have data on rare conditions and it will enable to collection of data on neurological conditions among children under the age of 12.

The purpose of the CCHS neurological questions are 2-fold:

1-) To estimate self-reported prevalence (the number of people living with a condition) of select neurological conditions from individuals selected for the survey and all members of their household.

2-) To identify individuals with neurological conditions to participate in a follow-up survey, the Survey on Living with Neurological Conditions in Canada (SLNCC).

Besides providing information regarding neurological conditions, the prevalence questions will be linked to the other information on respondents and their households from the core CCHS such as sociodemographic data and information regarding other chronic medical conditions. These information linkages will provide a rich source of data to supplement the data on neurological conditions in respondents and their households.
The neurological questions were developed by the Incidence, Prevalence and Co-morbidities Expert Advisory Group and have undergone rigorous qualitative testing which included feedback from both specialists and patients from the neurological community prior to their inclusion in the 2010-2011 CCHS.

The survey questions are currently in the field. Data from the 2010 CCHS cycle will be available this summer in July 2011. The final data set that covers both years will be available in summer 2012.

**SURVEY ON LIVING WITH NEUROLOGICAL CONDITIONS IN CANADA (SLNCC)**

The Survey on Living with Neurological Conditions in Canada (SLNCC) is a follow-up of individuals with neurological conditions identified through the Neurological Conditions Household Component of the 2010-2011 CCHS. The goal of the SLNCC is to gather information on the impacts of neurological conditions on people living with the conditions and their caregivers.

The SLNCC will be administered to approximately 7,000 CCHS respondents or members of their household who have been identified as having a neurological condition. The SLNCC is a 20 minute telephone survey that includes questions on the following: general health, diagnosis of neurological condition, chronic medical conditions, social supports, medication use and side effects, restriction of activities, incontinence, work activities, formal assistance or care received, informal assistance or care received, out of pocket expenses related to a neurological condition, stigma experience, depression and socio-demographic factors such as education and income.

In early 2010, a Surveys Working Group of content experts was formed to lead the development of the SLNCC as well as the Survey of Neurological Conditions in Institutions in Canada. The SLNCC has been developed in close collaboration with the Surveys Working Group, the Public Health Agency of Canada and Statistics Canada. Statistics Canada will also be administering the survey. The SLNCC has undergone rigorous qualitative testing in both English and French and will be in the field for two cycles of data collection in September to October 2011 and February to March 2012.

Survey data will be available for December 2012.

**SURVEY OF NEUROLOGICAL CONDITIONS IN INSTITUTIONS IN CANADA**

The population living in long term care facilities and other institutions are not covered by community surveys, such as the Canadian Community Health Survey Neurological Conditions Household Component and the Survey on Living with Neurological Conditions in Canada that are part of the National Population Health Study on Neurological Conditions.

Many people with neurological conditions, particularly those with a more advanced form, live in long term care institutions. This is related to the higher level of care required.

A survey of a representative sample of long-term residential care facilities and of hospitals with dedicated long-term care beds will therefore be conducted through Statistics Canada to measure the prevalence of selected neurological chronic conditions among the population living in institutions. Administrators of facilities will be asked to provide numbers of individuals living in their institution with
the following neurological conditions: multiple sclerosis, epilepsy, cerebral palsy, spina bifida, hydrocephalus, muscular dystrophy, dystonia, Tourette's syndrome, Parkinson's disease, amyotrophic lateral sclerosis (ALS or Lou Gehrig’s disease), Huntington's disease, stroke, traumatic brain injury, traumatic spinal cord injury, brain or spinal cord tumour, and Alzheimer's disease or related dementia, broken down by age and sex.

The Surveys Working Group of the National Population Health Study on Neurological Conditions is providing advice to PHAC regarding the Survey of Neurological Conditions in Institutions in Canada, including question development and methodology.

In fall 2010, Statistics Canada conducted a feasibility study with a sample of residential care facilities to determine if administrators are willing to answer the survey and able to provide data. The outcomes of the feasibility study were very favourable, but were limited to residential care facilities in Ontario. A second round of feasibility testing is planned to address gaps in the initial testing, including facilities in Quebec and other provinces, as well as examining the feasibility of hospitals with long-term care beds to be identified, answer the survey, and provide accurate data on neurological conditions in their long-term care patient population. Once the survey questionnaire is developed, it will undergo qualitative testing in both English and French.

MICRO-SIMULATION

One of the elements of the National Population Health Study on Neurological Conditions (NPHSNC) is the development of a micro-simulation model to project the costs and impacts of neurological conditions on Canadians over the next 5, 10, 15 and 20 years. As part of the Government of Canada’s initiative to build onto existing projects, this piece has been committed to the Statistics Canada POHEM model.

POHEM is a longitudinal policy-oriented micro-simulation framework developed by the Health Analysis Division of Statistics Canada, a pioneer of policy-relevant health-related computer simulation models in Canada. POHEM has been shown to be a useful tool for modelling disease and health-related characteristics and to evaluate health interventions and policies among the Canadian population. POHEM uses Monte Carlo micro-simulation methods and rich banks of Statistics Canada data to generate individual lives that realistically represent the lifecycle dynamics of the Canadian Population. The model simulates life-trajectories for individual persons and adds the individuals up to create aggregate results for the total population. The life of each simulated person unfolds by exposure to different life-like events, such as initiation and cessation of smoking, changes in weight, incidence and progression of diseases. The model generates realistic “future projections” of status quo trends and provides users with the ability to test “what if scenarios” related to potential policy and program

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Data sources used for previous POHEM models are nationally representative cross-sectional and longitudinal surveys, cancer registries, hospitalization databases, vital statistics, Census, treatment cost data as well as parameters from the published literature. Statistics Canada has also built several databases that are key inputs to micro-simulation models such as taxation and social policy simulation databases, CLAssification and MEasurement System (CLAMES) databases of functional health capacity (disease severity level), life tables, and health states associated with individual chronic conditions (the latter developed in collaboration with the Public health Agency of Canada).
interventions. POHEM is a tool to evaluate the impact of health interventions and policies at the population level before such interventions are implemented.

POHEM has been used to estimate lifetime cost of breast cancer, colorectal cancer and lung cancer as well as the impact of preventive tamoxifen and colorectal cancer screening. Recently, POHEM models have been developed for osteoarthritis, acute myocardial infarction and diabetes, as well as for risk factors such as obesity and physical activity. The Canadian Partnership Against Cancer has selected POHEM to develop a cancer risk management platform. The platform is a web-enabled micro-simulation model designed for direct and easy use by cancer control and other health policy decision makers facilitating the evaluation of strategies prevention, screening and treatment. “STAR (Simulation Technology for Applied Research) Team Project” a multi-university team, whose key objectives are to develop a set of validated simulation models for obesity-sensitivity chronic diseases (cancer, heart disease, diabetes, and osteoarthritis) and to project future health outcomes under different policy scenarios, is currently using the POHEM model for their work. POHEM is also currently being used to develop physical activity evidence-based models that both simulate patterns of daily physical activity and mortality in Canada; and simulate dynamics of physical activity from longitudinally observed trends to evaluate impact on health over the life course.

Using outputs from components of the NPSNC, a POHEM model will be developed to project direct and indirect costs associated with individual neurological conditions and neurological conditions as a collective. Disease prevalence, mortality, impact on quality of life and caregiver burden will also be projected through this model.

Status: Early discussion on data requirements for the model have been undertaken in order to include the needed elements in the surveys. Further discussion will be needed around incorporating findings from projects into the model. PHAC plans to coordinate a Working Group in February 2011 to advise on data inputs for model and facilitate the gathering of disease-specific information from experts in the field.