

Brain Matters



The National Population Health Study of Neurological Conditions – The Study Notes



The Neurological Health Charities Canada Bi-Annual Membership Meeting on October 23, 2012

The National Population Health Study of Neurological Conditions (NPHSNC) includes three national surveys, 13 Pan Canadian research studies, the inclusion of neurological conditions as one of the groups of disorders that are tracked in the Canadian Chronic Disease Surveillance System, a Microsimulation Project, and concludes with a year-long Synthesis Process. Previous newsletters have provided extensive details about each individual project, but how do all of these components fit together? Throughout the NPHSNC, each project focused on one of four main themes: scope (which includes incidence, prevalence and comorbidities); risk factors for onset and prognostic issues; impact on quality of life and the economy; and health service utilization and gaps. While all these projects differed in methodology, they will ultimately all come together and provide a holistic view of how neurological conditions affect Canadians. However, it is important to understand the significance of each theme and what the information gathered could mean to those who are living with or are affected by a neurological condition.



Members:

- ALS Society of Canada
- Alzheimer Society of Canada
- Alzheimer Society of Ontario
- Brain Injury Association of Canada
- Canadian Alliance of Brain Tumor Organizations
- Canadian Epilepsy Alliance
- Canadian Neurological Sciences Federation
- Centre for ADHD Awareness Canada
- Dystonia Medical Research Foundation Canada
- The Foundation Fighting Blindness
- Headache Network Canada
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- Ontario Federation for Cerebral Palsy
- Ontario Neurotrauma Foundation
- Ontario Rett Syndrome Association
- Parkinson Societies in Ontario
- Parkinson Society Canada
- Spina Bifida & Hydrocephalus Association of Ontario
- Tourette Syndrome Foundation of Canada

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Incidence and Prevalence

When looking at incidence and prevalence, our researchers are looking to answer the following questions:

- How common are each of the neurological conditions in Canada?
- How many new cases occur in Canada?
- How do we best track/monitor these conditions?
- How do we ensure that the information we are using to track these conditions is correct?

Our researchers are answering these questions by using various methods. Systematic reviews allow researchers to look at other population-based studies that report on incidence and prevalence of neurological conditions. Reviews are used to provide some baseline estimates of the number of people living with various neurological conditions in Canada and around the world. In addition, researchers are also using administrative data collected on Canadians as they navigate the health care system, such as physician billing and hospitalization data. Examining administrative data helps to ensure that the information inputted into the system correctly codes or captures various neurological conditions. For surveillance purposes, this strategy is utilized for some of the more common neurological conditions, not necessarily for rarer conditions. Surveys, conducted through Statistics Canada, collect self-reported data on the number of people living with a neurological condition among the Canadian household population. This tool is able to help gather prevalence data on all of the priority conditions, as well as break down the data by location, gender and age.

Risk Factors

Through our examination of risk factors the NPHSNC asks:

- What are the risks associated with the development and progression of neurological conditions?

Researchers will again systematically assess Canadian and world literature on risk factors for developing neurological conditions, and risk factors associated with the progression of neurological conditions. This data can be used to identify appropriate risk management measures to mitigate the burden of neurological conditions in Canada.

Impact

When exploring the impact of neurological conditions, our researchers have looked at the following questions:

- What is the current and projected economic impact of neurological conditions on the Canadian economy?
- How do neurological conditions impact the quality of life of people living with neurological conditions, their families, and their caregivers?
- What is the impact of a neurological condition on the everyday life experiences of Canadians?

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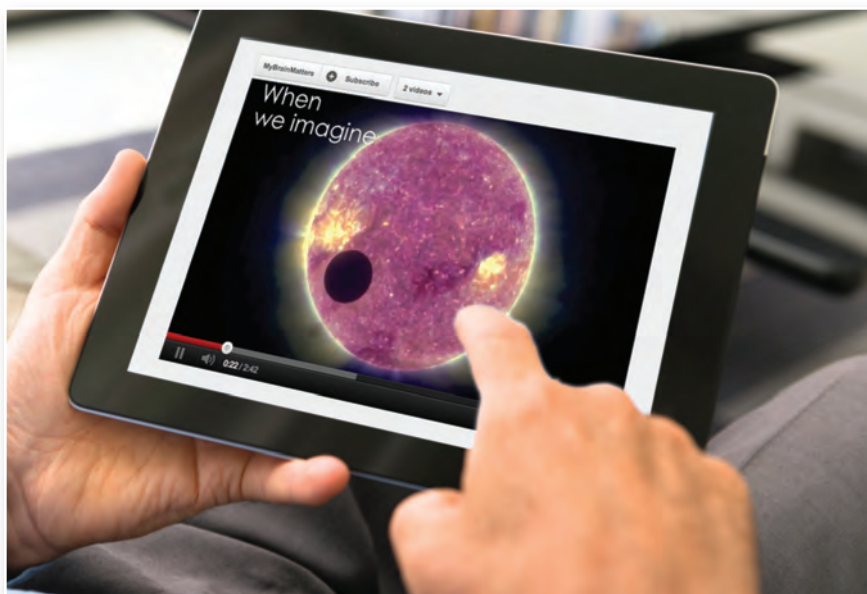
Researchers will seek to understand the impact on the economy and on the quality of life that neurological conditions have on individuals, families and caregivers. The NPHSNC will utilize surveys, online questionnaires, and interviews by telephone and in-person to gather this information. The economic impact will be analyzed through the use of models that will use the current costs of living with a neurological condition and project these costs over five, 10 and 20 years. The data from these projects can help to affect service and policy development for people with neurological conditions in Canada.

Health Services

Health services are the last category of the NPHSNC. We are hoping to identify:

- What are some of the current health and related services across the country?
- What are some of the exemplary services offered and where are the gaps in service?

The researchers will be creating an inventory of health and related services across the country that are available to individuals living with a neurological condition and their caregivers. These services will be examined across the continuum of care where the identification of exemplary services and gaps can assist with current and future program planning and service delivery.

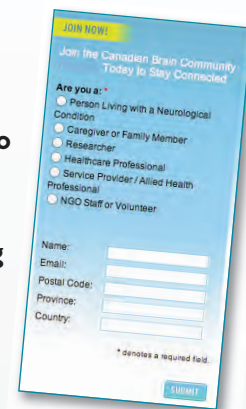


View our videos on YouTube at:

<http://www.youtube.com/watch?v=3ztn0-OO8rA>
<http://www.youtube.com/watch?v=B6YWkQXAen4>

Call to Action!

Now is your chance to get involved! During the next year, the NHCC will be hosting various webinars, online chats, and in-person events to disseminate the knowledge gathered from the NPHSNC. To receive information, and become involved please visit www.mybrainmatters.ca.



Remember to also:



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Brains matter.

RESEARCH



Millions of Canadians are living with a brain condition today!

We need to learn more about this experience to better serve individuals and families. That's why the NHCC is collaborating with the Public Health Agency of Canada to lead Canada's first-ever National Population Study of Neurological Conditions.

Research teams across Canada are working to build a better understanding of:

- ✓ the incidence & prevalence of brain conditions in Canada
- ✓ their impact on individuals & families
- ✓ risk factors for onset & progression
- ✓ co-existing conditions
- ✓ best practice health & support services

Register to receive information and regular updates about the national study at www.mybrainmatters.ca or call the NHCC at **(416) 227-9700 x3476**.

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EDUCATION



COLLABORATION



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