

**Neurological Health Charities Canada (NHCC)
Pre-Budget Submission
February 19, 2016**

Preamble

The brain is the most complex part of the human body. It is the seat of intelligence, interpreter of the senses, initiator of body movement, and controller of behaviour. Most Canadians take for granted the vital role the brain plays in one's ability to cognitively and physically function. How we respond and interact with our environment is all dependent on the health of our brain.

Neurological conditions affect every aspect of a person's life and the lives of their families – and greatly impact our economy and health care spending.

There are a diverse number of neurological conditions; however, the challenges experienced by individuals and caregivers living with these conditions are not so diverse. In fact, they are very common across most conditions.

In response to the common needs faced by Canadians with neurological conditions, charitable organizations came together with a louder voice. Founded in 2008, Neurological Health Charities Canada's (NHCC) goal is to improve lives of Canadians affected by neurological conditions through advancements in research, better public policy, and increased awareness.

Most neurological conditions are chronic and progressive, and few are curable.

Background

In 2009, NHCC entered into a formal partnership with the Public Health Agency of Canada (PHAC) to co-manage the federal government's \$15 million investment into a national population health study of neurological conditions – Canada's first-ever study of its kind for neurological conditions. The objectives were to improve understanding of: the impact; risk factors; health service needs; and, scope (incidence and prevalence).

The project included three national surveys, 13 pan-Canadian research projects, microsimulation modeling to estimate impacts over the next 20 years, and expanded ongoing surveillance to include four neurological conditions. The project engaged approximately 177,000 Canadians with neurological conditions and caregivers, and 130 researchers from 30 academic and non-academic institutions across Canada. Released in 2014, *"Mapping Connections: An Understanding of Neurological Conditions in Canada"* (referred to herein as "Mapping Connections") is the final report synthesizing key findings from the research.

What we learned from "Mapping Connections" & Recommendations for Moving Forward

"Mapping Connections" confirmed that, regardless of diagnosis, more than 3.6 million Canadians with neurological conditions experience similar challenges. NHCC reported in our paper *"A Brain Strategy for Canada"* (2010), that the common challenges facing Canadians with neurological conditions are: research; prevention (primary, secondary, tertiary); caregiver support; income security; integrated care and support; genetic fairness; and public awareness and education.

Research

"Mapping Connections" provided an important first step to research and data collection on neurological conditions in Canada. It also identified many knowledge gaps that this project did not address, as well as the need for baseline data collected in "Mapping Connections" to be kept up-to-date.

Budget Recommendation #1: Build and maintain information on neurological conditions by leveraging mechanisms that are in place for ongoing and expanded data collection.

- Through the commitment to "Mapping Connections", four neurological conditions are now included in the Canadian Chronic Disease Surveillance System. PHAC and NHCC will work together on the eligibility of other neurological conditions (i.e. case definitions) and move forward with an expansion of surveillance to those eligible conditions.
- Included in the research is the development of a toolkit and an identification of best practices for the establishment and management of disease registries. Disease registries are databases of information on a specific disease population that is a powerful tool for collecting data, identifying trends, and increasing involvement in clinical trial research. A small number of registries exist for certain neurological conditions. Parkinson Canada is ready to participate in a pilot project utilizing the toolkit funded through "Mapping Connections" to test its efficacy.
- Put mechanisms in place to collect scope and impact data on an ongoing basis to ensure that the baseline data collected for "Mapping Connections" stays relevant and up-to-date (i.e. Canadian Community Health Survey, Survey of Neurological Conditions in Institutions, and the Survey on Living

with Neurological Conditions in Canada). Also, expand data being gathered on neurological conditions through the Canadian Longitudinal Study on Aging (CLSA).

Prevention

“Mapping Connections” provided direction on risk factors and the research gaps that currently exist in this area. The research provided the following:

- Potential modifiable risk factors for certain neurological conditions were identified in the research (e.g. smoking associated with Alzheimer’s disease and dementia); however the presence of an associated risk factor does not imply causation.
- Canadians with a neurological condition are found to be more than twice as likely to report mood or anxiety disorders and twice as likely to report symptoms consistent with depression.
- The existence of a mental health disorder in combination with other symptoms of neurological conditions can impact the capacity of individuals and families to respond to, and self-manage, the disabilities associated with these conditions. Under-diagnosis and under-treatment of mental illness in association with neurological conditions is an ongoing barrier to improving health and well-being.
- Currently, neurological conditions do not fit within the chronic disease framework in Canada and many provinces/territories due to the focus on primary prevention. A better understanding of risk factors for neurological conditions could lend itself to a more integrated and responsive public health approach:
 - A research project included in the suite of projects for “Mapping Connections” is an analysis of the use and gaps in health and community based services for Canadians with neurological conditions. The analysis found that the current Chronic Care Model could be expanded to meet the specific needs of people with neurological conditions. The goal of an expanded model is to have an activated and informed person and family, a proactive team of service providers, a person-centred health system and healthy public policy to achieve improved well-being and better health outcomes for persons with neurological conditions.

Budget Recommendation #2: As identified in “Mapping Connections”, much more investigation is needed into modifiable risk factors for neurological conditions. Such as:

- **Clinical or public health relevance of statistically validated risk factors;**
- **Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition;**
- **The relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions, which would allow for the assessment of the potential effectiveness of prevention measures at the individual and population levels;**
- **A more comprehensive picture of co-morbid or co-existing conditions, specifically the relationship between neurological conditions and mental health, and the impact on health outcomes.**

Caregiver Support

Caregivers of individuals with neurological conditions experience distress twice as often as caregivers to individuals without neurological conditions. Distress increases for those providing care to individuals with neurological conditions accompanied by cognitive impairment or behavioural issues. Furthermore, 25% of parents of children with neurological conditions had financial issues in the previous year.

Many Canadians live decades with a neurological condition, which requires time and attention from family and/or friends that have stepped into a caregiving role. **NHCC applauds the government for extending the Compassionate Care Benefit to 26 weeks, and is willing to work with the government to increase the flexibility and accessibility of the Benefit, so that it extends beyond just end-of-life care.**

Income Security

As stated in the 2015 Liberal platform, “when Canadians are in good physical and mental health, they are able to work better, be more productive, and contribute more fully to our economy while living healthier, happier lives”. Compared to the general Canadian population, Canadians with neurological conditions are five times more likely to be unemployed and 12 times higher when migraine is excluded. **NHCC supports the recommendations in the Institute for Research on Public Policy’s paper *Leaving Some Behind: What Happens when Workers Get Sick (2015)*. For example, these recommendations include the introduction of employment support services to help facilitate a return to work through the Employment Insurance sickness program and an expansion of the program from 15 to 26 weeks of coverage.**

Integrated Care and Support

More than half of the Canadians receiving home care or living in long-term care facilities have a neurological condition. In comparison to the general population, Canadians living with a neurological condition utilize more health services (acute hospitalizations are up to 110 times higher and physician visits are up to nearly six times higher) and are nearly three times more likely to report ‘fair’ or ‘poor’ general health.

33% of administrators of publicly funded acute care hospitals, long-term care facilities, and community outpatient centres from all regions of Canada, indicated that their facility did not accept patients with psychiatric diagnoses or severe behavioural disorders. Only 9% of these service providers had access to a neuropsychologist, and only 3% had access to a neuropsychiatrist.

The need for integrated care and support lends itself to budget recommendation #2. More data is need on risk factors for neurological conditions in order for neurological conditions to be responded to within a public health approach. Furthermore, NHCC recommends exploring the research conducted on the expanded Chronic Care Model.

Genetic Fairness

Canada continues to be a country without protection for its citizens from discrimination based on an identification of genetic risk. Many neurological conditions have genetic links, which makes this a great concern to families where neurological conditions are known.

NHCC supports Bill S-201, Genetic Non Discrimination Act, an act to prohibit and prevent genetic discrimination.

Public Awareness and Education

Up to 36% of Canadians age 15 years and older with a neurological condition perceived that others felt uncomfortable around them or avoided them, that they were left out of activities, or that they were embarrassed by their condition.

Many knowledge translation products were developed through the “Mapping Connections” project; however NHCC would like to further identify concrete next steps to better address awareness and education about neurological condition in partnership with the federal government, and other stakeholders.

Leveraging the work of “Mapping Connections”, as well as the other great work happening in the country regarding the brain, we need to bring the country together around these issues.

Budget Recommendation #3: NHCC will partner with the federal government to develop a Canadian Brain Council that is modeled after the European Brain Council.

The purpose of the Council will be to:

- a) **Promote dialogue between community and health service providers, scientists, researchers, clinicians, industry, and thought leaders;**
- b) **Interact with key areas of government that impact brain health outcomes;**
- c) **Raise awareness and promote up-to-date education about the brain;**
- d) **Disseminate information about brain research.**

It will serve as a knowledge hub to bring together existing resources, consider emerging trends and gap areas, and disseminate information and engage more partners in finding solutions. It will also serve as a bridge bringing together neurological and mental health sectors.

NHCC will establish the Canadian Brain Council through our extensive networks in all sectors related to the brain across Canada, and will hold a summit with stakeholders to begin the engagement and development.

The Future of Neurological Conditions in Canada

Over the next 20 years, the number of Canadians living with Alzheimer’s disease and other dementias and Parkinson’s disease is expected to almost double, as are the caregiving needs and total annual health costs for these conditions. For example, the number of Canadians hospitalized with a traumatic brain injury is projected to increase by 28%.

Health care costs for Canadians with neurological conditions could be \$0.6 to \$13.3 billion greater than costs for Canadians without these conditions.

In Conclusion

NHCC is specifically recommending three inclusions in the budget:

1. Build and maintain information on neurological conditions by leveraging mechanisms that are in place for ongoing and expanded data collection;
2. Investigate two key gaps identified in “Mapping Connections” – risk factors, and the relationship between neurological conditions and mental health;
3. Partner with NHCC to establish a Canadian Brain Council that is modeled after the European Brain Council.

Investment in these three areas is estimated to cost \$100 million over five years.

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