



Driving research to action on Canadian Brain Health

Canadians urgently need action on brain health now

Brain conditions – brain illnesses, disorders and injuries – are one of the leading causes of disability in Canada and, indeed, worldwide. More than ten million Canadians – almost one third of us – will have a brain condition in their lifetime – whether from birth, early childhood, young adulthood, middle age or as seniors.ⁱ

There is a cost to individuals and to Canada

- ❖ Brain conditions impact individuals and their families in all aspects of life. They make it harder to work, succeed academically and participate in everyday activities, resulting in lost income, financial hardshipⁱⁱ and lost productivity for Canada as a whole;
- ❖ Working-age Canadians with brain conditions are five times more likely to be permanently unemployed than Canadians without brain conditionsⁱⁱⁱ;
- ❖ Nearly a quarter of parents of children with brain conditions reported financial problems because of their caregiving responsibilities – pay cuts, demotions and/or the inability to work outside the home.^{iv}
- ❖ Neurological and mental health disorders cost the Canadian economy \$61 billion annually^v – more than cancer and cardiovascular disease combined;
- ❖ Between now and 2031, indirect costs due to premature death and disability will increase in working age people^{vi} and total health care costs for Parkinson disease and dementia will double^{vii}.

(See Appendix A for details about brain conditions across the life span.)

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries. Brain conditions include neurological and mental health conditions. NHCC focuses on neurological health and the intersection of neurological and mental health conditions throughout the lifetime of individuals.

The way forward

Canada's investment of \$15 million in 2009 forged the way toward a better understanding of the impact of brain conditions through the Government of Canada-sponsored [National Population Health Study of Neurological Conditions](#), the most comprehensive examination of brain illnesses, disorders and injuries ever undertaken in Canada.

The subsequent 2014 report, [*Mapping Connections*](#), provided new information important to improving the lives of people living with brain conditions. However, it also emphasized there is still much work to be done. The knowledge obtained through this research was the first step in assessing the scale and direction for needed action.

In 2018, NHCC led an assessment, funded by the Public Health Agency of Canada, of the status of the knowledge gaps identified in Mapping Connections. The resulting report, [*Brain Health in Canada: Assessment of Knowledge and Policy and Program Implementation Gaps Identified in Mapping Connections Four Years On*](#)^{viii}, found that while some progress had been made in closing knowledge gaps for several of the identified conditions (dementia, MS and traumatic brain injury), there are still significant knowledge gaps for the great majority of conditions. These knowledge gaps result in a lack of understanding and a lack of support for Canadians affected by brain conditions and will require significant investment in brain health research to improve outcomes

It is time to move forward on closing these pressing knowledge gaps.

NHCC recommendation

NHCC recommends that the Government of Canada follow up on its significant initial investment in brain health research and commit resources to ensure Canada takes immediate action on brain health by:

- 1. Working with NHCC to lead the development of Phase 2 brain health research focused at filling the knowledge gaps identified in *Mapping Connections*;**
- 2. Working with NHCC to test, in community settings, a new expanded model of chronic care for neurological conditions that has been identified as an immediate way to apply research findings to improve the lives of Canadians affected by brain conditions.**

1. Phase two brain health research details

Knowledge gaps that need addressing by Phase 2 research are:

- 1.1. Gaps in the knowledge of the impacts** about how brain conditions affect various communities and socio-economic groups differently including:
 - Individuals in Indigenous populations (First Nations, Inuit and Metis);
 - Children affected by a brain condition, and those living with an affected parent or sibling;
 - Socio-economically-disadvantaged communities and/or remote communities who have limited access to resources;
 - Women who disproportionately develop certain brain conditions, or, if not affected personally, more often tend to take on the role of caregivers to those who are.
- 1.2. Gaps in knowledge of health services use** and availability of services for individuals with brain conditions including:

- a. Individuals who experience mental health issues as part of their neurological condition including the important issue of stigma and access to services;
- b. Individuals who have cognitive decline resulting from a neurological disease or injury;
- c. How application of eligibility criteria affects access to services for individuals with a brain condition.

1.3. Gaps in knowledge of the scope of neurological conditions including prevalence, incidence and comorbidities including:

- a. Individuals with less prevalent brain conditions (rare disorders) such as Huntington disease;
- b. Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury and stroke), and the persistence of these conditions into adulthood;
- c. Infrastructure gaps including standardization of diagnostic codes used in physician billing claims and hospital data in all provinces/territories and standardization of case definitions and algorithms.

1.4. Gaps in knowledge about the risk factors for the development and progression of brain conditions including:

- a. Risk factors for the progression of neurological conditions;
- b. Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions.

(See Appendix B for the complete list of knowledge gaps.)

2. Expanded Chronic Care Model for Neurological Conditions

Equally important is the opportunity to test in the community a new Expanded Chronic Care Model for Neurological Conditions. Individuals with brain conditions face disjointed, fragmented care across multiple settings and care providers.^{ix} *Mapping Connections* documents a lack of knowledge or awareness of brain conditions among health service providers and limited availability and/or accessibility of necessary services, particularly for people living in rural areas.

NHCC believes it is important to test the new model in selected community settings to determine if it can improve healthcare and social service outcomes and delivery for individuals affected by brain conditions as well as providing greater support to caregivers.

Estimated cost of recommendations

Recommendation 1: Work with NHCC to lead the development of Phase 2 brain health research focused at filling the knowledge gaps identified in *Mapping Connections*.

Estimated cost: \$50 million over five years

Recommendation 2: Work with NHCC to test, in community settings, a new expanded model of chronic care for neurological conditions that has been identified as an immediate way to apply research findings to improve the lives of Canadians affected by brain conditions.

Estimated cost: \$10 million over two years

Moving forward

NHCC looks forward to collaborating again with the Government of Canada on research to fill in the gaps that were clearly identified in *Mapping Connections* and to lay out a path forward for vital policy and program changes that will make a real difference in the lives of Canadians affected by brain conditions. We know that these proposed solutions will get real results for real people. These issues cut across region, gender, age and socio-economic background. Brain conditions affect us all. It is time to act.

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Appendix A

Brain conditions can occur anytime to anyone during the life span

As a coalition of brain health charities, NHCC focuses on neurological health and the intersection of neurological and mental health conditions throughout the lifetime of individuals. We know that implementing our recommendations will improve the lives, productivity and prosperity of the millions of Canadians living with brain conditions and their families. Here are just a few of the conditions that affect so many Canadians.

- ❖ **At birth – Cerebral palsy**, characterized by the loss or impairment of motor function, results from brain damage caused by injury or abnormal development while a child’s brain is still developing — before birth, during birth or immediately after birth. Cerebral palsy is the most common childhood disability^x;
- ❖ **Childhood – Rett syndrome** is a neurodevelopmental condition. It has a devastating impact: loss of spoken language, gross motor and fine motor skills and many other medical complications. There is currently no cure^{xi}. **Brain tumours** can occur at any age, but in children are a leading cause of death^{xii}.
- ❖ **Adulthood** – Conditions such as **Huntington disease** and **multiple sclerosis (MS)** occur most frequently in midlife (from 30 to 55). In addition, dystonia, MS and conditions such as depression that can be associated with neurological conditions can be episodic in nature, resulting in periods of disability that can vary in severity and duration, and persist for the rest of the lifespan^{xiii};
- ❖ **Older adults** – Neurodegenerative conditions like **Parkinson disease** and various types of **dementia** most typically occur in adults over 60 with the incidence rising with increasing age^{xiv}. While **stroke** can happen at any time, it occurs more frequently in those over 65^{xv}. Stroke is the tenth leading cause of disability in Canada^{xvi};
- ❖ **Entire lifespan** – **Traumatic brain injury (TBI)** and **spinal cord injury** can occur across the entire lifespan from young children to older adults, and ranges from concussion to severe impairment. TBI occurs frequently in males between 15 and 25 years of age, often as the result of bicycle, motorcycle or motor vehicle collisions or sports-related injuries; in adults because of work-place injuries; and in older adults because of falls^{xvii}.

Appendix B

NHCC Mapping Connections: Identified Knowledge Gaps

1. Gaps in the knowledge of the impacts of neurological conditions on affected individuals, their families, caregivers, and communities:

- Impact of neurological conditions on Canadians living in varying social and economic situations;
- The impact of neurological conditions on First Nations, Inuit and Metis individuals;
- The impact of neurological conditions on children affected by a neurological condition, and those living with an affected parent or sibling;
- Impact on formal caregivers for individuals with severe, debilitating neurological conditions;
- Canadians who were excluded from surveys such as CCHA and SLNCC;
- Canadians with less prevalent conditions (i.e.: ALS, Huntington's disease).

2. Gaps in knowledge of health services use, availability of services to benefit people with neurological conditions, and recommended improvements to services for people with neurological conditions:

- Inconsistent availability of multidisciplinary care;
- How application of eligibility criteria affect access to services for individuals with a neurological condition;
- Data on health services for Canadians living with a neurological condition were lacking or deficient in:
 - Distribution and quality of health services across various regions and jurisdictions;
 - Costs of providing care for individuals with a neurological condition in continuing care and acute care;
 - Personal cost of medications for individuals with each neurological condition;
 - Perceptions of health care providers on the accessibility, timeliness and quality of health services for individuals with a neurological condition;
 - Provision of health care for First Nations, Inuit and Metis populations, for vulnerable populations, and for children with a neurological condition.

3. Gaps in knowledge of the scope of neurological conditions, including prevalence, incidence, and comorbidities.

- Lack of epidemiologic and administrative data on:
 - Certain neurological conditions in the early stages (e.g., multiple sclerosis and Parkinson's disease);
 - Less prevalent conditions, (e.g., ALS, dystonia and Huntington's disease);
 - Neurological conditions typically excluded from participation in national population surveys;
 - Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury and stroke), and the persistence of these conditions into adulthood.
- Infrastructure gaps included the need for:
 - Standardization of diagnostic codes used in physician billing claims and hospital data in all provinces/territories;
 - Standardization of case definitions and algorithms as well as their periodic review;
 - Ongoing consideration and incorporation of newly available data, e.g., pharmaceutical or costing data;
 - Data capture and reporting of benign brain tumours in existing provincial/territorial cancer registries.

4. Gaps in knowledge about the risk factors for the development and progression of neurological conditions consist of a deficiency of lack of data on risk factors for neurological conditions:

- 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;
- Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions, (assessment of the potential effectiveness of prevention measures at the individual and population levels).

Mapping Connections: An understanding of neurological conditions in Canada. Public Health Agency of Canada; 2014. ISBN 978-1-100-24442-6

References

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- ⁱ Brain Canada annual report, 2018, <https://braincanada.ca/annual-reports>
- ⁱⁱ Public Health Agency of Canada. *Mapping Connections: An understanding of neurological conditions in Canada.* Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6, p. 24.
- ⁱⁱⁱ *Mapping Connections*, p. 24.
- ^{iv} *Mapping Connections*. P. 26.
- ^v 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction
- ^{vi} *Mapping Connections*, p. 30.
- ^{vii} *Mapping Connections*, p. 46.
- ^{viii} Accessed at: <https://mybrainmatters.ca/wp-content/uploads/AssessRptMappingConnectKnowledgeGaps-WebVersionJan2019.pdf>
- ^{ix} *Mapping Connections*, p. 42.
- ^x Accessed at <https://www.ofcp.ca/about-cerebral-palsy>
- ^{xi} Accessed at <https://www.rett.ca/rett-syndromertt/what-is-rett-syndrome/>
- ^{xii} Accessed at <https://www.brainumour.ca/2494/brain-tumour-facts>
- ^{xiii} Accessed at <http://episodicdisabilities.ca/home.php>
- ^{xiv} Licher S, Darweesh SKL, Wolters FJ, et al Lifetime risk of common neurological diseases in the elderly population *J Neurol Neurosurg Psychiatry* Published Online First: 02 October 2018. doi: 10.1136/jnnp-2018-318650: <https://jnnp.bmj.com/content/early/2018/08/26/jnnp-2018-318650>
- ^{xv} Kelley-Hayes M, Influence of Age and Health Behaviors on Stroke Risk: Lessons from Longitudinal Studies. *J Am Geriatr Soc.* 2010 Oct; 58(Suppl 2): S325–S328. Accessed at : <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3006180/>
- ^{xvi} Lang JJ et al. Global Burden of Disease Study trends for Canada from 1990 to 2016. *CMAJ* November 05, 2018 190 (44) E1296-E1304, Accessed at <http://www.cmaj.ca/content/190/44/E1296>
- ^{xvii} Chan V, Zagorski B, Parsons D and Colantonio A. Older adults with acquired brain injury: a population-based study. *BMC Geriatr.* 2013; 13: 97. Published online 2013 Sep 23. doi: 10.1186/1471-2318-13-97.