

**Written Submission for the Pre-Budget Consultations in  
Advance of the Upcoming Federal Budget**

**Renewal of a National Population-level  
Neurological Health Survey for Canada**

By: Neurological Health Charities Canada

Submission: April 17, 2026

# List of Recommendations

## Recommendations

### Immediate

1. Convene a multi-stakeholder working group to develop a National Population-level Neurological Health Survey for Canada.
2. Address the needs of Canadians affected by neurological conditions by adopting a patient and caregiver informed approach to survey design.
3. Fund a National Population-level Neurological Health Survey for Canada through the 2026 Federal Budget.
4. Incorporate the mental health impact of neurological conditions into a National Population-Level Neurological Health Survey for a more wholistic view on the toll these conditions take on individuals and families.
5. Respect individual privacy and the data sovereignty of First Nations, Inuit and Métis peoples through updated survey protocols, redesign and implementation plans.

### Longer-term

6. Build national capacity to collect, monitor, and report on population and health care system data related to neurological conditions.
7. Investigate the use of innovative technologies such as AI to consolidate fragmented approaches to population-level neurological health data collection, record keeping, analysis, and storage.

## Renewal of a National Population-level Neurological Health Survey

Canadian society continues to diversify as people enjoy longer lives and in-migration grows due to conflicts or deteriorating socio-economic conditions within the geopolitical context. These changes coupled with improvements in neurological research, diagnosis, and treatment point to a need to ensure the neurological health of Canadians and impacts to caregivers are better documented and understood. We are at a pivotal time when improved understanding about the neurological health of Canadians and their need for support can make a difference in health care planning for the future. To do this, Neurological Health Charities Canada (NHCC) proposes the development of a National Population-level Neurological Health survey for Canada.

A renewed National Population-level Neurological Health Survey for Canada builds on the 2009 investment of \$15 million which resulted in the 2014 report *Mapping Connections*. At the time, *Mapping Connections* was the most comprehensive examination of neurological illnesses, disorders and injuries ever undertaken in Canada and led to the inclusion of four neurological health conditions under the Canadian Chronic Disease Surveillance System (CCDS). These results are now more than a decade old and there is still work to be done to address gaps in the data and an opportunity to improve the efficiency of data collection tools, resources, and methodologies.

Data-driven, evidence-informed decision making is a Federal Government priority as demonstrated by its investment in the 2023 *Pan-Canadian Cancer Data Strategy*. Initiatives such as the *pan-Canadian Health Data Strategy* and the *First Nations Data Governance Strategy* are crucial steps in establishing the infrastructure needed to facilitate access to better quality and more comprehensive planning data<sup>1</sup>.

### The Impact of Neurological Conditions

Neurological conditions — neurological illnesses, disorders, and injuries — are one of the leading causes of disability in Canada and worldwide. The range of neurological conditions is astounding with more than 400 described, ranging from cerebrovascular diseases to neurodevelopmental and neurodegenerative diseases and disorders to rare diseases for which Canadians can wait years for accurate diagnosis. It is estimated that one in five Canadians are affected. The avoidant costs associated with inaction include the following:

- estimates put the cost of managing neurological diseases or conditions at \$61 billion annually<sup>ii</sup> - more than cancer and cardiovascular disease combined;
- loss of productivity - working-age Canadians with neurological conditions are five times more likely to be permanently unemployed than Canadians without brain conditions<sup>iii</sup> and between now and 2031, indirect costs due to working-age premature death and disability will increase;<sup>iv</sup> and

- as the population ages total health care costs for Parkinson’s disease and dementia will double<sup>v</sup>.

## **Leadership at National and Global Levels**

While all levels of government have important roles in prioritizing and supporting neurological health, the Government of Canada has unique responsibility and authority as both convenor and a leader among Provinces and Territories. The federal government already leads the way on the collection, assessment, and integration of health data for public health purposes.<sup>vi</sup> In recent years, health transfer funding agreements secured provincial and territorial endorsement of the *Pan-Canadian Health Data Charter* and encouraged the adoption of common standards and policies related to data as outlined in the *Shared Pan-Canadian Interoperability Roadmap*. This is a good start and more crucially, it lays the groundwork for a National Population-level Neurological Health Survey.

Globally, the United Nations and the World Health Organization recognize that brain health – both neurological and mental health – is a pressing issue that all countries must address. Over the past 30 years, the number of deaths due to neurological disorders has increased by almost 40 percent worldwide<sup>vii</sup>. Researchers attribute this increase to population growth, ageing populations, and the lack of available treatments for neurological conditions. This past year, discussions at the G7 and world economic forums have raised the profile of the Brain Health Economy<sup>viii</sup> – the prioritization of which confers clear economic competitive advantage – incorporated within which is the growing need to invest in defensive capabilities.

In May 2022, the Seventy-fifth World Health Assembly unanimously adopted the *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders*. The Plan addresses worldwide challenges and gaps in providing care and services for people with epilepsy and other neurological disorders and ensures a comprehensive, coordinated response. Canada endorsed the Plan and a more complete and up-to-date National Population-level Neurological Health Survey can better inform its actions.

## **The Current Gaps in Data-Informed Health Decision Making**

While *Mapping Connections* resulted in some important insights into the neurological health of Canadians, it did not address all neurological conditions. This resulted in certain neurological conditions receiving heightened surveillance and attention while others remain less understood, continuing to impact the health and lives of Canadians. All individuals with neurological conditions deserve to have their health prioritized by the Government of Canada so that those diagnosed or caring for a loved one receive timely and appropriate services and care.

The COVID-19 pandemic exacerbated the health inequities among Canadians and revealed gaps in the data necessary to understand the impacts of the pandemic on those affected by neurological disease. An updated National Population-level Neurological Health Survey will give us a better understanding of which diseases are most prevalent among specific populations, what socioeconomic factors have the greatest impact on outcomes and more. Improved prevention, diagnosis, and treatment of neurological disease; the protection of individual privacy; and respect for data sovereignty of First Nations, Inuit and Métis peoples can be incorporated into the design of a new survey.

### **Value of Population-level Neurological Health Surveillance Data**

Data has the power to transform the wellbeing of those living with or caring for someone with a neurological condition. It provides critical information that helps shape approaches to screening, diagnosis, treatment and services, and informs policies that affect the health of Canadians. Early morbidity, co-morbidities and concurrent mental health diagnoses, and improvements to the lives of those impacted the all hallmarks of success in a consistent approach to collecting complete high-quality data, linking relevant data sets, and making it easily accessible to those who need it must be a priority.

*Mapping Connections* released in 2014 revealed a total affected population estimate of 3.6 million Canadians diagnosed with a neurological condition. It offered Canadian data on 18 brain conditions and resulted in the implementation of chronic health surveillance for some neurological conditions. While *Mapping Connections* remains in use by the Public Health Agency of Canada as part of its CCDS and Health Canada continues to apply its insights to decision-making surrounding health care policy and investments, an updated survey is needed to improve the performance and efficiency of Canada's national health care system and the standards by which is it governed under the *Canada Health Act*.

### **Urgent Action Items and Recommendations**

NHCC recognizes the progress made over the past decade by the Federal Government in efforts to modernize Canada's health care system and attract top -tier research talent from around the world<sup>ix</sup>. NHCC requests the Government of Canada work with the neurological community to ensure that the unique needs of Canadians affected by neurological conditions are prioritized and proactively addressed by completing essential groundwork to support research through a National Population-level Neurological Health Survey.

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### **Long-term**

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**Recommendation:** Government of Canada demonstrate national leadership on neurological health by convening a working group to develop a National Population-level Neurological Health Survey for Canadians.

### **What a National Population-level Neurological Survey for Canada Would Accomplish**

A National Population-level Neurological Health Survey for Canada addresses the current patchwork approach to the collection of neurological health data. It will have a profound impact on quality of life for millions of Canadians living with neurological conditions. Neurological health is a key public health priority within and an economic advantage to Canada. The implementation of a National Population-level Neurological Health Survey for Canada would create the framework for a society where:

- Neurological health is valued, better understood, promoted, and prioritized within health policies, plans, and budgets;
- Neurological disorders are prevented and treated, avoiding deaths and disability, and quality of life is improved through seamless access to health care services, essential medicines, and ongoing research; and
- Social, economic, and educational needs are prioritized and individuals living with neurological conditions and their caregivers are free from discrimination.

## Moving Forward on Neurological Health

All individuals with neurological conditions deserve to have their health prioritized by the Government of Canada through a better informed, standardized and coordinated system of care. NHCC prepared to co-lead a collaborative that is patient and caregiver informed and that guides data and knowledge towards actions resulting in the best quality of life for Canadians affected by neurological conditions.

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Neurological Health Charities Canada (NHCC) is a coalition of seventeen health charities representing millions of Canadians living with neurological diseases, disorders, and brain injuries. NHCC focuses on neurological health as well as the intersection of neurological and mental health conditions and ensuing socioeconomic factors that influence the lives of individuals and their families.

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## References

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- <sup>ii</sup> 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction
- <sup>iii</sup> 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.
- <sup>iv</sup> Mapping Connections, p. 30.
- <sup>v</sup> Mapping Connections, p. 46.
- <sup>vi</sup> Atlas: country resources for neurological disorders – 2nd ed. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
- <sup>vii</sup> Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016 *Lancet Neurol* 2019; 18: 459–80 Published Online March 14, 2019 doi: 10.1016/S1474-4422(18)30499-X.
- <sup>viii</sup> [Brain Health on the Global Stage in Davos During World Economic Forum 2025 – European Brain Council \(EBC\)](#)
- <sup>ix</sup> Canada Global Impact + Research Talent Initiative, December 9, 2025 [Government of Canada launches new initiative to recruit world-leading researchers - Canada.ca](#)