

**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

Submitted: August 2, 2024

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 2025 Federal Budget.
4. Incorporate the mental health aspects of neurological conditions into a National Population-Level Neurological Health Survey to better understand the impacts of neurological disease on Canadians.
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

Aging, diversity and the realities of a post-pandemic society coupled with emerging trends in neurological research, diagnosis, and treatment present an unprecedented opportunity for collaboration and resolve. 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 to collaborate with the federal government to develop 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 focused on understanding the impact of brain conditions 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. While providing new information, the results are now a decade old and there is still work to be done to address gaps and an opportunity to incorporate new tools, resources, and methodologies.

Data-driven, evidence-informed decision making is a priority and NHCC recognizes that the federal government supports the collection of high-quality health data as demonstrated by its investment in the 2023 *Pan-Canadian Cancer Data Strategy*, one of the data-focused initiatives stemming from the *Working together to improve health care for Canadians plan*. Initiatives such as the *pan-Canadian Health Data Strategy* and the *First Nations Data Governance Strategy* provide critical guidance to help establish an infrastructure that promotes access to better quality and more comprehensive dataⁱ.

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. One in three Canadians (more than 10 million) will have a neurological condition in their lifetime.

- Neurological and mental health disorders cost the Canadian economy \$61 billion annuallyⁱⁱ – more than cancer and cardiovascular disease combined;
- Working-age Canadians with neurological conditions are five times more likely to be permanently unemployed than Canadians without brain conditionsⁱⁱⁱ;
- Between now and 2031, indirect costs due to working-age premature death and disability will increase^{iv} and as the population ages total health care costs for Parkinson’s disease and

dementia will double^v.

Demonstrating Leadership at National and Global Levels

NHCC believes now is time for the Government of Canada to demonstrate leadership on neurological health by working with the neurological community to develop and implement a National Population-level Neurological Health Survey. 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 leader. The federal government already leads the way on the collection, assessment, and integration of health data for public health purposes.^{vi} Recent health transfer funding agreements secured provincial and territorial endorsement of the *Pan-Canadian Health Data Charter* and encourage the adoption of common standards and policies related to data as outlined in the *Shared Pan-Canadian Interoperability Roadmap*. Capturing up-to-date data on the neurological health conditions affecting Canadians through a National Population-level Health Survey aligns with the federal government's commitment to act in the best interest of Canadians, their families and health care workers to deliver concrete results^{vii}.

Globally, the United Nations and the World Health Organization have recognized 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^{viii}. Researchers attribute this increase to population growth, ageing populations, and the lack of available treatments for neurological conditions.

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 is well positioned to move forward on key actions which can be better informed by a more complete and up-to-date National Population-level Neurological Health Survey.

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 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. In turn, this will help us improve prevention, diagnosis, and treatment of neurological disease. In addition, a redesigned and updated Survey will also protect individual privacy and respect the data sovereignty of First Nations, Inuit and Métis peoples.

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. But when it comes to neurological health data in Canada, gaps persist. To reduce early morbidity, co-morbidities and concurrent mental health diagnoses, and improve the lives of those who are impacted, 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 chronic disease surveillance guidelines, and Health Canada continues to apply its insights to decision-making surrounding health care policy and investments, an updated National Population-level Neurological Health Survey is needed to improve the performance of Canada's national health care system and the standards by which it is governed under the *Canada Health Act*.

Urgent Action Items and Recommendations

NHCC recognizes that the Government of Canada has made commitments to modernize the health system by improving how health information is collected, shared, used, and reported to Canadians to promote greater transparency on results and inform decisions as part of the *Working Together to Improve Health Care for Canadians* plan^{ix}. NHCC requests the Government of Canada work with the neurological community to ensure that the unique needs of Canadians affected by neurological conditions are proactively addressed by completing essential groundwork through a National Population-level Neurological Health Survey.

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While the above establishes a path for the steps necessary to improve the lives of Canadians with a neurological condition, beginning by convening a working group to commence this important work will affect an immediate improvement in the outlook and on the lives of individuals, their families, and caregivers.

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

NHCC believes that a National Population-level Neurological Health Survey for Canada addresses the 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. It is the impetus for looking at neurological health in a new way and in making neurological conditions a public health priority within 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 with representation in health policies, plans, and budgets;
- Neurological disorders are prevented and treated, avoiding deaths and disability, and improving quality of life through seamless access to health care services from childhood to adulthood, 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. Efforts to modernize the health care system through standardized health data represent an agreed, shared priority under the *Working together to improve health care for Canadians* plan. NHCC is ready to help lead this unprecedented collaborative approach which would drive knowledge to action resulting in the best quality of life for Canadians affected by neurological conditions. It is critical that governments work collaboratively with stakeholders to ensure that a National Population-level Health Survey is patient and caregiver informed so that it will have the greatest impact for all.

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

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- ^v Mapping Connections, p. 46.
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