



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

SUBMISSION TO THE ADVISORY PANEL ON HEALTHCARE INNOVATION 2014

An Innovative Model for Change Success of a Government-NGO Partnership

Executive Summary

Six years ago, with the exception of a few brain conditions and select jurisdictions, there was very little evidence on the scope and impact of brain conditions in Canada. A unique partnership between the Government of Canada and Neurological Health Charities Canada (NHCC) on the four-year National Population Healthy Study of Neurological Conditions addressed a shared but unmet need.

This collaboration resulted in:

- a) a rich new Canadian database on brain conditions that will drive action to improve the lives of individuals and families affected by brain conditions; and,
- b) the Government of Canada and the brain community, specifically a non-governmental organization representing the voice of the lived experience, learning a new, effective way of working together.

As an adaptable approach that can be implemented at any level of government, the Government of Canada-NHCC partnership can be viewed as an innovative model that enhances transparency, facilitates active participation, and, in the case of research, strengthens the relevance of results to Canadians.

Members:

ALS Society of Canada

Alzheimer Society
of Canada

Alzheimer Society
of Ontario

Brain Injury Canada

Canadian Alliance
of Brain Tumour
Organizations

Canadian Epilepsy
Alliance

Canadian Neurological
Sciences Federation

Centre for ADHD Awareness
Canada

Dystonia Medical
Research Foundation
of Canada

The Foundation
Fighting Blindness

Headache Network
Canada

Heart and Stroke
Foundation of Canada

Huntington Society
of Canada

March of Dimes Canada

Mood Disorders
Society of Canada

Multiple Sclerosis
Society of Canada

Muscular Dystrophy
Canada

Ontario Federation
for Cerebral Palsy

Ontario Neurotrauma
Foundation

Ontario Rett Syndrome
Association

Parkinson Society
Canada

Parkinson Societies
in Ontario

Spina Bifida &
Hydrocephalus
Association of Ontario

Tourette Syndrome
Foundation of Canada

Success of a Government-NGO Partnership

Collaborative governance translates Idea-to-Research-to-Action for Canadians impacted by brain conditions

The Issue: Why Innovation was Necessary

Alzheimer's disease, cerebral palsy, epilepsy, multiple sclerosis, and Parkinson's disease are a few of the more than 1,000 known brain conditions.* Most worsen over time and have no known cause or cure. They are the leading cause of disability in Canada.¹ Brain conditions affect individuals of all ages and place significant demands on the family and friends who support their affected loved ones. More than 10 million, or one in three Canadians, are estimated to be living with a brain condition, and one in two have had a brain condition impact their family.¹

Brain conditions can present at birth, begin in childhood or young adulthood, or develop later in life. Many brain conditions are associated with aging, and as a result, the impact of brain conditions is expected to increase as Canada's population ages. While Canada ranks as a leader in the field of science related to the brain,² very little information has been available as to the true scope of brain conditions in Canada, as well as their personal, societal and economic impacts. Improved data are needed to inform future policy decisions and support families, communities, governments and health care systems to prepare for the growing impact of brain conditions in Canada.³

The Catalyst: Neurological Health Charities Canada

In 2008, a number of brain health charities recognized a need and opportunity to work together to address crosscutting issues to improve the quality of life for all persons with brain conditions, their families, and caregivers. United as Neurological Health Charities Canada (NHCC), the coalition now has 24 members representing the voice of people with the lived experience of brain conditions in Canada. With a research to action focus, NHCC provides leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education, research and innovation related to brain health.

The Solution: The National Population Health Study of Neurological Conditions

In 2008, as a recently united coalition, members of NHCC met with representatives of the Government of Canada to discuss the lack of information on brain conditions in Canada. In response, in 2009, the federal government committed \$15 million over four years for the National Population Health Study of Neurological Conditions (the 'Study'). The Study was the most comprehensive study of brain conditions ever conducted in Canada, filling knowledge gaps related to the extent of brain conditions in Canada, the use and gaps in health services, economic costs, risk factors, and personal and societal impacts of these conditions.

An Innovative Model of Governance

Early discussions between NHCC and the Public Health Agency of Canada (the Agency) identified the complementary nature of the Government of Canada's epidemiological, surveillance, research and policy expertise, with NHCC's knowledge of the real-world

* Brain conditions include diseases, disorders and injuries of the brain, spinal cord, nervous system and senses.

challenges faced by people affected by brain conditions and understanding of the overall brain community.[†] There was a recognized need for an innovative approach to synchronize research efforts within the complex brain community, and an opportunity to leverage the experience and expertise of both the Government of Canada and NHCC. Through the Study, NHCC and the Government of Canada, specifically the health portfolio, entered into a unique partnership, which included shared decision-making and management of all aspects of a broad program of research, and co-branding of a comprehensive report.

With the common goal to reduce the paucity of information on brain conditions in Canada, stakeholders from the brain community were engaged at the outset to define the most relevant issues and priorities, a shared vision, and an action plan for the Study. An expansive research program was developed and included 13 pan-Canadian research projects, three national surveys, expansion of ongoing surveillance, and the development of models to project the future impacts of brain conditions.

With ultimate accountability to the Minister of Health, an Implementation Committee provided oversight to the Study. The Implementation Committee was co-chaired by the Agency and NHCC and included representatives from the Agency, the Canadian Institutes of Health Research, Health Canada, NHCC, and an individual with a brain condition. Ad hoc working groups convened temporarily to support the work of the Implementation Committee and filled gaps in expertise.⁴ For example, a Scientific Advisory Committee provided expert scientific advice and managed and evaluated the Study's scientific elements; a Synthesis Panel highlighted key findings from the research projects, knowledge gaps, and main themes into the final report; and a Stakeholder Engagement Panel ensured stakeholder insights, including from people with the lived experience, were integrated with the scientific findings in the report.

The Success Story: Idea to Research to Action through Collaborative Governance

The Study successfully engaged 130 researchers and 177,000 Canadians affected by brain conditions, marking an unprecedented level of collaboration within the brain community. It generated a new level of understanding of the scope of brain conditions in Canada as well as the impacts and costs of these conditions on individual Canadians, families, health care systems and society. Research findings were synthesized into one summary report, *Mapping Connections: an understanding of neurological conditions in Canada*,⁵ which was released by the Minister of Health in September 2014.

"The study represents a new level of collaboration within the neurological community, and provides findings that have the potential to significantly improve the lives of Canadians living with neurological conditions, their families and caregivers." - Joyce Gordon, Chair NHCC

The Study identified or developed:

- a rich new Canadian base of information that will drive policy, awareness initiatives, and new research efforts related to brain health;
- better ways to meet and manage the health needs of those affected by brain conditions, including the development of an adapted chronic care model;⁶
- models and projection data on the future impacts and costs of seven brain conditions, which will inform future planning, policy and program design;

[†] The brain community consists of all stakeholders with an interest in brain conditions/brain health, including affected individuals, their families and caregivers, health charities, researchers, health care providers, public policy leaders, etc.

- preliminary data on risk factors for onset, which may inform strategies for the prevention, early detection, and mitigation of brain conditions; and,
- evidence to inform the national surveillance of brain conditions, including the addition of four conditions to the Canadian Chronic Disease Surveillance System.

The collaborative working relationships and networks developed within the brain community combined with the above noted successes are already informing and advancing innovations to improve the quality of life of Canadians affected by brain conditions. For example, the Ontario Rett Syndrome Association (an NHCC member organization) used the guidelines and toolkit for the development and maintenance of registries for brain conditions in Canada, created as part of the Study, to establish the Canadian Rett Syndrome Registry. This new registry will populate a national database to enable and attract research into new and improved treatments for Rett syndrome.

Both the NHCC coalition and the National Population Health Study of Neurological Conditions were critical to the rapid development and advancement of the Canadian Rett syndrome registry. We place exceptional value on this unique collaborative approach that is leading to significant impacts for families affected by our rare condition.

- Terry Boyd, Board President, Ontario Rett Syndrome Association

Enabling Factors for Success

From the beginning, the Government of Canada and NHCC had a commitment to shared responsibility for the Study. Although a formal governance model was not explicitly articulated in the Study's design, it is useful to examine how a combination of enabling factors, consistent with conditions of success described in other collaborative governance models, contributed to success and meaningful results.^{7,8,9}

- **Collaborative Leadership** - Buy-in by the highest leadership level, including the Minister of Health and senior leaders from the Agency and NHCC, was essential in bringing the Study and the collaborative model to existence and sustaining its momentum.
- **Common Agenda**: Engaging stakeholders from the outset and throughout the Study's duration supported the development of a shared vision, a transparent process, and a general sense of ownership by the brain community, including individuals and families with the lived experience.
- **Mutually Reinforcing Activities**: Approximately one-third of the 130 researchers were involved in multiple projects of the Study. Researchers developed enhanced linkages within the brain community and learned a new way of working together, in which specific research projects and activities were linked within the broader program of research of the Study and informed by people with the lived experience.
- **Continuous Communication**: The multi-stakeholder nature of the Study and its research program required an ongoing stream of communications, in varying formats, designed for a variety of audiences. Frequent and open communication, both within and between the Implementation Committee and the varying stakeholders, was essential in building the trust required to work efficiently and effectively together, and maintaining the pace and direction of the Study.
- **Backbone Support**: The Implementation Committee, with dedicated staff from the health portfolio and NHCC, was a critical link in the Study. The Committee provided ongoing support to guide the strategic direction of the Study, provide strength with technical expertise and time, align activities, mobilize resources, and ensure decisions were appropriately supported and followed through.

Evaluation: The Value and Effectiveness of the Government-NGO Partnership

In addition to the tangible outputs and outcomes related to the generation of new knowledge of brain conditions, the anticipated impact of the Government-NGO partnership was clearly described within the intent of the Study. Congruent with other approaches, multiple evaluation processes and a variety of methods were used to enable learning and assess the contribution of the effectiveness and value of the Study and its model of collaborative governance.¹⁰

Based on the Interim Performance Study, the Government-NHCC partnership was viewed positively. The formal governance structure of the Study created an environment of trust and transparency, with a balance in power and responsibility between the Government and NHCC. This served to leverage extensive in-kind support from the health charities, their respective communities, and the research community, and created a broad sense of ownership of the Study within the brain community.

Consistent with other large-scale initiatives and collaborations, the process was not without challenges.^{11,12} For example, the multi-stakeholder nature of the Implementation Committee brought together a diversity of cultures and opinions. An initial learning period to build relationships and understand cultural differences was necessary to create a mindset shift that set the stage for a more effective and efficient collaboration in the latter part of the Study. Despite their differences, partners were highly committed to the collaborative governance model and the success of the Study, and there was a sense that the brain community and the research would be strengthened as a result of the collaboration.

At least 83% of Implementation Committee members agreed or strongly agreed that participants of the Study were successful in these components of common ground:

- working together and involving each other
- having open communication
- managing conflict
- collectively negotiating parameters for action.

- Interim Performance Study

The Government of Canada is currently conducting a final evaluation on the effectiveness of the unique governance approach and the implementation process of the Study. As stakeholders await the final evaluation, anecdotal reports indicate the Study was a success both in terms of outcomes and the partnership model. There is a general sense that, as a result of the partnership, the Government of Canada gained a better understanding of the needs of Canadians affected by brain conditions, NHCC gained an improved understanding of government process and policies, and that the evidence generated by the Study will help chart a path to improved outcomes for Canadians affected by brain conditions. In addition, the in-kind support leveraged from the collaborative partnership is expected to result in a return on investment beyond the initial financial contribution of \$15 million from the Government of Canada, from which all stakeholders will benefit.

“...the notion of the government reaching out and collaborating with people that are on the ground, living this every day, is not only one of authenticity, but it results in a much better product at the end of the project”

- non-government Implementation Committee member, Interim Performance Study

Building on the Partnership, Extending the Reach, Adapting the Model

The Study demonstrated the significant and growing personal, economic and societal impacts of brain conditions in Canada, and a successful model to unite the brain community towards a common goal. There is a continued need for action to improve the lives of Canadians affected by brain conditions and to support the sustainability of the health care system. This includes addressing remaining knowledge gaps, transforming policy and programs, and implementing and adapting successful innovations.

Having an established relationship and improved understanding of cultural differences as well as a good base of knowledge, senior leaders from the federal health portfolio and NHCC have discussed the value, including return on investment of the Study, that could be maximized by building on the innovative partnership model in additional areas of shared interest related to brain health. In addition, with a common agenda, the government-NGO partnership model utilized in the Study, could readily be implemented in other areas or levels of government as a way of harnessing the power of both sectors to drive innovation, its uptake, and better outcomes for Canadians affected by serious health conditions.

The Study demonstrated that brain conditions impact individuals and families in many similar ways. This finding, combined with the broad ownership of the Study by the brain community, is driving a shared sense of responsibility among stakeholders to take collective action to reduce the impacts of brain conditions in Canada. In this regard, NHCC member organizations are using the value of collaborative governance to harness regional strengths (including through Provincial and Territorial associations linked with national NHCC member organizations) and support innovations that maximize value for all stakeholders in the brain community.

For example, the Spinal Cord Injury Knowledge Mobilization Network, co-funded by the Ontario Neurotrauma Foundation (an NHCC member) and the Rick Hansen Institute, and involving members of the Canadian Neurological Sciences Federation (another NHCC member) supports best practices implementation in six academic rehabilitation sites in three provinces (Alberta, Ontario and Quebec), accounting for approximately 80% of the Canadian spinal cord injury demographic. This network utilizes collaborative governance towards the value proposition of better health, better care, better lived experience and better value for persons with spinal cord injury. It is now positioned to engage more broadly with other stakeholders, including provincial and territorial associations.¹³

Recognizing the success and adaptability of the spinal cord injury network, and building on data generated from the Study, a new partnership between Brain Injury Canada and March of Dimes Canada, in collaboration with the Ontario Neurotrauma Foundation and the Canadian Neurological Sciences Federation (all NHCC members), is directing its attention to a similar, value-based, pan-Canadian approach to acquired brain injury.

Summary

Six years ago, with the exception of a few brain conditions and select jurisdictions, there was very little evidence on the scope and impact of brain conditions in Canada. The partnership between the Government of Canada and NHCC on the Study, which included a collaborative governance model, served to advance research to address a shared but unmet need.

The power of this collaboration is twofold:

- a) a rich new database on brain conditions now exists in Canada and will drive efforts to improve the lives of individuals and families affected by brain conditions; and,
- b) the Government of Canada and the brain community, specifically an NGO representing the voice of the lived experience, learned a new, effective way of working together.

“There is no ‘silver bullet’ solution to systemic social problems, and these problems cannot be solved by simply scaling or replicating one organization or program.”

– What is Collective Impact, FSG⁸

As an adaptable approach that can be implemented at any level of government, the Government of Canada-NHCC partnership can be viewed as an innovative model that enhances transparency, facilitates active participation, and strengthens the relevance of results.

References

- ¹ NeuroScience Canada. The Case for Canada's Increased Investment in Neuroscience Research. 2006 (http://braincanada.ca/files/NS_case_for_support_08f.pdf)
- ² V Larivière et al. (2010) Bibliometric Analysis of INMHA-related Research, 1997-2008. Prepared for INMHA-CIHR. www.cihr-irsc.gc.ca/e/documents/INHMA_Bibliometric_Report_e.pdf
- ³ Caesar-Chavannes CR, MacDonald S. Cross-Canada Forum – National Population Health Study of Neurological Conditions in Canada. Chronic Diseases and Injuries in Canada 33 (3) June 2013.
- ⁴ Public Health Agency of Canada. The National Population Health Study of Neurological Conditions - Governance of the study. (<http://www.phac-aspc.gc.ca/cd-mc/nc-mn/gov-dir-eng.php>)
- ⁵ 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.
- ⁶ Jaglal et al. Development of a Chronic Care Model for Neurological Conditions (CCM-NC). BMC Health Services Research 2014 14:409.
- ⁷ Collective Impact Forum. How Public Policy Can Support Collective Impact. 2014 (<http://collectiveimpactforum.org/resources/how-public-policy-can-support-collective-impact>)
- ⁸ FSG. What is Collective Impact. (<http://www.fsg.org/OurApproach/WhatIsCollectiveImpact.aspx>)
- ⁹ Centre for Social Innovation. Constellation Governance Model. (<http://socialinnovation.ca/constellationmodel>)
- ¹⁰ Cabaj, M. Evaluating Collective Impact: Five Simple Rules. The Philanthropist; 2014, 26:1, 109-124.
- ¹¹ Public Policy Forum. Collaborative Governance and Changing Federal Roles: A PPF and PRI Joint Roundtable Outcomes Report. May 2008 (http://www.ppforum.ca/sites/default/files/PRI_PPF_roundtable_en_0.pdf)
- ¹² Chun, M and Caddick, S. Funding Big Brain Initiatives: the benefits and hurdles. BioMed Central; 2014. (http://www.biomedcentral.com/biome/funding-big-brain-initiatives-the-benefits-and-hurdles/?utm_campaign=BMC00046)
- ¹³ Duda, M, Riopelle, R, Brown J. From theory to practice: an illustrative case for selecting evidence-based practices and building implementation capacity in three Canadian health jurisdictions. Evidence & Policy; 2014, 10:4, 565-577.