

Background

In June 2008, members of the newly-constituted Neurological Health Charities Canada met with key members of the federal government, including political representatives and bureaucrats, to discuss the paucity of epidemiological information about neurological conditions in Canada.

In October 2008, Prime Minister Stephen Harper made an election commitment of \$15M to fund a national study, working in collaboration with the NHCC. Since the election, the NHCC has been working to convert the election promise into an actual project approved by the Treasury Board.

In the meantime, the NHCC partnered with the Public Health Agency of Canada, CIHR and Health Canada to seek input from stakeholder and researchers about priority areas and potential methodologies. This feedback has been garnered via an on-line stakeholder consultation that generated over 3,000 completed questionnaires, a 2-day technical workshop involving approximately 40 researchers from across Canada, and a subsequent project to build on the finds of the workshop by reaching out to a wider group of researchers and beginning to build an inventory of literature and data/data sources to inform the work of the study.

Purpose of the Project

The purpose of the national study is to build a better understanding of the incidence, prevalence, impact, risk factors and co-morbidities of neurological conditions, specifically but not limited to the conditions represented within the NHCC.

Methodology

The project will be framed by five study groups consisting of researchers with expertise in one of the five research domains:

1. Incidence, prevalence & co-morbidities
2. Impact to individuals, families and society
3. Health System/Services
4. Risk Factors
5. Registries

The study groups have begun meeting by teleconference and will come together for a 2-day planning meeting in early November. Their work will be used to develop Calls for Research Proposals, to be issued by PHAC in late December/early January. Proposals will be due in February 2010 and the expectation is that decisions will be made and funds will flow to researchers in May 2010.

NHCC's Role

The NHCC will be responsible for all aspects of communication and coordination throughout the four-year project (beginning 2009-2010). In July, PHAC issues a directed call to the NHCC for this work. The project was allocated a total budget of \$1,024,999 over 4 years, beginning in the current fiscal year. The proposal was submitted to PHAC on August 17, 2009 and is currently under review. It is anticipated that funds will begin to flow to the NHCC in November 2009.

The proposal addresses four main objectives, with a total of 14 activities taking place under those objectives. The objectives are:

1. To represent the community of stakeholders as a member of the Neurological Study Project Implementation Team, with joint decision-making and leadership responsibilities.
2. To develop and support the five Research Project Teams (study groups).
3. To garner consumer input into project plans.
4. To Inform the neurological community about study activities and results.

(See NHCC Description of Activities Pg.3)

Governance

The NHCC will have a key role in all decision-making for the national study. Representatives of PHAC and the NHCC make up the Neurological Study Project Implementation Team. To date, the team has been meeting by conference call every 4-6 weeks. The NHCC is represented by the National Project Team: Joyce Gordon, Deanna Groetzinger, Bobbi Greenberg and Inez Jabalpurwala, with support from Shannon MacDonald.

Timelines

It is anticipated that project will be implemented according to the following timelines

Activity	End Date
Minister's approval of NHCC Proposal	Late September 2009
Treasury Board approval on \$15M commitment	Late September 2009
Research Planning: Final recruitment for study groups; teleconference meetings underway; November planning meeting	November 2009
Calls for Research Proposals	December 2009
Research Proposal deadline	February 2010
NHCC Web Site/Portal launched	March 2010
Recommendations to Minister re: research proposals to be funded	April 2010
Research funding awarded	May 2010
Annual Progress Meeting (to take place June 2010, 2011, 2012)	June 10,11,12
Final Research Reports due	December 2012
Consensus Development Conference	January 2013
On-line Stakeholder Consultation	February 2013
Report to Minister of Health	March 2013

NHCC Description of Activities (as proposed to PHAC)

Update: National Population Study of Neurological Conditions in Canada
17 September, 2009

Beginning Fall 2009 and ending March 31, 2013, the NHCC will undertake the following activities in support of the Canadian Neurological Population Study:

1. Participate as a decision-maker on the Neurological Study Implementation Project Team.
 - a. Coordinate and supporting meetings of the Implementation Project Team
 - b. Work in conjunction with health portfolio representatives
 - c. Contribute to strategic discussions, planning, oversight and evaluation of the overall project
2. Establish, coordinate and support five research project teams to advise the government on the study contents and methods.
 - a. Recruit research project team chairs and members
 - b. Coordinate meetings and conference calls
 - c. Ensure NHCC representative on each team
 - d. Provide ongoing project management and health/medical librarian support to each team as needed
3. Coordinate 2-day planning meeting for Research Project Teams (in collaboration with PHAC team)
 - a. Meeting planning and logistics
 - b. Document preparation
 - c. Engage, prep and support meeting facilitator
 - d. Develop evaluation and feedback mechanism
4. Enhance the capacity and content of the NHCC web site to include:
 - a. English and French content
 - b. Stakeholder database – on-line data collection
 - c. Research Project Team working documents – secure document sharing
 - d. Resource documents and papers – on-line library/resource centre
 - e. Regular content updates regarding the Canadian Neurological Population Study – appropriate for each stakeholder audience
 - f. On-line registration for meetings and events– annual progress meetings, consensus development conference
 - g. Feedback function – issue specific or general
5. Develop regular communication tactics to be distributed quarterly to the wider community – March, June, September & December
 - a. Process updates
 - b. Research project updates
 - c. Researcher profiles
 - d. Emerging findings
 - e. Solicit feedback on content
6. Participate in the development of the Calls for Proposals
7. Participate in review of Research Proposals
 - a. Recruit expert reviewers
 - b. Make recommendations for funding (working with PHAC)

8. Plan Annual Progress Meeting – June 2010, 2011, 2012
 - a. Meeting planning and logistics
 - b. Document preparation
 - c. Engage, prep and support meeting facilitator and presenters
 - d. Develop evaluation and feedback mechanism
9. Plan KT Consensus Development Conference – January 2013
 - a. Meeting planning and logistics
 - b. Document preparation
 - c. Engage, prep and support meeting facilitator and presenters (incl. research project teams)
 - d. Develop evaluation and feedback mechanism
10. Conduct on-line stakeholder survey to validate and garner final feedback regarding the consensus summary findings.
11. Develop an inventory of relevant researchers, data sources and literature.
12. Participate in external meetings and conference related to population-based research regarding neurological conditions and/or chronic disease prevention and management.
13. Contribute to the writing and editing of the final Project Report.
14. Release Project Report to the Canadian neurological community (once approved by the Minister of Health)
 - a. Public launch event (working in conjunction with PHAC and the Minister's office)
 - b. Distribution via NHCC web site and database

The total budget for these activities is \$1,022,587, allocated by year as follows:

Year 1, ending March 31, 2010	\$274,190
Year 2, ending March 31, 2011	\$249,299
Year 3, ending March 31, 2012	\$249,299
Year 4, ending March 31, 2013	\$249,799