



Enhanced Surveillance for Chronic Disease Program

**NATIONAL POPULATION HEALTH STUDY
OF NEUROLOGICAL CONDITIONS**

Invitation To Submit A Letter Of Intent (LOI)
Guide To Applicants

January 2010



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1. National Population Health Study of Neurological Conditions Program Overview

1.1. Introduction

A four year National Population Health Study was announced by the federal Minister of Health on June 5, 2009 which will be administered by the Enhanced Surveillance for Chronic Disease Program. Its purpose is to fill gaps in knowledge about individuals with neurological conditions, their families, and caregivers. A comprehensive report will be published by the Public Health Agency of Canada at the end of the study to provide a clear picture of the state of neurological conditions in Canada that will help governments and stakeholders plan programs and health services for Canadians living with these conditions and identify the scope for prevention.

The Public Health Agency of Canada has been working with the Neurological Health Charities Canada, Health Canada, the Canadian Institutes of Health Research, and Expert Advisory Groups on the implementation of the project.

1.2. National Population Health Study Objectives

The four-year national population health study will provide key information to improve current knowledge about the:

- Incidence, prevalence, co-morbidities of neurological conditions
- Risk factors for the development and for the progression of neurological conditions
- Use of health services, gaps in services, and recommended improvements
- Impact of neurological conditions now and projected over the next 20 years including economic cost.



1.3. Guiding Principles

The Letter of Intent submitted for funding under this program is required to respect the following principles in work plan development and implementation:

- High quality work – feasible, fills gap in knowledge, methods are appropriate, team has capacity to do the work, appropriate partnerships
- Relevant to supporting decision-making about health related policies and programs
- Build on existing projects and infrastructure where possible to maximize efficiency
- Population study - total population affected by neurological conditions is included: people who do and do not receive services as well as their families and caregivers
- Neurological and Nervous system dysfunction is the focus of the project. The priority conditions of interest are: ALS, Alzheimer's disease and related dementia, brain tumours, cerebral palsy, dystonia, epilepsy, Huntington's disease, hydrocephalus, neurotrauma (including brain and spinal cord injuries), multiple sclerosis, muscular dystrophy, Parkinson's disease, spina bifida, and Tourette syndrome. It excludes a primary focus on stroke and mental illness but includes these conditions as co-morbidities. Other neurological conditions may be included if they co-exist with one of the priority conditions.
- National study to give a Canadian picture.
- Range of characteristics of Canadians are studied – age, sex/gender, urban/rural, immigrant, official languages, north/south, community and institutional living, Aboriginal, etc.
- Best use of this investment at this time to improve the health of Canadians
- Future work can be built on this investment
- Multi-site, inter-disciplinary teams work together
- Collaboration with the Neurological Health Charities Canada (NHCC www.neurohealthcharities.ca) and its member organizations as appropriate to ensure individuals with neurological conditions are involved in the project development and implementation. The NHCC is a collective of organizations that represent people with chronic, often progressive, neurological and/or neuromuscular diseases, disorders, conditions and injuries (brain disorders) in Canada. The NHCC's role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health.

NHCC Members

ALS Society of Canada; Alzheimer Society of Canada; Canadian Alliance of Brain Tumour Organizations; Canadian Epilepsy Alliance; Canadian Neurological Sciences Federation; Dystonia Medical Research Foundation Canada; Huntington Society of Canada; March of Dimes Canada; Multiple Sclerosis Society of Canada; Muscular Dystrophy Canada; NeuroScience Canada; Ontario Federation for Cerebral Palsy; Ontario Neurotrauma Foundation; Parkinson Society Canada; Spina Bifida & Hydrocephalus Association; Tourette Syndrome Foundation of Canada



1.4. Focus of the Letter of Intent – Eligible Activities

1.4.1. National Population Health Study of Neurological Conditions

The Public Health Agency of Canada is requesting a Letter of Intent for the following projects to be conducted between September 1, 2010 and March 31, 2013:

1.4.1.1. Incidence and Prevalence of Neurological Conditions

1. A review of existing databases, tools and methods to assess incidence and prevalence of each of the priority neurological conditions in Canada and internationally, and a summary of Canadian and International data on incidence and prevalence from these data sources. (one project, approximate funding available is \$200,000)
2. Project(s) to determine the incidence and prevalence of each of the priority neurological conditions and to better understand co-morbid conditions including projects that will build on health administrative databases to also assess co-existing health conditions, health service utilization, and economic impact. Projects could also validate survey and/or administrative data being used to measure incidence and prevalence. (up to 6 projects with each one covering at least 3 of the priority conditions, approximate total funding available is \$1,500,000)
3. Project to build capacity for national registries for neurological conditions, including patient-driven online registries¹. The project will include: (one project with a collaborative team of investigators, approximate funding available is \$1,500,000)
 - Development of an inventory of existing neurological registries in Canada and internationally
 - Preparation of a report on neurological conditions in Canada using available data on neurological conditions in Canada from existing registries
 - Development of consensus guidelines on registry development including registry content (including quality of life)
 - Preparation of a toolkit for the development and implementation of registries for neurological conditions
 - Exploring the feasibility of expansion of existing registries, for example, adding new conditions, expanding to other parts of the country, or the addition of new data to a registry
 - Development of a national on-line patient-based registry using the guidelines developed

¹ Neurological Health Charities Canada (NHCC) could sponsor an on-line registry in the future so it is important that the website lends itself to this.



1.4.1.2. Risk Factors for developing Neurological Conditions and for Progression

4. A systematic review of factors influencing the onset of each of the priority neurological conditions. The review should include biological, lifestyle, socio-economic, environmental, and psycho-social factors as well as the presence of other health conditions. (one project, approximate funding available is \$300,000)
5. A systematic review of factors influencing the progression of each of the priority neurological conditions. The review should include biological, lifestyle, socio-economic, environmental and psycho-social factors, as well as co-existing health conditions, and health and community services. (one project, approximate funding available is \$300,000)
6. Project(s) to add new knowledge on the risk of developing a neurological condition or of prognostic factors that influence their progression (up to 3 projects, approximate total funding available is \$500,000)
 - Team must include population health, clinical, and basic science researchers
 - Project must address modifiable risk factors
 - Project must address a gap in the literature
 - Researchers must justify the population to be studied
 - Primary data collection or the use of secondary data must be Canadian
 - It is desirable that the project study risk factors that are common across several neurological conditions and that the neurological stakeholder and research communities participate in the planning.

1.4.1.3. Health Services

7. Project(s) on health and related services for people living with neurological conditions residing in the community and in institutions. (up to 3 projects, approximate total funding available is \$2,300,000)
 - Identification of the continuum of care needed for individuals living with neurological conditions (descriptive)
 - Review of the literature on best practice models of care to increase quality of life or slow its decline
 - Inventory of current health and related services across the country and identification of exemplary services and gaps in current practices
 - Provision of recommendations to improve health services including performance expectations, what is needed to adopt the recommendations, and the cost of implementing recommendations



1.4.1.4. Impact of Neurological Conditions on Individuals, Families, Caregivers and Communities

8. Project(s) to assess the impact of neurological conditions on individuals, families, and caregivers including those living in the community and in institutions across Canada. (up to 3 projects, approximate total funding available is \$1,150,000)
 - A systematic literature review of the biopsychosocial and economic impact of neurological conditions on individuals, families and caregivers and of the factors that influence the impact of these conditions including biological, lifestyle, psycho-social, socio-economic, and environmental factors as well as co-existing health conditions, self-management, and health and community services.
 - Documentation and analysis of the experiences of people living with neurological conditions both in the community and in institutions including approaches to self-management, challenges and coping strategies, use of services, gaps in services, and suggestions for improvements.
 - Assessment of the quality of life of persons living with neurological conditions across Canada, and the influence of personal and community factors (such as accommodations, urban layout etc.), health services and self-management.



1.5. Other Pertinent Information

1.5.1. Eligible Applicants

Eligible applicants include Canadian : universities/colleges; not-for-profit voluntary organizations and corporations, unincorporated groups, societies and coalitions, provincial, territorial, local governments and agencies, organizations and institutions supported by provincial and territorial governments (regional health authorities etc.), and individuals, deemed capable of conducting population health analytic projects.

1.5.2. Eligible Expenditures

Eligible costs include such expenses as personnel, travel and accommodation, rent, materials and supplies, costs of services and equipment, and evaluation and dissemination costs directly related to the proposed project.

1.5.3. Ineligible Activities and Expenses

- Profit-making activities;
- Provision of direct services for which governments are responsible;
- Audiovisual productions outside the context of a more comprehensive proposal;
- Creation and/or maintenance of web sites as a sole activity;
- Conferences, symposia, and workshops as stand-alone projects;
- Capital costs such as the purchase of land, buildings, or vehicles;
- Ongoing organizational support, or a percentage of overhead or administrative fees;
- Contingency allowances or other miscellaneous fees.



1.5.4. **Other Related Work**

The National Population Health Study on Neurological Conditions will also be conducting the following related work:

- Population study of the self-reported prevalence of the priority neurological conditions on 130,000 individuals and household members as an add-on to the Statistics Canada Canadian Community Health Survey from January 2010 to December 2011.
- A follow-up call-back survey of 6,000 individuals will be conducted for those reporting neurological diseases on the prevalence survey by Statistics Canada. Questions will focus on the impact, particularly on family life, quality of life, of these neurological conditions.
- A survey of a representative sample of long-term residential care facilities will be conducted by Statistics Canada to measure the prevalence of selected neurological chronic conditions among the institutionalised population.
- The Public Health Agency of Canada's existing Canadian Chronic Disease Surveillance System (CCDSS) using provincial/territorial health administrative databases will be enhanced to include selected neurological diseases. This database can provide information on the number of newly diagnosed individuals (incidence) as well as individuals living with the condition (prevalence), and use of health services and health outcomes.
- A contract will be issued to review the existing tools to measure quality of life and psychosocial impact of chronic conditions. The results of this review will be available for use by September 1, 2010.
- A contract will be issued to review methods of economic costing and modelling that could potentially be used to assess the economic burden of neurological conditions. The results of this review will be available by September, 2010. A Working Group will be established to lead the work with PHAC on the economic impact of neurological conditions.
- A contract will be issued to develop a micro-simulation model to project the future burden of key neurological diseases over the next 5, 10, 15, and 20 years. This model will project the future incidence and prevalence of these diseases, the future quality of life of Canadians living with these diseases in terms of disability-adjusted life years and health adjusted life expectancy (years lived in relative health), life expectancy, need for and use of health services, and the future direct costs of treating Canadians who are living with these conditions. A Working Group will be established to guide this work.
- A consensus meeting will be held in January 2013 to bring all the available study findings together. A report on neurological conditions in Canada will be developed to summarize the key findings of the suite of studies. The NHCC will be responsible for the on-going knowledge exchange of information generated by the study to all stakeholders including the public.



2. Application Process

The application process will consist of two stages: Letter of Intent and Full Proposal.

Upon completion of the LOI review, selected applicants will be invited to submit a full proposal which will be due on April 15, 2010. The anticipated start date for successful projects is September 1, 2010.

Details of the proposal procedure will be provided to those invited to submit a full proposal.

2.1. Expectations of Successful Applicants for Project Funding

Applicants whose projects are approved for funding will be required to enter into a Contribution Agreement with the PHAC to receive the funding for the project.

The contribution agreement requires that quarterly reports are submitted to PHAC outlining activities completed, any change in plans, and expenditures.

The Team Leader and other members of the approved projects will also be required to participate in regular teleconferences and an annual meeting in September 2010, 2011, and 2012 to share the results and progress of the project with other project Teams. The Team Leader and other project members will also participate in a consensus conference in winter 2013 to discuss the results of their project.

A final report on the project will be submitted to PHAC within 2 months of completing the project.



2.2. LOI Review

The letter of intent package will be screened for eligibility and completeness by the Public Health Agency of Canada staff. Ineligible and/or incomplete LOI packages will be screened out and applicants will be notified.

The relevance and scientific review will be conducted by representatives from the Public Health Agency of Canada, the Neurological Health Charities Canada, and expert researchers. Proposed projects will be assessed against the criteria listed below. Applicants will be notified by the third or fourth week in February of the results of the LOI review.

2.2.1. The Organization

- Clearly identifies its mandate
- Demonstrates the organization and the project team capacity to deliver the project

2.2.2. Project Alignment

- Provides information on evidence of need
- Addresses one or more of identified solicitation priorities

2.2.3. Partnerships and Coordinated Action

- Proposed activities add to and complement existing ones
- Project involves appropriate representatives and subject matter experts in key components of the project
- Capacity to build partnerships and make linkages

2.2.4. Preliminary Plan and Work Schedule

- Includes well thought out and relevant objectives and activities
- Project identifies clear, realistic and measurable end points
- Defines roles and responsibilities of the various groups and individuals
- Provides a realistic and complete table for project activities

2.2.5. Budget

- All sources of funding for the project are identified, including potential in-kind contributions
- The estimated amounts are reasonable

2.2.6. Value of Investment

- Suitability of investing in the project – priority issues addressed, potential outcomes and impact of project



3. How to Apply

3.1. Letter of Intent

The Letter of Intent package must include the following:

1. Official signed letter from your organization agreeing to sponsor the project, indicating the title of the proposed project; identifying the project focus; the target population, the project duration, and the amount of funding requested from the PHAC.
2. One page project summary in the following format:
 - a. The mandate of the organization is:
 - b. The partners with whom the organization will work on this project are:
 - c. The overall objective of the project is to:
 - d. The activities that the organization will undertake to meet the objectives are:
 - e. The expected result of the project is:
 - f. The results will be evaluated by:
 - g. The results of the project will be disseminated through:
3. Proposal with a **maximum of ten pages** which must clearly outline each of the elements below:
 - a. Project purpose and rationale
 - b. Project objectives and their link to the Program objectives
 - c. Target Population and justification
 - d. Conditions to be included and justification
 - e. Description of proposed activities
 - f. Identify the project team lead and members, and a brief description of their expertise and contribution to the project.
 - g. Description of your organization and its capacity to deliver the project
 - h. Description of the evidence of need (a gap exists and how the project will fill this gap)
 - i. List of potential partners and their role on the project
 - j. Preliminary work plan and timetable



4. Budget Summary

Please provide estimates of the proposed project budget including funding from other sources, in-kind contributions and the anticipated amount to be requested from PHAC using the table below.

Please provide a rationale for the project budget.

Confirmation of funding from other sources and in-kind contributions is not required at this stage.

Category	Year 1	Year 2	Year 3	Total
	Sept. 1, 2010 to March 31, 2011	April 1, 2011 to March 31, 2012	April 1, 2012 to March 31, 2013	
Personnel				
Travel				
Materials				
Equipment				
Rent and Utilities				
Evaluation/Dissemination				
Other				
Total Amount Requested from PHAC				
Other Sources of Funding				
In-Kind Contributions				
Total Amount of Project				

Please refer to the *Detailed Project Budget Supplement* document for additional information on eligible expenses related to the categories listed in the above table.



4. Submission Instructions

DEADLINE FOR LETTER OF INTENT:

Received by February 5, 2010 at 5:00 p.m. EST

PHAC will accept an LOI package that is sent electronically or by mail but not by facsimile.

PHAC will not accept an LOI that is received after the deadline.

If the submission is sent by mail please send **the original and 5 copies** of your Letter of Intent package to the following address:

Public Health Agency of Canada
Centre for Chronic Disease Prevention and Control
Chronic Disease Surveillance Division
c/o Hélène Lapalme
7th Floor, Room 729A3, 785 Carling Avenue
Address Locator: 6807A
Ottawa, ON K1A 0K9
e-mail: helene.lapalme@phac-aspc.gc.ca

The Public Health Agency of Canada (PHAC) is under no obligation to provide funding, or enter into a contribution agreement as a result of this invitation to submit a Letter of Intent.

PHAC ALSO RESERVES THE RIGHT TO

- Reject any submission received in response to this invitation;
- Accept any submission in whole or in part; and
- Cancel and/or re-issue this invitation to submit a Letter of Intent at any time.

Please note that PHAC will not reimburse an Applicant for costs incurred in the preparation and/or submission of a Letter of Intent Package in response to this invitation.