

Preparation for Canada's participation in the  
G8 Summit on Dementia Research

**Proposed Responses to the UK Guided Questions**

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## THE CONTEXT

As part of its presidency of the G8, the UK is hosting a summit on dementia research in London, UK on December 10-11, 2013. The summit aims to develop coordinated global action on dementia, which is fast becoming one of the greatest pressures on families, carers and health systems around the world as outlined in the 2012 report “Dementia: a public health priority”, jointly developed by the World Health Organization and Alzheimer's Disease International.

The summit itself will provide a forum for G8 nations to identify and agree to a new international approach to dementia research, to help break down barriers between industry, researchers and clinicians, and to secure a new level of cooperation needed to reach shared goals faster than nations acting alone.

This event will primarily involve health ministers from each of the G8 nations, along with the OECD Secretary General and the WHO Director General in the presence of research and industry experts. It is expected that the summit will result in a declaration setting out a joint commitment to defeating dementia, and a communiqué outlining next steps. In preparation for Canada's participation in the summit a set of guiding questions were provided (see below). Responses will be compiled and shared with the UK in advance of the summit.

The Canadian Institutes of Health Research (CIHR), in consultation with the Public Health Agency of Canada, has proposed initial responses to the questions provided, informed by discussions with stakeholders on the inception and deployment of the International Collaborative Research Strategy for Alzheimer's Disease, as well as the development of the National Population Health Study of Neurological Conditions (NPHSNC).

Since 2009, the International Collaborative Research Strategy for Alzheimer's Disease has facilitated the participation of Canadian researchers in key international partnerships. This strategy emerged as the result of numerous consultations in preparation for both the international and national initiatives that have been and are still being deployed. The NPHSNC will fill knowledge gaps about the impact of neurological conditions and was shaped with input from members of the Canadian neurological research community.

## UK GUIDED QUESTIONS AND PROPOSED RESPONSES

### ***1. What are the research priorities related to dementia?***

The International Collaborative Research Strategy for Alzheimer's Disease, the first of CIHR's Roadmap Signature Initiatives, is led by the CIHR Institute of Aging and co-led by the Institute of Neurosciences, Mental Health and Addiction. Stakeholders and researchers have been engaged in developing the goals for this strategy, which are:

- **Primary Prevention** – Prevent the disease from occurring through the identification of the mechanisms and/or conditions responsible for the neurodegenerative processes that lead to Alzheimer's disease and related dementias.
- **Secondary Prevention** – Delaying/slowing the clinical progression of an already developing disease through better understanding of the mechanisms, diagnosis and early intervention.
- **Quality of life** – Improve the quality of life of those living with the disease or who support those having the disease as well as to improve access to quality care and enabling the healthcare system to deal more efficiently with the rising number of individuals with dementia.

This initiative acknowledges that research advances should aim to prevent the cascade of events leading to neurodegenerative diseases that impact cognition, to delay when disease has started and to help those with the disease and those caring for them. Research in these areas will help provide Canadians with rapid access to the latest preventive, diagnostic and treatment approaches to Alzheimer's disease and related dementias.

Similarly, the National Population Health Study of Neurological Conditions seeks to fill knowledge gaps about neurological conditions, including Alzheimer's disease and related dementias, and their impact on individuals, their families, caregivers and health care systems. Areas of research are focused on understanding the:

- Scope of neurological conditions (incidence, prevalence, and co-morbidities);
- Risk factors for the development and progression of neurological conditions;
- Use of health services, gaps in services, and recommended improvements; and
- Current and projected impacts of neurological conditions, including economic cost.

## ***2. Which research priorities would benefit most from international collaboration? Why?***

There is recognition that the challenge of dementia is optimally addressed through collaborative approaches between researchers exploring different neurodegenerative diseases causing dementia, from different disciplinary perspectives, and including international research collaborations. New knowledge across all priority areas should lead to evidence to support more efficient care and services for health service and care providers, as well as transforming products and solutions for industry. For some questions there are advantages to comparisons between countries, for example for care and service delivery models.

Through the deployment of the international component, the International Collaborative Research Strategy for Alzheimer's Disease has facilitated the participation of Canadian researchers in key international partnerships.

As part of the National Population Health Study of Neurological Conditions, researchers considered international findings when examining the scope and potential risk factors for neurological conditions, which proved the instrumental value of coordinated and comparable research across countries.

**3. *What are the barriers to international collaboration on research, and how could they be overcome?***

International collaborations between researchers and stakeholders can be challenging. Encouraging face-to-face interactions when possible and supporting virtual meetings can alleviate geographical barriers. However, a bigger challenge stems from the regulatory differences and different processes between funding agencies between countries. The latter can be overcome through existing research collaboration models such as the EU Joint Programme – Neurodegenerative Disease Research (JPND): [www.neurodegenerationresearch.eu](http://www.neurodegenerationresearch.eu), or Centres of Excellence in Neurodegeneration in Aging: [www.coen.org/home.html](http://www.coen.org/home.html), where Canada has shown leadership.

**4. *How can international collaboration facilitate the use of existing knowledge, research, and best practices to immediately reduce the human and economic costs of dementia?***

Through international collaboration all countries benefit from solutions that have been shown to be effective in individual countries. International collaboration can be a unique accelerator for the dissemination of demonstrated solutions in terms of care, services or products. They can catalyze large-scale dissemination of knowledge and solutions developed in one country.

In addition there are benefits of international collaboration related to the research efforts. These include the sharing of best research practices, methodologies, animal models, data platforms as well as the pooling of data for conditions with a lower prevalence (such as frontotemporal dementia).

**5. *How can stakeholders work together internationally to better address prevention of cognitive impairment; delay the onset and progression of dementia; provide better care and treatments to those affected by dementia; and improve the quality of living and dying of those affected by dementia (including family/caregivers)?***

The research directions and partnership activities encompassed within the International Collaborative Research Strategy for Alzheimer’s Disease are fully aligned with all of the aforementioned directions. At this time, the International component of the International Collaborative Research Strategy for Alzheimer’s Disease has been deployed to benefit Canadian research collaborations with international colleagues.

The Canadian component of the International Collaborative Research Strategy for Alzheimer's Disease is now underway in the form of the Canadian Consortium on Neurodegeneration in Aging. This research Consortium is poised to become the Canadian research hub; for neurodegenerative diseases impacting cognition and will be aligned with the G8 orientations. Canada is optimally positioned to work with other G8 countries on these priority areas through research activities and in partnership with international stakeholders.

With the National Population Health Study of Neurological Conditions, we will have a stronger understanding of the burden of neurological conditions in Canada. As countries begin to understand the situation in their environments, and are able to learn from successful strategies in other countries, the international understanding of Alzheimer's disease and related dementias will continue to advance.

**6. *What are the barriers to sharing, adapting, and scaling up best and promising practices internationally?***

Similar to most G8 countries, Canada has a number of health service jurisdictions. For this reason it is important to engage researchers across Canada to share, adapt and scale-up the most promising practices. This is why the Canadian Consortium on Neurodegeneration in Aging as well as the National Population Health Study of Neurological Conditions has, and will continue to involve researchers across Canada and develop partnerships with most jurisdictions.

**7. *What roles can all stakeholders play in facilitating international collaboration on dementia?***

Stakeholders can connect, disseminate and support collaborative research activities and disseminate research evidence. Stakeholders can collaborate to position Canada optimally to engage in international research collaborations.

**8. *How can we ensure that we keep the concerns of people with dementia and their caregivers at the heart of the summit's discussions?***

Organizations representing the people with dementia and their caregivers need to be included upstream in discussions to ensure their needs and views are integrated in research activities. The Alzheimer Society Canada is a main partner of the Canadian Consortium on Neurodegeneration in Aging and is also actively involved in the National Population Health Study of Neurological Conditions. Organizations representing other groups of people with neurodegenerative diseases causing dementia are encouraged to partner in order to enhance knowledge transfer and exchange to the benefit of all those having to live with dementia, as well as their caregivers.