

# Canadian Institutes of Health Research– Institute of Aging: Profile

## When the Rising Tide Impacts the World: Addressing the Global Challenge of Dementia

Flamine Alary, Joanne Goldberg, and Yves Joanette  
*Institute of Aging, Canadian Institutes of Health Research*

Manuscript received: / manuscrit reçu : 29/05/17

Manuscript accepted: / manuscrit accepté : 29/05/17

La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Yves Joanette, Ph.D., FCAH  
Scientific Director, CIHR Institute of Aging  
4565 ch. Reine-Marie  
Montréal, QC H3W 1W5  
<yves.joanette@umontreal.ca>

Nearly 10 years ago, the Alzheimer Society of Canada brought national attention to the rising challenge of dementia by publishing a landmark analysis entitled “Rising Tide: The Impact of Dementia on Canadian Society” (Alzheimer Society of Canada, 2010). The image was strong, and unfortunately also very accurate. The number of Canadians who will live with dementia will double by 2050. This number will have to be at least doubled, since for every person living with dementia there is at least one caregiver whose health and wellness is also affected by dementia. The magnitude of the challenge requires a major response from the research community in order to understand the causes of dementia, its treatment, and risk reduction strategies, and to ensure the best quality of life for those currently living with dementia. The Canadian Institutes of Health Research’s (CIHR’s) Dementia Research Strategy was introduced to foster this effort. The Canadian Consortium on Neurodegeneration in Aging (CCNA), introduced in 2014, has now become the flagship research of this effort. As well, the recently published report by the Standing Senate Committee on Social Affairs, Science and Technology (SOCI), along with Bill C-233 which received royal assent, are encouraging indicators that the effort might be re-energized as we see that the needs are even greater than initially imagined.

But the rising tide is not limited to Canada. The world community also realizes that the rise of the tide is a challenge for each and every country. The aging of the population – and mostly the increase in the proportion

of the most aged among elders – is now a reality for all countries. Age is still the main risk factor for the development of dementia. The increase in the number of older individuals, and the relative booming of the oldest among those elders, represent the perfect storm conditions for an explosion of the number of cases of dementia. This trend is not happening only in Canada, but also in all high-income countries. As well, this trend is occurring in low- and middle-income countries, including China, India, and several countries in Africa, in which the overall population is still relatively young. The global recognition of the challenge of dementia is only quite recent. The recognition by the World Health Organization (WHO) of the seriousness of the dementia challenge as a global public health priority was expressed only in 2013 by its director general, Margaret Chan. In the context of a political push for dementia by the G8 countries under the leadership of the United Kingdom’s then prime minister, David Cameron, Chan wrote:

“I can think of no other condition that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other condition that places such a heavy burden on society, families, communities, and economies. I can think of no other condition where innovation, including breakthrough discoveries, is so badly needed.” (Chan, 2013)

This response from the WHO, although arriving only recently, arrived strongly. Following this fundamental

standpoint, a series of actions followed with active participation by Canada.

The first action taken after the G8 Dementia Summit was the First WHO Ministerial Conference in 2015 that allowed for a broad consensus. Three concrete initiatives emerged from this meeting: (1) the creation by the WHO of a Global Dementia Observatory (GDO); (2) the constitution of a WHO-led working group in order to prioritize the required research to face the global challenge of dementia; and (3) the initiation of the work towards the development of a WHO Global Action Plan.

The first WHO area of action is a member state-supported effort at gathering and making available a multitude of data for policy makers, including world data regarding the magnitude of the challenge of dementia in every country; including the resources spent for care, prevention, and research in each country/region; and the nature of the care/prevention policies and their impacts. Canada, through its Public Health Agency, is among the supportive countries of this GDO. The GDO will represent a unique source of data to engage in practical and in implementation research needed to ensure health and wellness for those living with dementia and their carers.

The second WHO area of action has already yielded a thorough reflection on what should be prioritized in terms of dementia research in the coming years. A paper, to which one of the authors (YJ) contributed, was published recently based on a research prioritization exercise. The priorities underscore the importance of a renewed approach to the research on dementia. Many of the efforts up to now – particularly in clinical research – have lamentably failed to identify sources of hope for those living with dementia, as well as the whole population for which dementia represents the most feared health condition linked to aging. More specifically, the group, under the leadership of Tarun Dua from the WHO, has proposed the following research avenues (Shah et al., 2016):

- Explore single and multi-domain approaches for primary and secondary prevention of dementias on the basis of evidence regarding risk/protective factors and the relationship with other chronic diseases
- Understand the influence and interactions of non-modifiable (e.g., gender, genetics, age) and modifiable (e.g., physical activity, diet, and cognitive stimulation) risk and protective factors for dementia in population-based samples
- Determine the feasibility, optimal mode of administration, and effectiveness of interventions to address risk factors for dementia (including physical activity, cognitive activity, education, nutritional factors, and others)
- Identify clinical practice and health system-based interventions that would promote a timely and accurate diagnosis of dementia in primary health-care practices

- Establish longitudinal cognitive surveillance of healthy individuals to detect earliest changes that distinguish premanifest neurodegenerative diseases causing dementia from normal aging, and which may be used as endpoints in primary prevention clinical trials
- Develop and validate biomarkers – including biological, genetic, behavioural, and cognitive markers – for neurodegenerative brain diseases causing dementia, to identify similarities and differences between diseases and dementia subtypes, and assess progression from premanifest to late-stage diseases
- Diversify therapeutic targets and approaches (e.g., amyloid and/or tau; pharmacological and non-pharmacological interventions)
- Promote collaborations to explore more efficient trials, adaptive trials, and combination therapy for dementia
- Identify, validate, and apply better outcome measures for clinical trials of cognition, function, and other biomarkers for neurodegenerative diseases causing dementia
- Understand the contributions of vascular conditions to neurodegenerative diseases causing dementia
- Identify underlying mechanisms of resilience to neurodegenerative diseases causing dementia at all stages (such as cognitive reserve, protective genotypes, and neuroprotection)
- Investigate biological processes of neurodegenerative diseases to understand their contributions to dementia to optimise individualised therapeutic strategies
- Understand the role of inflammation and of the immune system in the initiation/onset and progression of neurodegenerative diseases that lead to dementia

But the availability of data and the identification of research priorities will not be enough to face the global rising tide. The WHO World Health Assembly approved on May 29 a Global Action Plan. This plan was introduced by a number of countries including Canada and brings the attention and participation of all countries to ensure that the most urgent topics shall be addressed.

The GDO will also provide the monitoring mechanisms for the WHO Global Action Plan regarding the public health response to dementia. The Global Action Plan framework is based on the Organisation for Economic Co-operation and Development (OECD)/WHO dementia care framework, the 10 objectives identified in the 2015 *Addressing Dementia: The OECD Response* report (OECD, 2015) as well as the recommended objectives for a national dementia plan made in the Alzheimer's Disease International report entitled *Ideas and Advice on Developing and Implementing a National Dementia Plan* (Pot, Petrea, & Bupa & Alzheimer's Disease International [ADI], 2013). The new WHO Global Action Plan on the public health response to dementia is thus organized around seven key action areas:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction

4. Dementia diagnosis, treatment, care, and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation

A human rights approach to these seven key action areas will be put forward as cross-cutting principles of the Global Action Plan. The rights of individuals living with dementia will be inspired by the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments. Other cross-cutting principles include empowerment and engagement of people with dementia and their carers; evidence-based practice for dementia risk reduction and care; multi-sectorial collaboration on the public health response to dementia; universal and social care coverage for dementia, equity, appropriate attention to dementia prevention, cure, and care.

The plan is asking for all countries not only to recognize the challenge of dementia, but also to commit seriously to providing efforts and resources to face the rising tide and to support those living with dementia and their carers to have a better quality of life. Canada is well positioned since there are already a lot of commitments to face the rising tide of dementia. However, the current efforts are obviously not enough, at all levels. This is why it is important to note that both Canada's Senate and House of Commons were engaged in reflections that could enhance the Canadian effort and engagement. The SOCI Sixth Report was published on November 16, 2016, and adopted by the Senate on November 22, 2016; this is extremely encouraging as it aligns very well with the nature of the recommendations that were approved in May 2017 at the World Health Assembly. The other piece of encouragement comes from the private Bill C-233 that received royal assent and asking for a national dementia strategy for Canada. As far as research is concerned, it is to be noted that both the WHO and the Canadian Senate are asking for a major enhancement of the collaborative efforts made in Canada. Through its Dementia Research Strategy and its CCNA, Canada has become a world reference in collaborative research between disciplines, sectors, and institutions. The SOCI Committee report calls for enhanced research resources and efforts, but in an orderly and efficient manner by capitalizing on the already successful CIHR Dementia Research Strategy.

Such initiatives are not occurring only in Canada, and not only in the academic sector. A multitude of efforts are under way across the world, such as the U.S. National Alzheimer's Project Act, or the recently introduced U.K. Dementia Research Institute which has many characteristics in common with the Canadian CCNA. At the same time, industry – pharma as well as IT – has been orienting R&D towards dementia. However, the road to success is not easy as the fact is that all pharma-driven clinical

trials over the past 15 years have had negative results. Obviously, a global super-coordination body bringing together all stakeholders is needed.

This is why, as a follow-up to the G8 Dementia Summit, the World Dementia Council (WDC) was established in December 2013 (<https://worlddementiacouncil.org>). Made up of individuals representative of all the stakeholders, including people living with dementia, the Council's role is to ensure that the necessary synergy between the large number of private and public initiatives will be achieved, in connection with NGOs representing patients and carers, and also including individuals living with dementia. The WDC is currently the only global interface between all stakeholders involved. It plays that role in a truly global perspective with an enhanced membership embracing the whole planet. The World Dementia Council works closely with all stakeholders, including the WHO, as well as many other critical organizations such as the OECD. Coordination is its role by connecting the dots in a synergistic manner to the benefit of the health and wellness of those living with dementia. The Council thus provides a unique platform to bring together the efforts of industry, member states, NGOs, and many recently introduced organizations, such as the Global Council on Brain Health (<http://www.aarp.org/health/brain-health/global-council-on-brain-health/>) as well as the Global Brain Health Institute. The former is an effort by AARP and Age UK to identify the reliable and science-proven risk reduction factors that can be proposed to enhance the population's empowerment vis-à-vis controlling the risk factors to develop a neurodegenerative disease causing a dementia, as well as the risk factors to develop the clinical signs of a dementia when a neurodegenerative disease is present. At the same time, the Global Brain Health Institute (<http://www.gbhi.org>) represents a philanthropic-supported effort to identify and train the leaders of tomorrow globally that are needed to face the challenge for dementia.

Nearly 10 years after the Alzheimer Society of Canada rang the bell to signal that the tide was rising, Canadian researchers and policy makers are reacting boldly. But it is only the beginning. The rise of the tide has not been stopped in Canada, and it now threatens the rest of the world. Because Canada has always reacted in a collaborative and determined way to previous challenging situations, and because we never dropped the rest of the world when our contribution could make a difference, we now have the responsibility to step up our efforts to contain the rising tide, here and abroad. In doing so, we will not only enhance health and wellness in our Canadian aging population, but we will also contribute to create another source of pride for a country that is looked upon as a small but bold leader in the world of public health.

## References

- Alzheimer Society of Canada. (2010). *Rising tide: The impact of dementia on Canadian society*. Toronto, ON: Author. Retrieved from [http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC\\_Rising\\_Tide\\_Full\\_Report\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf)
- Chan, M. (2013). WHO director-general addresses G8 dementia summit [Transcript of speech]. Retrieved from World Health Organization website: <http://www.who.int/dg/speeches/2013/g8-dementia-summit/en/>
- Organisation for Economic Co-operation and Development (OECD). (2015). *Addressing dementia: The OECD response*. Paris, FRA: OECD.
- Pot, A. M., Petrea, I., & Bupa and Alzheimer's Disease International (ADI). (2013). *Improving dementia care worldwide: Ideas and advice on developing and implementing a National Dementia Plan*. London, ENG: Bupa/ADI.
- Shah, H., Albanese, E., Duggan, C., Rudan, I., Langa, K. M., Carrillo, M. C., ... Dua, T. (2016). Research priorities to reduce the global burden of dementia by 2025. *The Lancet Neurology*, 15(12), 1285–1294.