

CADTH Horizon Scan

# Understanding the Portrait of Dementia Care in Canada: A CADTH Panel of Experts

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## Conflicts of Interest

Dr. Zahinoor Ismail received consultation and advisory fees from Lundbeck/Otsuka. Dr. Tarek K. Rajji received in-kind equipment support from Newronika; in-kind research online accounts from Scientific Brain Training Pro; participated in 2021 in advisory board meeting for Biogen Canada Inc.; and participated in 2021 in advisory board meeting for Biogen Canada Inc. Dr. Sandra Black served as ad hoc advisor to some pharma companies developing drugs for treatment of Alzheimer Disease (Biogen and Hoffmann La-Roche); and participated in education series on dementia especially imaging-sponsored. There were no other declarations.

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## Key Messages

- The prevalence of dementia is increasing annually and there is an ongoing, increasing, and evolving demand for enhanced care for dementia patients in Canada.
- CADTH facilitated a 5-member clinician panel to garner the perspectives of individuals who are currently providing care to Canadian patients with dementia and/or participating in dementia-related health research.
- The panel highlighted several themes pertaining to the current portrait of dementia care in Canada and health system readiness for future burdens of disease, including:
  - improved patient diagnosis
  - development of standardized and collaborative health care
  - increasing patient access to specialist and treatment resources
  - preparing for new and effective therapies.

## Background

It is projected that by the year 2030, 1.4 billion people worldwide will be aged 60 or older and this number will increase to over 2 billion by 2050.<sup>4</sup> This demographic shift has led to an increasing number of people living with dementia. According to the Alzheimer Society of Canada, over 700 000 Canadians are currently living with Alzheimer disease (AD) or other forms of dementia, with over 75 000 new diagnoses each year, a number that is expected to rise.<sup>5</sup> The estimated annual cost of dementia care to the Canadian health care system is \$10.4 billion, a number that is expected to double by 2031.<sup>6</sup>

The *National Strategy for Alzheimer Disease and Other Dementias Act* was passed in 2017 and has driven the development of a national Dementia Strategy for Canada aimed at outlining common principles and a national objective to guide action relating to dementia care across all levels of government. The plan encompasses 3 national objectives including prevention of dementia, advancing therapies toward a cure, and improving the quality of life for people living with dementia and their care partners.<sup>12,13</sup>

Dementia refers to an umbrella set of symptoms affecting cognition (including memory), mood, and behaviour. It is a chronic condition that worsens progressively over time and may be preceded by prodromal stages of mild cognitive impairment (MCI). There are several conditions that may underlie the development of dementia and include AD, Parkinson disease, stroke, as well as Lewy body and frontotemporal dementias.

Current diagnostic approaches for AD and other causes of dementia involve cognitive and neurologic assessments, medical neuroimaging, and clinical evaluation by trained specialists such as psychiatrists, cognitive neurologists, and geriatricians.<sup>7,8</sup> This process may also be supported by laboratory testing of blood and cerebrospinal fluid (CSF) for associated biomarkers (e.g., amyloid, phosphorylated tau, etc.) and screening for risk-associated genes such as presenilin, and offer further possibilities for the diagnosis of dementia.<sup>9</sup>

There are currently no curative or disease-modifying therapies approved for the treatment of dementia in Canada, with current options limited to symptom management and psychosocial interventions. There are several new therapies being evaluated for the treatment of

dementia including novel biologic drug therapies,<sup>10</sup> and non-pharmacological approaches including neuromodulation, which was reviewed in a recent Horizon Scan document produced by CADTH.<sup>11</sup>

## Panel Objectives

- To hear the perspectives of Canadian clinician experts and researchers to help develop a current portrait of care of dementia care in Canada.
- Gain insights regarding health system readiness and current barriers to delivering quality and equitable care to patients.

## Approach

### Panel Selection

A 5-member panel was convened ([Table 1](#)) to include clinicians and researchers involved in care for dementia patients in Canada.

### Panel Discussion

A roundtable discussion took place on February 3, 2022. The topics of discussion focused on describing the current state of dementia care in Canada and identifying considerations on the readiness of our current health system to provide quality, accessible, and equitable health care to an aging population. Discussions were held in an open forum format, facilitated by members of CADTH and centred on a framework of components of the system of care that was shared with participants before the discussion.

**Table 1: Expert Panel Members**

Name	Background
Dr. Sandra Black Toronto, ON	Dr. Black is a neurologist specializing in cognition and stroke and is a clinician scientist based at Sunnybrook Health Science Centre. She held the inaugural Brill Chair in Neurology at the University of Toronto, has contributed to over 700 scientific publications, and has been appointed to the Order of Ontario and as an Officer to the Order of Canada.
Dr. Zahinoor Ismail Calgary, AB	Dr. Ismail is a neuropsychiatrist and a professor of psychiatry, neurology, and epidemiology at the University of Calgary. He is Chair of the Canadian Consensus Conference on Diagnosis and Treatment of Dementia and a clinical scientist focusing on dementia prognostication, early detection, and treatment.
Dr. Luca Pisterzi Toronto, ON	Dr. Pisterzi is the Director of Strategy and Operations for the Toronto Dementia Research Alliance.
Dr. Tarek Rajji Toronto, ON	Dr. Rajji is a geriatric psychiatrist, the Executive Director of the Toronto Dementia Research Alliance, and the Chief of the Adult Neurodevelopment and Geriatric Psychiatry Division at the Centre for Addiction and Mental Health. He is also a clinician scientist and the Director of the Geriatric Psychiatry Division at the University of Toronto.
Dr. Carmela Tartaglia Toronto, ON	Dr. Tartaglia is a cognitive neurologist at the University Health Network, a clinician scientist at the Tanz Centre for Research in Neurodegenerative Diseases, and an associate professor at the University of Toronto.

## Expressed Needs and Insights

From their professional experiences, panel members were asked to provide insight on the current portrait of dementia care in Canada and potential barriers relating to health system readiness and future potential to provide high quality patient care. Below is a summary of key themes and ideas distilled from the discussion, along with relevant quotes to help illustrate these thoughts.

### Improve Patient Diagnosis

Receiving a timely and reliable diagnosis is often the first step to receiving quality medical care of dementia. The topic of diagnosing dementia and its diverse spectrum of related diseases was raised on several occasions by the clinicians participating in this panel discussion. The panelists indicated that the current processes for dementia diagnosis in Canada must evolve moving forward and that several emerging health technologies may facilitate this improvement.

“I think we’re just starting to understand the complexity and heterogeneity of these diseases, which makes it very hard to know who should get what and when.”

There is variability in the clinical presentation, detection, and symptoms associated with both dementia and prodromal MCI. Recent advances in the field have demonstrated the intricacy of dementia pathology, including co-occurrence with other conditions and the complex interplay of various vascular, genetic, and biochemical factors. There are also subtle cognitive symptoms in the early stages of dementia which can delay provision of appropriate care if they are overlooked or misdiagnosed. Further, there is a demonstrable need to expand the current system of health data coding to better track and manage additional symptoms associated with prodromal dementia including changes in behaviour, mood, and mobility. The clinicians agreed that there should be an increased focus on earlier diagnosis to facilitate the opportunity for those living with dementia to access effective treatments. It was noted that therapies for those living with moderate to severe AD are limited and there is a desire to identify and treat patients sooner.

It was further highlighted throughout the discussion that it can be challenging for patients to receive a timely and reliable dementia diagnosis for several reasons including, difficulty in diagnosing the condition for non-specialists and medical professionals without advanced training in aging and associated conditions, shortage of available specialists and care facilities (e.g., memory care clinics), limited access to diagnostic resources and equipment (e.g., PET scans, biomarker screening), and a need for increased standardized screening for cognitive impairment at all levels of health care. Several of these ideas were echoed by the panel in subsequent themes throughout this report.

Recent advances in the areas of genetic and biomarker screening provide novel methods for diagnosing the neurodegenerative conditions causing dementia and are viewed by clinicians as powerful tools for the future. Wider availability of genetic testing in both hospitals and commercial kits (e.g., 23andME) provides broader access for screening of genetic risk factors associated with various diseases, including dementia. There is emerging evidence for the role of genetic risk factors for the development of AD. The panel agreed that these ongoing developments may improve diagnosis in the early stages of dementia and in younger individuals.



“Patients themselves are self-identifying...there is not a standardized approach.”

There was further consensus from the experts on the use of biomarkers for diagnosing dementia. Biomarkers are measurable indicators of a disease and are used to both diagnose and monitor several medical conditions. In the case of dementia and associated disease this includes aberrant levels of proteins like amyloid, total and phosphorylated tau, and neurofilament light chain. These proteins can be tested in either blood or CSF and are considered by the panel to be reliable and cost-effective in their use for diagnosis dementia. There was a strong consensus among the panelists that the future of Canadian dementia care should place increased emphasis on the use and accessibility to biomarker testing, as this will improve timely and equitable access to quality care.

## Develop Standardized and Collaborative Health Care

Health care in Canada is provided at multiple levels with input from a range of medical professionals across several geographic jurisdictions. Collaborative care involves a team-based approach to care in which various health professionals provide multidisciplinary primary care and resources for patients. These integrated, collaborative care models are shown to drive better health outcomes for patients and improved access to services and resources.<sup>14,15</sup> A need for more standardized and collaborative care models with embedded research capabilities for dementia was another core theme that echoed through the discussion.

“We’ve understood that together we can do so much more than we can do apart and actually have been developing standardized assessment tools and imaging, which I think can impact what’s going on in the rest of Canada.”

The panelists were united in their views that allied health support including non-specialist physicians and nurse practitioners are crucial to providing dementia care to Canadians. They also shared the view that this will only increase in the future. Delayed access to specialists is often a bottleneck in the care pathway for many dementia patients, often resulting in delays for patients in receiving accurate diagnoses and appropriate treatment. One way to overcome this barrier according to clinicians is a more collaborative approach in which primary care physicians and other allied health professionals identify patients and provide access to resources and specialists as required. An example of such an approach is being explored in multi-specialty interprofessional team-based (MINT) memory clinics, which the panel agreed are an innovative and valuable resource in the care of dementia.

“I think one way to get around this is that we need to create different consultation support and engagement of the specialist with the primary care sector.”

“Standardization of existing treatments leads to much better outcomes but also leads to significant acceleration to accessing the right treatment.”

As mentioned previously, the diagnosis of dementia and underlying neurodegenerative diseases can be a challenging endeavour. A focus on enhancing standardized or algorithmic dementia care models was raised by the panel. The enhanced model should encompass standardized diagnostic criteria nationwide including the potential use of biomarkers, periodic screening for cognitive impairment for aging patients, improved capture of dementia for health records and medical data, defined clinical pathways with support for specialist referrals, and more effective therapeutic options.

The clinicians indicated that modifying current funding models pertaining to specialists providing care for dementia patients should also be considered. It was proposed that the future of dementia care should incorporate elements of virtual care, to expand the access to Canadians of physicians specializing in the diagnosis and treatment of dementia. This type of virtual care is currently being offered in MINT memory clinics across Ontario.

The importance of the patient perspective in building toward a future of accessible, quality care for those living with dementia was another point emphasized by the clinician panel. CADTH engaged a panel of Canadian dementia patients and caregivers to explore what is important to those with lived experience with dementia.<sup>1</sup> It was also suggested that future discussion relating to the current and future portrait of dementia care involve a multistakeholder panel approach with collaborative input at all levels of the health care system including specialists, general practitioners and family physicians, nurse practitioners, patients, insurance providers and pharmaceutical manufacturers, further underscoring the desire for a more collaborative approach to dementia care.

## Enhance Patient Access to Resources

Improving access to care resources for patients living with dementia emerged as a foundational theme throughout the panel discussion. The panel indicated that 1 barrier to the current and future of dementia care in Canada is a frequent delay or waiting period for patients to access specialists and the necessary resources to accurately diagnose and treat the condition effectively. A report by the RAND Corporation assessing Canada's health system readiness for new dementia therapies estimated that the average wait time to receive a diagnosis or access treatments in Canada was 28 months.<sup>10</sup>

According to clinicians, primary driver of these access delays is an overall lack of specialist clinicians trained to appropriately diagnose and treat dementia, especially in early stages of MCI. The panel expressed an immediate need for more specialists and increased allied health support for those currently treating patients across the country. The panel indicated that increasing the opportunity for primary care physicians, nurse practitioners and other allied health professionals to access additional training in aging in tandem with a more integrated, collaborative approach are essential to decreasing the current delay from symptom onset to accessing care for Canadians. A Canadian Institute for Health Information report that showed that only 2 out of 5 family doctors in Canada felt well prepared to treat and manage dementia and related conditions in their communities, despite over 80% indicating that they often deal with dementia patients in their practice.<sup>16</sup>

The panel noted barriers in access to essential resources used for the diagnosis and treatment of dementia. One example centred on neuroimaging equipment frequently used to diagnose dementia and follow disease progression and responses to treatment. This often involves the use of MRI (MRI) and PET (PET) scans to assess brain and vasculature pathologies, and presence of dementia-related depositions including amyloid protein. The panel indicated an immediate need for increased access to PET scanners and other technologies used to assess patients and their disease progression. It is estimated that there were 51 PET scanners located across Canada as of 2018 and that they are primarily used for diagnosis and treating various cancers.<sup>10,17,18</sup> It was also mentioned that increasing the use of biomarkers for diagnostic purposes will decrease the demand for neuroimaging resources and are cost-effective compared to current options.

“We were very behind in our access to technologies. There are PET scanners, they are just not being used for the purposes of dementia diagnosis.”

The panel further indicated a need to improve patient access to specialty care clinics including specialist memory care clinics and experimental treatment options involving IV infusion sites. These clinics are often the location for providing collaborative, team-based care to dementia patients in which they can access specialist services including medical imaging, biomarkers screening and genetic testing referrals, access to treatment options including IV infusions when required, and additional caregiver resources. The panel unanimously highlighted the value of these clinics and their associated services and believed that increasing both their number and accessibility was an essential consideration for the future of dementia care in Canada.

## Need for Novel Treatment Options and Health System Readiness

There are currently no approved disease-modifying or curative treatments for dementia. Current options commonly involve daily management of symptoms and rely heavily on the patients and their caregivers to monitor and balance the disease with daily life. There was a consensus among the panel that Canada has a need for new and effective treatments of dementia, and that the health care system must be readied to appropriately explore and implement new therapeutic options as they become available. The panelists also referenced a report from the RAND Corporation that specifically highlighted that the current health care system in Canada is not ready to optimally receive and implement the next generation of therapies for dementia patients,<sup>10</sup> and that this must be addressed to accommodate the projected health burden of an aging population.

There are currently medications and pharmacological treatments that are prescribed by physicians to help patients manage dementia, including cholinesterase inhibitors, to potentially improve memory and cognitive functions. Antidepressant drugs and antipsychotic drugs may be used to manage behavioural and neuropsychiatric symptoms of dementia (e.g., agitation, psychosis), although they are generally prescribed off label. Although, antipsychotic drugs carry black box warning for substantial risk and are associated with uncertainties surrounding their prescriptions, dosing regimens, and overall effectiveness in real-world settings for dementia patients.<sup>19</sup>

“Canada’s readiness for any disease-modifying agent is really lacking because of needing to prove that you have Alzheimer’s disease before you could actually access any of the therapies.”

New therapeutic drugs are currently being investigated to treat AD and other forms of dementia, including several disease-modifying options that target the underlying pathologies contributing to the disease. For example, the next generation of AD therapies feature several antibody-based therapies targeting proteins linked to the disease including beta-amyloid and tau proteins.<sup>9,10,20</sup> There are also several therapies that target the *BACE1* gene that is involved in producing a toxic form of amyloid that deposit in the brains of some patients.<sup>21</sup> The panel echoed that these new therapeutics have the potential to improve the quality of dementia care in Canada, but that several hurdles remain to be overcome before this can occur.

“Many times, the real-world efficacy or the effectiveness of these interventions become much lower than what is shown in the studies, and I think part of that is because real practice deviates quite a bit from what the evidence suggests.”

The panel also highlighted that the role of real-world evidence is expected to increase for assessing the clinical benefits and cost-effectiveness of new therapies. It was felt that clinical trials are often under representative of a highly diverse real-world patient population, and this is reflected in the current uncertainties relating to current therapeutic drug options and their effectiveness for treating dementia. It will therefore be important to access reliable and quality sources of health data and real-world evidence to inform future decision-making related to providing dementia care to Canadians.

## Opportunities for Further Learning

The following are areas for future improvement and learning opportunities for future panel discussions pertaining to dementia care in Canada, as proposed by both CADTH and the clinician experts:

- interdisciplinary, multistakeholder panel discussion bringing patients and clinicians together with additional input from allied health professionals including primary care physicians, nurses, nurse practitioners, care partners, and other entities participating in the provision of dementia care to Canadians
- expanding the clinician panel to include specialists from outside of Ontario and Alberta to gather a more comprehensive perspective relating to the needs of Canadian dementia patients and care providers.

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