

Developing a Provincial Framework for Dementia Care in Ontario

Results of an Evidence Scan



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Executive Summary

In December 2024, the Improving Care in Ontario Act received royal assent. This Act directs the Minister of Health to develop a provincial framework designed to support improved access to dementia care. This direction includes the requirement that a future framework “takes into consideration existing dementia care frameworks, strategies and best practices” and “leverages the expertise and capacities of key partners in Ontario’s health system”¹.

In response to the new legislation, in January 2025, Provincial Geriatrics Leadership Ontario, and entity funded under the Ministry of Health’s Dementia Strategy, initiated an evidence scan that identified 41 previously published dementia strategies, frameworks and other publications, and synthesized the findings to inform the development of a Provincial Framework for Dementia Care, and support consultations with relevant parties.

The current evidence has been synthesized into four thematic areas including: prevention, awareness and research; equitable access to integrated and skilled care; diagnoses, treatment and post diagnostic care; care and support across the continuum. Results of the evidence scan were reviewed critiqued by representatives of provincial programs and numerous gaps in the existing evidence were identified.

Experts reviewing the evidence scan suggested that a future dementia care framework must take a broader approach than is reflected in current examples—going beyond diagnostics and treatments to focus on workforce capacity, integrated care, and behavioral health supports. Additionally, research and engagement are needed to ensure the anticipated provincial framework is inclusive of equity-deserving populations, caregivers, and underrepresented service areas (e.g., behavioral health, palliative care).

Finally, a clinical consultation was recommended to gather input on the core clinical functions, structures, and priorities that should be included in the provincial framework.

¹Improving Dementia Care in Ontario Act, S.O. 2024, c.32, s.1(2)

Introduction

In Ontario, in 2023, more than 173,000 people over age 66 were living with a diagnosis of dementia, and on average used 11 or more medications, visited a physician roughly 11 times a year and more than 85,800 people living with dementia (49.6%) required homecare services². In the same year, over 56,000 (32.5%) older adults living with dementia visited the emergency department and more than 41,000 (24.0%) experienced a hospitalization³. A significant number of people living with dementia require support to remain at home.

Significant previous work and thinking has been undertaken in Ontario and beyond to conceptualize systems of care for people living with dementia. This evidence scan consolidates previous efforts to inform the design of a Provincial Framework for Dementia Care described in the 2024 Improving Dementia Care in Ontario Act. This scan was also conducted as a precursor to consultation with clinicians engaged in the clinical work of dementia care which includes activities such as assessments, diagnoses, treatments and ongoing care activities. Much of this clinical work is carried out by primary care, supported by specialized clinical dementia services (also called specialized geriatric services and seniors' mental health) that operate across all health care sectors (e.g. hospitals, community settings, long-term care etc.). Of the 173,000 people aged 66 and older (the majority) living with dementia in Ontario in 2023, nearly 32,000 visited a geriatrician, over 12,000 visited a geriatric psychiatrist and roughly 17,000 visited a neurologist², and their associated interprofessional teams. In Ontario, in 2023, there were approximately 1600 health professionals working in these interprofessional clinical teams in a variety of programs (e.g. primary care-based memory clinics, specialized memory clinics, geriatric and seniors' mental health outreach teams, hospital-based programs, etc.) (see Appendix 1) and collectively they supported 120,000 patients with dementia and/or other problems associated with aging, through more than 500,000 clinical visits .

The main question guiding our scan was "what do available policy documents identify as the priorities of dementia care and how could these be adapted to inform the development of a dementia care framework for Ontario?"

2. Warren, C., Mondor, L., Bronskill, S., Paterson, M., Plumtre, L., An, D. (2023). Characteristics and Utilization of Physician Specialist Services among Older Adults with Dementia and Frailty in Ontario – 2023 Update, Applied Health Research Questions (AHRQ) # 2024 0800 263 001. Toronto: Institute for Clinical Evaluative Sciences.

3. Srugo, S., Jiang, Y., de Groh, M. (2018). Living arrangements and health status of seniors in the 2018 Canadian community health survey. <https://www.canada.ca/en/public-health/services/reports-publications/health-promotion-chronic-disease-prevention-canada-research-policy-practice/vol-40-no-1-2020/living-arrangements-health-seniors.html>

Methods

Our search included a review the policy (grey) literature for previously published dementia strategies, frameworks and other publications advocating for improved dementia care and management across jurisdictions. Other documents (previous dementia policy and strategy documents) known to the research team were also used in the evidence scan.

Our search terms included:

- Dementia Framework;
- Dementia strategy;
- Dementia Framework Europe/Australia/UK/Ireland/Scotland/Europe/USA/New Zealand/India/China;
- Dementia Strategy Australia Europe/Australia/UK/Ireland/Scotland/Europe/USA/New Zealand/India/China.

We included documents published in English between 2007 and 2024. Where there were multiple versions of the same document, the most recent document was used.

Sources from India, China and the Philippines were specifically sought as these populations are among the largest immigrant communities in Canada. Unfortunately, we were unable to locate a copy China's dementia strategy in English, and found only references to dementia strategies in India and the Philippines, but no publicly available version of these frameworks. Our review also found reference to a lack of infrastructure for dementia care in both India and the Philippines and articles calling to the development of dementia care in both countries. We did not search specifically for individual European countries due to time limitations and note that doing so in future may identify additional useful resources. Of particular note was a high quality framework from New Zealand (2013), which was included.

We presented preliminary results to clinical experts for feedback on Feb 24, 2025 and this feedback is included in this report.

Results

We identified and screen 41 publications as follows:

- Canada
 - National (10)
 - Ontario (10)
 - Quebec (4)
 - British Columbia (1)
- Scotland (2)
- Northern Ireland (1)
- England (3)
- Europe (1)
- New Zealand (1)
- Australia (2)
- USA (2)
- India (2)
- China (1)
- International (multi-country) (1)

All documents are included in the reference section of this report. We identified broad themes that were consistent across publications and summarize main points within each theme. Slide 6 illustrates these broad themes, and these themes are explained in further detail in slides 7 to 11.

Informing a Provincial Framework for Dementia Care In Ontario

- Modifiable risk factors
- Screening and prevention
- Anti-ageism and anti-stigma strategies
- Diverse research agenda

Prevention, Awareness and Research

Equitable Access to Integrated & Skilled Care

- Equitable access to high-quality dementia prevention, diagnosis and care
- Skilled and knowledgeable dementia-trained workforce
- Integrated care models

Whole Person Centred Dementia Care

- Diagnostic services
- Post-diagnostic care
- Treatments

Diagnosis, Treatment and Post-Diagnostic Care

Care and Support Across the Continuum

- Home care and community supports
- Care for caregivers
- Palliative care for people living with dementia
- Dementia sensitive acute care

Implementation (including structural, administrative and technology supports), Evaluation and Outcome Measurement

Prevention,
Awareness and
Research



Dementia Prevention

- 45% of cases could be prevented
- Potentially modifiable risk factors (middle age) need to be optimized early for greatest impact
- Public health agencies need to be engaged to support public awareness of the impact of modifiable risk factors on dementia risk
- Access to primary care (cardiovascular screening and management, audiology access, depression/mental health supports) in mid-life is essential to optimize primary prevention
- Ability for people to engage in primary prevention of dementia is heavily dependent on social determinants of health and other health equity factors

Increase Public Awareness of Dementia

- Dementia is not normal aging
- Need to promote increased awareness of dementia and promote the importance of early recognition/diagnosis
- Need to address the stigma associated with dementia to support early recognition, diagnosis and treatment

Dementia Research

- Ongoing prevention research – further risk factor identification, impact of interventions to address dementia risk New pharmacotherapy research
- Non-pharmacologic research (impact of dementia friendly communities/ environments)
- Research into the efficacy and evaluation of implementation strategies used to implement the dementia framework, including technology, and that can help patients access care
- Need for more diversity within dementia research

Equitable
Access to
Integrated &
Skilled Care



Equitable Access

- Framework must incorporate a critical social justice lens
- Must recognize people/populations at increased risk due to inability to access prevention strategies, assessment or ongoing care
- Indigenous people: increased risk of developing dementia; more barriers to care (for prevention, diagnosis and post-diagnostic care)
- Culturally diverse communities across Canada need to be considered throughout the framework (indigenous, ethnic populations, 2SLGBTQIA+)
- Socioeconomic status directly impacts dementia risk and access to care

Skilled Workforce

- Need to increase capacity for dementia care across disciplines and settings
- Include dementia content during certification programs (medicine, nursing, PSW, allied health); increase availability of additional certification across disciplines (medicine, nursing and NPs, PSW, allied health)
- Add shortfall of geriatricians and geriatric psychiatrists; need to optimize the capacity of other health disciplines to help care for people with dementia (family physicians, NPs, RNs, OTs, PSWs, etc.)
- Continuing education across settings and disciplines to enhance quality of dementia care

Integrated Care

- Collaborative care models to improve patient care experience (primary care, community care, specialist geriatric care, palliative care)
- Integration of specialized geriatric care into primary care settings
- ED and acute care avoidance by enhancing access to care in the community
- Integrate CSS programs into ED environment
- Increased access to care in the community to reduce potentially avoidable ED use
- Prevent harm when people with dementia are admitted to acute care environments
- Palliative care for people with dementia

Diagnosis,
Treatment and
Post-Diagnostic
Care



Diagnosis

- Access to a diagnosis
- Accessible diagnostic care for all people
- Special consideration to Indigenous people and culturally appropriate and safe care for all people in Canada
- Emphasis on diagnosis in the primary care setting, with a need to increase the capacity of primary care providers
- Specialist referral limited to atypical cases, to increase access to specialized services for those who need it most
- Need to overcome barriers to diagnosis/referral processes to promote early diagnosis and implementation of care

Treatment

- Early access to available pharmacotherapies (cholinesterase inhibitors and memantine)
- Emerging therapies: accessibility (and cost/system capacity) considerations
- Pathway development for access to immunoglobulin therapies/clinics
- Genetic testing, PET imaging/CSF analysis for AD diagnosis confirmation
- Serial neuroimaging for ARIA-E and ARIA-H during treatment
- Supportive factors to slow the progression of dementia
- Hearing impairment, vascular risk factor control, mental health support, social engagement, etc.

Post-Diagnostic Care

- Approach to care: dementia should be treated as a chronic disease, managed via accessible, collaborative care models, integrated within primary care, providing culturally safe care throughout the course of the disease
- Ensure access to ongoing dementia care throughout progression of the disease (e.g. pathways)
- Emphasis on Living Well with dementia
- Be connected to community and home-care supports
- Ensure caregivers are supported, well-informed and prepared as dementia progresses
- Engage in conversations about advanced care planning / goals of care, including the role of palliative early in the course of the disease

Care and Support Across the Continuum



Home Care & Community Supports

- Access to home care supports that are available, flexible and reliable
- Access to activation & respite services, to support people to remain at home longer
- Person centered approaches to behaviour changes by accessible, skilled care providers
- Connection with community programs (Alzheimer's society) for caregiver support
- Access to LTC if/when needed

Care for the Caregiver

- Caregivers are recognized, valued and supported
- Caregivers have access to information about dementia care and progression
- Caregivers have access to tools and information to help them prepare for the future

Palliative Care

- Ensure access to home-based primary and dementia care as disease progresses, to help people remain at home longer
- Develop / adopt guidelines for the provision of palliative care for people with dementia
- Ensure access to knowledgeable palliative care teams for people with dementia

Leadership

- Establish a leadership infrastructure aligned with Ontario Health mandated to oversee dementia care and implement the provincial Dementia Care Framework
- Provide support to the Framework and its activities

Implementation Supports (including technology)

- Technology as a supplement to face-to-face care should be explored
- Exploration of the use of digital cognitive assessments to increase access to early assessment
- Use of tele-medicine and virtual supports to reach those in rural and remote areas to access dementia care
- Optimize home automation to promote and prolong autonomy and support safety

Evaluation

- Developmental evaluation
- Key system and program level performance indicators and data
- Use of Dashboards to monitor and report performance (continuity of care, connection with specialists, ED visits, etc.; data is used to evaluate program effects in real time to address local/regional needs)

Implementation (including technology supports), Evaluation and Outcome Measurement

Feedback from Clinical Experts: Gaps and Limitations in the Evidence

The results of the initial evidence scan were presented on February 24, 2025 to the Ontario Partners for Excellence in Aging Care (OPEAC), a group convened by Provincial Geriatrics Leadership Ontario and the Provincial Coordinating Office of Behavioural Supports Ontario to bring together partners/leaders representing key government-supported provincial programs* and organizations that provide clinical services to older adults with complex health and social care needs who are well-positioned to contribute to Ontario's Health Aging Care Continuum.

Clinical experts highlighted gaps in the current evidence on dementia frameworks. This feedback is provided in detail in the following slides to offer guidance to the Ministry of Health and others about areas requiring further examination.

*Behavioural Supports Ontario, Community Paramedicine, GeriMedRisk, Nurse Led Outreach Teams, Ontario Hospital Association, Provincial Geriatrics Leadership Ontario, Rehabilitative Care Alliance

Feedback from Clinical Experts: Gaps and Limitations in the Evidence (continued)

1. Limited Focus on Workforce and Direct Care Needs

- The scan did not identify significant evidence that sufficiently emphasizes health human resource (HHR) challenges, particularly the shortage of PSWs, nurses, geriatricians, and other specialists trained to care for individuals with dementia.
- Existing frameworks largely focus on clinical services, but they do not adequately identify mechanisms for training of direct care workers in managing dementia-related behaviors and mental health comorbidities.
- Some long-standing support programs, such as specialized geriatric services (SGS) and seniors' mental health (SMH), are underfunded and not expanding despite increasing demand.

2. Over-emphasis on Medical and Pharmacological Approaches

- Participants noted that existing frameworks lean heavily toward diagnosis, treatment, and emerging disease-modifying therapies rather than holistic, person-centered care.
- There is no consensus within the clinical community on the role, cost-effectiveness, and accessibility of new disease-modifying therapies (DMTs) for dementia.
- A new framework should balance investment in new treatments with funding for behavioural supports, caregiver support, and non-pharmacological interventions.
- There is a need for more discussion on appropriate diagnostic pathways, including concerns about access to specialized imaging and genetic testing required for newer treatments.

Feedback from Clinical Experts: Gaps and Limitations in the Evidence (continued)

3. Behavioural and Mental Health Supports Are Underdeveloped

- While some frameworks mention behavioural supports, they do not clearly define a comprehensive behavioural health strategy for individuals with dementia across different settings (home, community, LTC, hospitals).
- There is no systematic approach to supporting individuals with severe behavioural symptoms in LTC, leading to inconsistent access to specialized care units (e.g., behavioural units).
- Mental health services for older adults with dementia remain fragmented and difficult to access, particularly for those with severe and persistent mental illness (SPMI) who may not fit into traditional dementia care pathways.

4. Gaps in Dementia Care for Marginalized and Underserved Populations

- The scan did identify current equity concerns, including barriers faced by Indigenous populations, culturally diverse communities, LGBTQ2S+ individuals, and those in rural/remote areas. The remedies are underdeveloped.
- Many marginalized groups experience delays in diagnosis, limited access to dementia-friendly services, and culturally inappropriate care models that do not meet their needs.
- Evidence scan did not surface sufficient material related to intellectual disability and dementia.

Feedback from Clinical Experts: Gaps and Limitations in the Evidence (continued)

5. Lack of Clear, Scalable Models for Integrated Care

- While some frameworks mention integrated care, they do not provide practical, scalable models for linking primary care, specialized dementia services, community programs, and LTC.
- There is limited evidence on how to ensure timely access to specialist support for primary care teams managing complex dementia cases.
- Community-based programs and home care supports are often overlooked or underfunded compared to institutional care.

6. Insufficient Focus on Patient and Caregiver Autonomy

- The current frameworks address the need for autonomy and informed decision-making for people living with dementia. The remedies are underdeveloped.
- Participants emphasized that patients should not be automatically directed to LTC when other housing or community support options may be available.
- Caregivers' mental health and well-being need stronger focus, particularly through expanded respite services, financial support, and mental health resources.

Feedback from Clinical Experts: Gaps and Limitations in the Evidence (continued)

7. Lack of a Comprehensive Palliative and End-of-Life Care Strategy

- The evidence identified in the scan identified palliative and end-of-life care for people with dementia as a key component of the care continuum. Not yet well integrated into routine dementia care.
- There is inconsistent access to palliative services for individuals with dementia, leading to inappropriate hospitalizations and medical interventions near end-of-life.

8. Fragmentation in Data Collection, Evaluation, and System Coordination

- Existing frameworks lack clear monitoring and evaluation mechanisms to assess the effectiveness of dementia care programs over time.
- There is no centralized data infrastructure to track dementia diagnoses, treatment patterns, and outcomes across different care settings.
- The current frameworks do not sufficiently address cross-sector coordination, which is essential to ensuring seamless transitions between home care, community services, hospitals, and LTC.
- Return on investment approaches are not well described in the evidence.

Recommended Next Steps

Clinical experts strongly recommended that:

1. Future dementia care frameworks must take a broader approach—going beyond diagnostics and treatments to focus on workforce capacity, integrated care, and behavioural health supports.
2. A clinical consultation is necessary to gather input on the core functions, structures, and priorities that should be included in the provincial framework.
3. Additional research and engagement are needed to ensure the framework is inclusive of equity-deserving populations, caregivers, and underrepresented service areas (e.g., behavioral health, palliative care).

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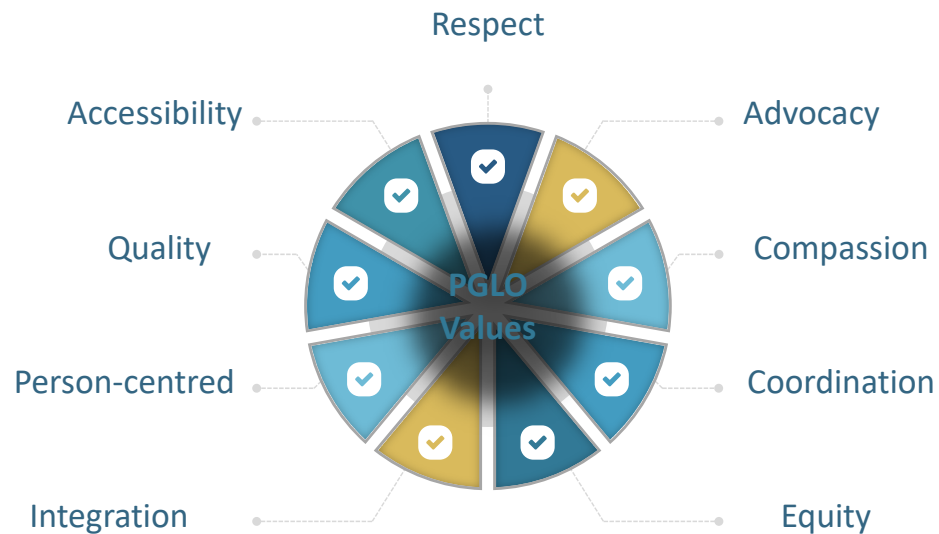
Provincial Geriatrics Leadership Ontario



Funded under the **Dementia Strategy** of the Ministry of Health to lead the provincial coordination of specialized physical, cognitive, social and mental health services for older adults.



Advances integrated, person-centred care for older adults living with complex health conditions, including dementia and frailty, and their care partners, in Ontario.



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