

REPORT OF A CONSULTATION ON DEMENTIA CARE IN ONTARIO

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CO-HOSTED BY:



Alzheimer Society



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Table of Contents

Key rerms	2
Executive Summary	3
Clinical Dementia Care in Ontario	5
Background: Hosting A Dementia Care Clinical Consultation	6
Our Approach to Consultation	7
Scope and Limitations	8
Prevention	9
Screening vs. Assessment: Where the Line Is Drawn	13
Screening	14
Assessment	20
Diagnosis	25
Care Planning	28
Treatment and Management	32
mplementation Considerations to Enable Dementia Care Clinical Activities	36
Conclusion	40
Appendix 1: Participants (Alphabetically by Organization)	41
Appendix 2: Selected Evidence	42

Key Terms

Dementia: According to the Alzheimer Society of Canada "Dementia is a broad term that describes a set of symptoms that may include memory loss, changes in mood, and difficulties with thinking, problem solving and language. While they may seem small at the start, they can affect the day-to-day lives of people with dementia."

Dementia is now called Major Neurocognitive Disorder (MND) in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). According to the American Psychiatric Association, however, "the term dementia is not precluded from use in the etiological subtypes where that term is standard." This means that the word "dementia" is still commonly used when clinicians (also referred to in this report as health and social care providers) talk about specific types of conditions – like Alzheimer's disease. For simplicity, we have used the term "dementia" in this report.

Care Partners: According to Bennett et al. "Care partnering includes providing assistance to an individual with a health condition to meet their self-care deficits, the commitment to a care partner relationship, and the recognition that people with self-care deficits are care partners contributing to their own care." Throughout this document, we have used "care partner," which can include families and friends, rather than the similar term caregiver, to be consistent with language used by the Alzheimer Society of Ontario and many people with lived experience of dementia.

Clinical Management: The term "management" is commonly used in clinical practice guidelines and clinical care and is relevant to the context of this document. Our use of this term is not intended to promote dementia care practices that are impersonal, paternalistic or "done to" people living with dementia, and we strongly advocate for the co-design of care plans with people living with dementia and tailoring of care to best suit their individual needs.

¹ Alzheimer Society of Canada. (2024). What is Dementia. https://alzheimer.ca/sites/default/files/documents/What-is-dementia-Alzheimer-Society-2024.pdf

² American Psychiatric Association. (2013). Highlights of changes from DSM-IV-TR to DSM-5. https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM_Changes_from_DSM-IV-TR_-to_DSM-5.pdf

³ Bennett, P. N., Wang, W., Moore, M., & Nagle, C. (2017). Care partner: A concept analysis. *Nursing outlook*, 65(2), 184–194. https://doi.org/10.1016/j.outlook.2016.11.005 (p. 184)

Executive Summary

In April 2025, Provincial Geriatrics Leadership Ontario (PGLO), the Alzheimer Society of Ontario (ASO), and the Behavioural Supports Ontario Provincial Coordinating Office (BSO PCO) convened a province-wide clinical consultation to define the core clinical activities essential to high-quality dementia care in Ontario. This initiative supports the development of the Ontario Ministry of Health's Provincial Framework for Dementia Care, as outlined in the *Improving Dementia Care in Ontario Act, 2024*, which received Royal Assent in December 2024.

The consultation brought together 131 clinical experts and partners to identify the clinical services required across the dementia care continuum—from prevention and screening to assessment, diagnosis, care planning, and treatment and management. Participants emphasized that dementia care must be person-centred, equitable, and integrated across all care settings, with timely access to specialized supports and culturally safe services.

Key findings include:

- Prevention must be a lifelong, community-wide effort, integrating brain health promotion, risk reduction, and public education across sectors.
- Screening should be risk-based and accessible in diverse settings, supported by standardized tools and clear referral pathways.
- Assessment must be purposeful, person-centred, and culturally safe, with multidisciplinary teams conducting comprehensive evaluations tailored to individual needs.
- Diagnosis should be accurate, timely, and linked to care planning, with primary care supported by standardized pathways and access to advanced diagnostics.
- Care planning must begin at diagnosis and evolve over time, incorporating legal, safety, and psychosocial considerations, and involving care partners as coplanners.
- Treatment and management require holistic, team-based approaches that address medical, behavioural, and social needs, with strong support for care partners and community-based services.

The report also outlines implementation considerations for consistent dementia care across Ontario and recommends a whole-system approach - one that integrates care across sectors, clarifies workforce roles, and embeds dementia-specific tools and workflows into practice. Key considerations include:

- building interprofessional teams;
- addressing workforce shortages;

- ensuring culturally safe and equitable care; and
- supporting early access through public awareness.

Sustainable funding, digital infrastructure, and ongoing engagement with people living with dementia and their care partners are essential to ensure long-term success and accountability. A coordinated, province-wide approach, led by a government-mandated agency leveraging the Ontario Health infrastructure, is recommended to ensure that all people in Ontario living with dementia—and their care partners—receive consistent, compassionate, and effective care.

Clinical Dementia Care in Ontario

In Ontario, the clinical work of dementia care, such as screening, assessment, diagnosis, treatment and ongoing care activities, is often led by primary care, supported when required by specialized clinical teams with specific training and scope of practice in these areas. In 2023, of 173,000 people aged 66 and older living with dementia in Ontario, nearly 32,000 visited a geriatrician, over 12,000 visited a geriatric psychiatrist and roughly 17,000 visited a neurologist,⁴ and long wait times for these services suggest considerable demand and undersupply. Many people living with dementia also require the support of specialized clinical dementia services (also called specialized geriatric services, seniors' mental health services and behavioural supports). These services are made up of skilled interprofessional teams (e.g. nurse practitioners, nurses, occupational therapists, physiotherapists, pharmacists, social workers and others) who work with geriatricians, geriatric psychiatrists, neurologists, and primary care providers (i.e. physicians and nurse practitioners) and who have specific expertise in dementia and aging care.

These expert interprofessional clinical teams provide significant system capacity for dementia assessment, support and ongoing care. In Ontario, in 2023-24, there were approximately 1900 health and social care providers 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.) and collectively they supported over 130,000 individuals living with dementia and/or other problems associated with aging, through more than 530,000 clinical visits. Health and social care providers working in specialized clinical services also support a robust research and educational infrastructure for dementia care in Ontario, including clinical trials to test new therapies, research into effective approaches and models of care for people living with dementia, and education and mentorship about dementia care delivered through a variety of events and continuing educational offerings.

Also in 2023, 93.8% (more than 160,000) of older people diagnosed with dementia visited a physician, most commonly a primary care physician. According to the Canadian Institute for Health Information (2024), as many as 2 out of 5 primary care physicians reported feeling unprepared to manage the clinical care of people living in the community with dementia and reasons for this include "the complexity of dementia, difficulties diagnosing dementia, lack of access to specialists (particularly in rural and remote areas), insufficient knowledge of community-based resources, time constraints and challenges coordinating

⁴ Warren et al., 2023.

⁵ Kay, K. (2025). Specialized and focused geriatric services asset inventory. Provincial Geriatrics Leadership Ontario. https://geriatricsontario.ca/resources/the-current-state-of-specialized-older-persons-care-adetailed-look-at-specialized-geriatric-services-in-ontario/

⁶ PGLO Geriatric Continuing Professional Education Links https://geriatricsontario.ca/resources/continuing-geriatric-education-links/

⁷ Warren et al., 2023.

patients' and families' needs." Dementia care requires an infrastructure for accessible team-based clinical care, with dementia-educated clinicians of all health disciplines, and timely access to specialized supports when needed. Participant experiences and their clinical observations suggest that dementia is worsened by any hospitalization, therefore the clinical work of dementia care is complemented by the important contributions of home care and community and social service agencies, such as Ontario's Alzheimer Societies, community care agencies and others, who provide necessary ongoing supports for living with dementia through what might be a 12-to-20-year trajectory.

Background: Hosting A Dementia Care Clinical Consultation

On April 22, 2025, Provincial Geriatrics Leadership Ontario (PGLO), The Alzheimer Society of Ontario (ASO) and the Behavioural Supports Ontario Provincial Coordinating Office (BSO PCO) hosted a consultation with dementia care clinical experts. The session was convened to inform an emerging broader provincial framework for dementia care and to provide key input to the Ontario Ministry of Health's (MOH) developing Provincial Framework for Dementia Care, described in new legislation, the *Improving Dementia Care in Ontario Act*, 2024.

Through consultation with clinicians providing care to people living with dementia, we clarified and documented the clinical activities essential to high-quality dementia care. We focused on clinical services, regardless of setting, that are required for individuals experiencing mild cognitive impairment (MCI) and dementia, with activities related to prevention, screening, assessment, diagnosis, care planning, treatment, and management (including follow-up care). Participants were asked to consider what is required, not what is available in all regions, to focus on ideas, not necessarily consensus, and to describe clinical activities to inform the future Provincial Framework and subsequent dementia service design and delivery. The resulting report (this document) is not intended to duplicate or replace existing clinical guidance documents.

Participants acknowledged this focused conversation did not address other critical aspects of dementia care, including community supports, home care, care partner supports, housing, public awareness, research and other areas, topics that participants recommended be addressed by the MOH in its ongoing work.

6

⁸ Canadian Institute for Health Information. Family doctor preparedness. Accessed October 5, 2024.

Our Approach to Consultation

This consultation was preceded by an evidence scan initiated by PGLO that identified 41 published dementia strategies, frameworks and other publications from around the world. The findings were synthesized in a report to support the consultation. The initial scan was reviewed and critiqued by a small group of clinical experts to identify gaps and limitations in the report. A copy of the evidence scan report can be accessed at https://geriatricsontario.ca/resources/developing-a-provincial-framework-for-dementia-care-in-ontario-results-of-an-evidence-scan/.

We invited individuals in clinical and administrative leadership roles with expertise in dementia care from across Ontario. Participants invited to the virtual consultation were asked to review the evidence scan report and respond to a pre-work survey to identify relevant clinical activities in the areas of screening, assessment, diagnosis, care planning, treatment, and management (including follow-up care). Thirty responses were received in the pre-work survey, and responses were used to pre-populate the collaboration software (Padlet) used during the virtual consultation. Numerous responses received in the pre-work survey pointed to the need to expand the scope of the planned consultation to include clinical activities related to prevention. Our survey also asked participants to identify evidence (e.g. references to policy briefs, best practice guidelines, published reports, articles, evaluation studies, etc.) supporting their responses. These resources are listed in Appendix 2: Selected Evidence.

The virtual consultation was held on April 22, 2025, from 8:00 to 10:00 am. One hundred and thirty-one (131) participants attended, and those wishing their names to be included in this report are listed in Appendix 1. Following brief introductory remarks, participants were randomly divided into six breakout rooms reflecting the clinical areas of prevention, screening, assessment, diagnosis, care planning, treatment, and management. Each breakout group was asked to respond to the following questions:

- What clinical activities are essential for this component? (What)
- Which people ought to do this clinical activity? (Who)
- In which settings ought this clinical activity occur? (Where)

Participants documented their own responses using collaboration software (Padlet) and then were invited to "like" (by clicking a symbol) or to comment in writing on the responses of others. Breakout room facilitators then invited open discussion and assigned notetakers to support the capture of key points. This process was repeated two additional times, with the subsequent two rounds allowing participants the opportunity to choose their own breakout room (and preferred discussion topic). Participants returned from breakout discussions to a large group, where reflections were invited and recorded. As participants wanted more time to offer input, the collaboration software link was provided and kept open for an additional week, and participants were also invited to email reflections to the

organizers. The session wrapped up with a sense that while much was accomplished in two hours, the conversation had just begun.

This report was circulated in draft form to all participants for review prior to finalization to provide an opportunity to refine ideas and correct any misinterpretations.

Scope and Limitations

This report describes relevant clinical activities in the areas of prevention, screening, assessment, diagnosis, care planning, treatment, and management related to dementia care, informed by expert clinicians who carry out these activities. This focus was intentional to improve awareness of the requisite clinical activities for high-quality dementia care, to inform effective health service design. This scope, while necessary, is limited. For example, this consultation did not address home care service requirements, legal requirements, consent and capacity issues, academic training (except for general implications for education), long-term care staffing, and remuneration. The needs of care partners were partially identified in related clinical activities; however, further work is required to fully reflect the complex issues and support needs of care partners in dementia care. We also recognize that there are many more clinicians, including primary care practitioners and specialists, who were not part of this consultation. Finally, while many participants engage regularly with people living with dementia through day-to-day clinical work, research activities and patient and family advisory mechanisms, this consultation was confined to clinicians and did not include people living with dementia. These limitations serve as a call to action for future consultations that gather additional insights and perspectives, particularly those of people living with dementia and their care partners, to inform a fulsome provincial framework for dementia care.

Prevention

Participants emphasized that dementia prevention must be a lifelong, community-wide effort that extends beyond the healthcare system. Prevention activities should focus on promoting brain health through physical activity, nutrition, sleep, social engagement, and management of chronic conditions such as hypertension and diabetes.⁹

Participants highlighted the importance of addressing social determinants of health—such as access to dental, vision, and hearing care—and called for greater investment in community-based programs, urban planning, and retirement preparation that support cognitive well-being. There was strong support for integrating prevention into public health campaigns, school curricula, and primary care, while also ensuring culturally safe strategies for diverse communities. Importantly, prevention was viewed not only as a primary strategy but also as a critical component of secondary and tertiary care for those already living with dementia.

Participants highlighted clinical activities clearly related to prevention in dementia care, which are grouped thematically.

Core Clinical Activities Related to Prevention of Dementia

1. Health Promotion and Risk Reduction

- Promote brain health through public health campaigns and clinical conversations that emphasize:
 - physical activity;
 - healthy diet and nutrition;
 - · stress management;
 - adequate sleep;
 - social connection and engagement; and
 - proactive management of mental health issues (e.g. depression).
- Integrate dementia prevention messaging into school curricula, primary care, and community programs across the lifespan.
- Increase awareness of modifiable risk factors, including hypertension, diabetes, hearing loss, and substance use.¹⁰
- Support hearing assessments and access to hearing aids, including removing financial barriers, due to the strong link between hearing loss and cognitive decline.

9

 $^{^{\}rm 9}$ For a full list of modifiable risk factors see https://www.thelancet.com/commissions-do/dementia-prevention-intervention-and-care

¹⁰ Ibid

• Encourage dental, vision care, and concussion prevention as part of holistic prevention strategies.

2. Public Awareness and Education

- Expand public education campaigns to raise awareness of early cognitive changes and the benefits of early diagnosis.
- Tailor prevention messaging to diverse communities, using culturally safe and linguistically appropriate materials.
- Provide clear, evidence-informed information through trusted and consistent sources.
- Increase awareness among care partners and older adults about dementia risk, early signs, and when to seek help.

3. Community-Based and Environmental Strategies

- Promote social prescribing, a process that enables health and social care providers to connect individuals with community supports,¹¹ and reduce isolation through community engagement, linking with work underway across Age Friendly Communities.¹²
- Support neighbourhood and urban planning that fosters walkability, social connection, and active living.
- Encourage retirement planning that includes lifestyle, social, and cognitive engagement—not just financial preparation.

4. Clinical Prevention and Early Intervention

- Integrate proactive conversations about dementia prevention into routine healthcare visits.
- Address secondary and tertiary prevention by supporting people already living with dementia to maintain function and reduce further decline through:
 - nutrition and hydration support;
 - physical activity programs;
 - ongoing social and cognitive engagement; and
 - sleep management.¹³

5. System-Level Supports and Equity

¹¹ https://www.socialprescribing.ca/about-social-prescribing

¹² https://sagelink.ca/age-friendly-communities-ontario/

¹³ https://www.aging-us.com/article/202591/text

- Collaborate with public health and community support services (CSS) to deliver prevention programs.
- Ensure low-barrier access to prevention resources for equity-deserving populations.
- Develop culturally safe prevention strategies that reflect the values and needs of diverse communities.
- Increase awareness of the risks associated with over-the-counter medications and substance use, particularly in older adults.

Roles and Responsibilities in Dementia Prevention

Participants emphasized that dementia prevention must be a shared responsibility across sectors, involving a wide range of health and social care providers, organizations, and community members. Primary care providers, public health nurses, and community health centres were identified as key players in delivering prevention education and lifestyle interventions across the lifespan. Public health agencies were seen as essential partners in designing and implementing population-level strategies, including school-based education and community-wide health promotion.

In acute care settings, Geriatric Emergency Management (GEM) programs (including nurses and other team members), along with emergency department admitting staff, were recognized for their role in identifying high-risk individuals and providing early education and resources. Participants also highlighted the importance of community-based roles, including dementia champions, peer supporters, and community ambassadors. These individuals can help raise awareness, reduce stigma, and connect people to resources.

A coalition approach—involving organizations such as the Alzheimer Society of Ontario, Heart & Stroke Foundation, and Diabetes Canada—was recommended to align messaging and interventions. Ultimately, participants called for a lifespan approach to prevention, engaging diverse groups such as teachers, mental health providers, urban planners, and care partners to create environments and systems that support brain health and reduce dementia risk.

Where Dementia Prevention Activities Should Occur

Participants emphasized that dementia prevention should occur beyond traditional healthcare settings, embedded throughout communities and across the lifespan. Prevention activities should take place everywhere people live, learn, work, and gather—including homes, schools, libraries, senior housing, community hubs, and spiritual spaces.

There was strong support for engaging education settings to promote brain health from an early age, with suggestions such as intergenerational programs that connect students with older adults to reduce stigma and foster social engagement.

Community organizations including seniors' centres, recreation facilities, and even businesses (e.g. garden centres, museums, theatres) were seen as important venues for inclusive, age-friendly programming. Specific suggestions included embedding risk reduction programming in community hubs such as: Seniors' Active Living Centres, retirement homes, and naturally-occurring retirement communities (NORCs).

Participants also highlighted the need to reach rural and remote communities, suggesting creative partnerships with local institutions such as post offices. Home care services, such as those offered through Ontario Health atHome, were identified as key platforms for delivering personalized prevention strategies. Finally, participants called for prevention to be embedded in policy and planning, including poverty reduction and urban design, to address the broader social determinants of cognitive health.

Implications for Education

There is a need to educate health and social care providers, individuals at risk, and care partners on the importance of lifestyle modification as a non-pharmacological strategy for risk reduction.

Screening vs. Assessment:

Where the Line is Drawn

In dementia care, screening and assessment are two related but distinct stages in the clinical pathway. We explain when screening stops and assessment begins.

Screening is a preliminary, broad, and often brief process designed to identify individuals who may be at risk of dementia or who are experiencing cognitive decline. It typically involves standardized tools that flag potential concerns, even in people who are not yet showing clear symptoms.

Screening is often done in primary care, community settings, or during routine health checks, and may include:

- cognitive screening tools;
- dementia risk factor screening (e.g. for frailty, delirium, depression, falls, sleep apnea, or substance use);
- functional red flags (e.g. missed appointments, late bill payments, minor car accidents);
 and
- screening checklists or brief questionnaires.

Assessment, on the other hand, begins when screening results raise concerns or when a person, care partner, or provider notices changes significant enough to warrant a deeper investigation.

Assessment is:

- more detailed and diagnostic in intent;
- done by a provider with proficiency in dementia diagnosis and care and may include physicians and/or nurse practitioners;
- supported by trained health and social care providers using a multidisciplinary approach;
- often involves a comprehensive clinical assessment or in-depth cognitive, functional, medical, and psychosocial evaluations; and
- used to confirm or rule out a diagnosis, understand the nature and severity of impairment, and develop care plans.

In summary, screening stops and assessment begins when:

- a screening tool indicates potential cognitive impairment;
- an individual or care partner expresses concern that aligns with known dementia risk factors;
- a clinician observes changes requiring further investigation; and
- there is a need to determine a diagnosis, eligibility for treatment, or appropriate support and services.

Screening asks, "Is there a concern here?" while assessment asks, "What exactly is going on, and what do we do next?". Screening is for identifying individuals at risk of dementia; assessment is for diagnosing and planning care. Screening should be brief, accessible, and linked to action, while assessment is more in-depth and diagnostic and results in a plan for ongoing care and follow-up.

Screening

Screening is a foundational clinical activity in dementia care that enables early identification of cognitive changes, functional decline, and risk factors associated with developing dementia. Participant feedback emphasized the importance of embedding routine, risk-based, and context-sensitive screening into primary care and other health system touchpoints.

Screening should extend beyond memory concerns to include executive function, psychosocial indicators, and geriatric syndromes such as frailty, depression, and delirium. A range of tools—standardized, culturally safe, and adaptable to diverse settings—should be supported by clear pathways for follow-up assessment and referral. Participants also highlighted the value of public-facing and care partner-led screening tools to reduce stigma, enhance awareness, and promote timely engagement with care.

Participants highlighted clinical activities clearly related to screening in dementia care and identified several (but not all) screening tools as examples. The content is organized into thematic categories.

Core Clinical Activities Related to Screening in Dementia Care

1. Judicious Screening

Judicious screening is viewed as foundational to high-quality dementia care, particularly in primary care and public health contexts.

- Recognize that while routine cognitive screening in asymptomatic individuals is not recommended,¹⁴ judicious screening, usually conducted where concerning signs or clinical red flags are present, is seen as essential, especially in the prodromal or early stages of disease.
- Support lifestyle screening (e.g. physical activity, diet, smoking) which should be integrated into routine care to address modifiable dementia risk factors.
- Include hearing and sleep apnea screening, recommended due to their known associations with cognitive decline.
- Conduct medication reviews, substance use screening, and depression screening, which are important for identifying reversible contributors to cognitive symptoms.

¹⁴ Ismail, Z., Black, S., Camicioli, R. et al. (2020). Recommendations of the 5th Canadian consensus conference on the diagnosis and treatment of dementia. *Alzheimer's and Dementia*, *16*(8) 1182-1195. https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12105

• Screen for geriatric syndromes (e.g. frailty, falls) to support early identification of atrisk individuals.

2. Risk-Based Screening and Case Finding

Participants emphasized the high yield of simple, targeted screening based on individual risk profiles, case finding and clinical red flags.

- Focus on risk-based screening and case finding on individuals with:
 - o History of delirium, falls, cognitive decline, or missed appointments.
 - Changes in office-based clinical visits, such as more frequent primary care appointments or beginning to attend appointments accompanied by family members.
 - o Changes with medication self-management (e.g. medication errors, reports from community pharmacists about new use of blister packaging).
 - Family history of dementia or presence of co-morbid conditions (e.g. seizures, sleep apnea, substance use).
 - History of a recent move to a supported living environment (e.g. retirement home), particularly when prompted by changes in function.
- Conduct follow-up screening for individuals who have experienced delirium during hospitalization.
- Perform functional screening where concerning signs or clinical red flags (e.g. changes in ADLs/IADLs, hygiene, financial errors, driving incidents) are present to detect early cognitive changes.
- Conduct frailty screening and risk screening in emergency departments or for individuals with frequent primary care visits.
- Use social isolation screening and retirement planning education to promote cognitive resilience and mental engagement.

3. Opportunistic and Self-Initiated Screening

There is strong support for enabling individuals and care partners to initiate screening outside of traditional clinical encounters.

- Make self-screening tools and public-facing resources available for individuals and care partners.
- Make brief cognitive screening tools accessible without requiring a healthcare provider, especially for those with early concerns.

• Provide community support systems (e.g. family, friends, faith groups) to help identify individuals at risk and encourage screening.

4. Screening Tools and Approaches

Participants discussed a range of tools and emphasized the need for flexibility, cultural safety, and innovation, such as:

- The Mini-Cog, recommended for primary care due to its brevity and relevance to common dementias.
- The Montreal Cognitive Assessment (MoCA), 15 widely used but may not be appropriate for all.
- Alternative screening tools such as the Mini-Mental State Examination (MMSE),¹⁶
 Rowland Universal Dementia Assessment Scale (RUDAS),¹⁷ and Canadian
 Indigenous Cognitive Assessment (CICA).¹⁸
- Functional screeners and short cognitive screeners for population-level risk stratification.
- Culturally safe tools, which are essential to ensure equity and accuracy in screening.
- Artificial Intelligence (AI) and big data technologies, to enhance screening accuracy, reach, and personalization.
- Public awareness tools (e.g. checklists like those used in well-baby visits, infographics) that empower individuals to seek screening.
- A dementia registry to support population-based screening and follow-up.

5. Guidelines, Decision-Making, and System Supports

Effective screening must be embedded in a system that supports clinical decision-making and follow-up.

• Use clinical decision trees to guide which screening approach is appropriate for whom, reducing over-screening and improving relevance.

¹⁵ https://mocacognition.com/ (training free for students, faculty members, academic researchers and publicly operated healthcare institutions – proof of status required -

https://mocacognition.com/training-certification/)

¹⁶ https://www.parinc.com/products/MMSE (note payment required for use)

¹⁷ https://meded.temertymedicine.utoronto.ca/resource/rowland-universal-dementia-assessment-scale-rudas (freely available)

¹⁸ http://www.ccnateam18.ca/canadian-indigenous-cognitive-assessment-cica-tool.html (freely available)

- Link screening to clear care pathways, including triage and referrals (e.g. to specialists, behavioural supports, community and social service supports, etc.).
- Clearly distinguish between screening and assessment in clinical guidelines.
- Use screening strategies that address stigma and fear, which can deter individuals from seeking help.

6. Population-Level and Public Health-Oriented Screening

- **Population screening**: participants debated the merits of population screening; there was some support for functional and short cognitive screeners at a population level, although other participants cautioned against this approach in the absence of available interventions.
- **Public health framing**: screening and risk assessment were recommended as part of brain health education and a public health strategy.

Roles and Responsibilities in Dementia Screening

Participants emphasized that dementia screening should be a shared responsibility across the healthcare system, involving a range of providers and settings. Primary care providers—particularly family physicians and nurse practitioners—were most commonly identified as the central figures in initiating screening and making appropriate referrals. Participants noted that many primary care providers are currently overwhelmed, and providers often lack the time and resources to conduct screening during routine visits. This highlighted the need for additional support, such as interprofessional teams, education, training, and system-level tools, to enable early identification and follow-up.

Pharmacists were also recognized as key contributors to early detection. Their frequent interactions with individuals, ability to observe medication adherence issues, and established communication channels with primary care providers position them well to identify early cognitive concerns and facilitate next steps. Similarly, other regulated health and social care providers—including nurses, occupational therapists, physiotherapists, social workers, etc.—play important roles, particularly in home care and community settings where they may encounter individuals earlier and more frequently than specialists.

Community-based organizations, such as Alzheimer Societies in Ontario, were identified as valuable partners in delivering screening outside of traditional clinical environments. These settings are especially important for individuals who are not rostered to a primary care provider. In such cases, screening pathways must be flexible and responsive, offering routes to diagnosis and care through community health centers or mobile teams. Participants also emphasized the importance of involving family members, care partners, and community supports in identifying concerns and encouraging screening.

A centralized intake system was suggested to streamline referrals to specialized geriatric services following a positive screen, improving access and efficiency. Ultimately, participants advocated for a collaborative, multi-sectoral approach to screening, where individuals, care partners, and health and social care providers each have a defined role in a coordinated continuum of care.

Where Dementia Screening Should Occur

Participants identified that dementia screening should occur across a diverse range of settings to ensure accessibility, early detection, and continuity of care. There is strong consensus that screening must be integrated throughout the healthcare continuum, rather than confined to any single point of care.

Primary care settings—including family physician and nurse practitioner offices—are seen as the most common and appropriate starting point for screening. However, access to primary care is not universal, and participants stressed the need for alternative screening pathways for individuals without a primary care provider.

Community pharmacies and other community-based settings may be sites of screening activity, for example, physiotherapy clinics and fall prevention clinics. Older adults with undiagnosed cognitive impairment access these settings for different issues (e.g. falls, arthritic pain, and generalized weakness) and may have difficulty adhering to the prescribed exercise program and measures to prevent falls due to underlying cognitive impairment. Physiotherapists can play a key role in early identification by conducting targeted screening in these settings, which can lead to early identification.

Screening should also occur in specialized outpatient clinics that serve high-risk populations, such as dialysis, diabetes, and cardiology clinics. These settings offer opportunities to identify cognitive impairment in individuals with complex health needs. Similarly, emergency departments and acute care settings were noted as important venues for opportunistic screening, especially when cognitive issues may be contributing to the presenting complaint (e.g. medication non-adherence or functional decline). Some participants reflected on their experiences seeing large numbers of undiagnosed individuals in acute care.

Participants emphasized that screening should not be delayed until specialty clinics (e.g. memory clinics or geriatric teams) become involved, as these services are often accessed later in the disease trajectory. Instead, specialized services should receive referrals following initial screening. There is also a call for community-based screening, including through organizations like the Alzheimer Society of Ontario, and for online or self-directed screening tools to support individuals and care partners in initiating the process.

Importantly, screening must be coordinated across settings, with mechanisms in place to share results, respond to findings and track changes over time. This continuity is essential for informing appropriate assessment and care planning. Participants also cautioned

against generalized or population-wide screening without individual baselines, noting the risk of false positives due to factors like education level, mood, or comorbidities.

In summary, dementia screening should be multi-setting, flexible, and person-centred, occurring wherever individuals engage with the health and social care system—whether in primary care, community services, outpatient clinics, or acute care—and supported by systems that ensure follow-up, coordination, and equity in access.

Implications for Education

Public education should address risk factors as well as stigma and fear, which are barriers to early detection. To ensure quality and consistency, all health and social care providers involved in screening should receive training in the selection, administration, scoring, and interpretation of screening tools, as well as in how to communicate results and support individuals post-screening.

Assessment

Assessment is a critical component of high-quality dementia care, providing the foundation for accurate diagnosis, meaningful care planning, and appropriate interventions. Effective assessment must be person-centred, purposeful, and aligned with the individual's stage of dementia, care goals, and care setting.

Clinicians emphasized the importance of tailoring assessments to the person's needs—prioritizing what is essential to know over exhaustive data collection—and ensuring assessments are both clinically useful and resource-sensitive. This includes a focus on cognitive and functional abilities, care partner needs, and environmental factors, while avoiding unnecessary duplication. Clarifying roles, using validated tools appropriately, and embedding assessments as therapeutic and informative interactions are essential to improving quality, equity, and access across the dementia care continuum.

Based on the detailed participant feedback, core clinical activities related to assessment in dementia care are grouped thematically.

Core Clinical Activities Related to Assessment in Dementia Care

1. Person-Centred and Purposeful Assessment

- Use individualized assessment approaches that reflect the person's stage of cognitive impairment, setting (e.g. long-term care, community, clinic), and goals of care (e.g. function, safety, etc.).
- Identify clear goals of assessment (e.g. diagnosis, looking for reversible causes of cognitive impairment, etc.)
- Prioritize "need to know" over "nice to know" and avoid excessive or redundant assessments that do not add clinical value.
- Identify what matters to the person and care partner and include priorities such as quality of life, safety, and autonomy as part of the assessment.

2. Key Aspects of Assessments

While not an exhaustive list of all aspects of assessment, participants specifically referenced:

a. Cognitive Assessments

- Begin at an early stage (e.g. Subjective Cognitive Impairment or Mild Cognitive Impairment).
- Use standardized cognitive tools fit for setting and population.
- Consider neuropsychological evaluation for complex/uncertain cases.

- Include judicious use of biomarkers (e.g. cerebral spinal fluid, blood-based) where indicated, such as in instances of high index of suspicion for early Alzheimer's disease.
- Incorporate imaging as indicated, including positron emission tomography (PET).
- Conduct genetic testing where appropriate.

b. Function and Functional Cognitive Assessment

- Assess functional cognition, which evaluates how cognitive abilities affect the ability to perform daily tasks.
- Assess baseline functional status (i.e. basic and instrumental activities of daily living) and safety in real-world settings. For example, home environment, evidence of impairment (e.g. hygiene, food, clutter), and suitability for living independently.
- Tailor assessment to the stage of disease. For example, early-stage assessment may be more in-depth, covering multiple domains, including insight, while late-stage assessment may be focused on safety, care planning, and goals.

c. Comprehensive Clinical Assessment¹⁹

- Conduct a multi-domain assessment including, but not limited to:
 - Behavioural changes, cognition, continence, delirium, frailty, function, medications, mental health (e.g. mood, psychosis, anxiety), mobility and falls, neurological changes, nutrition and hydration, pain, physical exam, medical history, psychosocial changes, safety concerns, sensory changes, sleep, socio-cultural, and substance use.
- Use targeted assessment approaches when a full, comprehensive clinical assessment is unnecessary.
- Gather collateral information from care partners or family members to better understand behavioural and functional changes.

d. Care Partner Assessment

- Evaluate the care partner's capacity, health, burden, and support needs.
- Include care partners as co-clients of the assessment.
- Address family fears and legal implications compassionately and clearly.
- Identify and address the needs of individuals without care partners.

¹⁹ A comprehensive clinical assessment may include a comprehensive geriatric assessment (CGA) and/or a comprehensive seniors' mental health assessment.

e. Safety Assessment

- Assess cognition and function in relation to fitness to drive.
- Identify other safety concerns (e.g. firearms, heavy equipment use).
- Identify and respond to various forms of abuse, including physical, emotional, financial, and neglect.

3. Improving Assessment Processes

Participants identified a number of process improvement opportunities related to dementia assessment.

a. Clarify Roles and Pathways

- Identify which assessments are best suited for:
 - o Primary care (e.g. early detection, initial screening).
 - Acute care (e.g. delirium identification, minimizing deconditioning, referral to follow-up).
 - Specialized memory clinics (e.g. neuroimaging, neuropsychiatry).
 - Long-term care and retirement home (e.g. care planning, goals of care).
- Match team member expertise to assessment complexity.

b. Standardization and Appropriateness

- Standardize pre-appointment data collection, such as functional observations from individuals and care partners.
- Standardize core assessments across settings where feasible.
- Avoid using tools that are not validated or are inappropriate for the population/setting.

c. Efficient and Scalable Processes

- Streamline assessments to avoid duplication and over-assessment.
- Triage based on complexity rather than universally applying comprehensive assessments.
- Develop triage tools to determine the appropriate level of assessment (brief versus comprehensive).
- Consider "checklists" or guided tools to help prioritize.

• Promote interprofessional assessment models.

d. Informed Consent and Shared Decision-Making

- Ensure information sharing across health and social care providers and sectors to avoid duplication and support continuity of care.
- Ensure individuals and care partners are informed about:
 - o purpose of the assessment;
 - o potential risks and benefits; and
 - o what will be done with the information and the plan for follow-up.

di. Assessment as a Therapeutic Intervention

- Use the process itself to engage, support, and validate the person and their care partner.
- Consider assessment conversations as psychosocially supportive.

dii. Enablers for Effective Assessment

- Workforce planning: clarify who is responsible for what and build capacity across health and social care providers.
- Use of technology and tools: digital platforms, care partner-empowering checklists, decision aids.
- System-level guidance: define expectations for the scope of assessments by setting and complexity.

Roles and Responsibilities in Dementia Assessment

Participants strongly emphasized that dementia diagnosis is within the scope of practice of primary care practitioners (i.e. family physicians and primary care nurse practitioners). Participants suggested the need for supports to enable primary care teams to do this work, including access to dedicated primary care-based memory services (e.g. MINT Memory Clinics) and referral pathways to specialized geriatric services for more complex needs. Home- and community-based assessments were highlighted as essential, particularly for individuals with significant frailty or limited access to clinic settings. Shared care models, real-time information sharing, and clear delineation of roles across the continuum were reinforced as ways to ensure quality and avoid duplication. Greater access to trained staff in all settings, alongside incentives for primary care involvement, would enhance reach and reduce delays in care.

Participants emphasized the need for a multidisciplinary, collaborative approach to dementia assessment, with clearly defined roles based on complexity and setting. While all regulated health professionals can be trained to contribute to assessments—including completing elements of the comprehensive clinical assessment —the composition and

leadership of the team should be matched to the needs of the individual. For example, family physicians and nurse practitioners frequently serve as most responsible providers (MRPs). Care of the Elderly (CoE) physicians, geriatricians, and geriatric psychiatrists typically consult on complex cases, while occupational therapists, social workers, nurses, pharmacists, and other allied health and social care providers bring critical expertise to the assessment of functional cognition, behavioural symptoms, and medication optimization.

Where Dementia Assessments Should Occur

Participants highlighted the importance of flexibility and responsiveness in the location of dementia assessments, emphasizing that assessments should occur in the setting that best meets the individual's needs and context—whether that is primary care, specialized clinics, long-term care, hospitals, or the person's home. Home and community-based assessments are particularly valuable for individuals with limited mobility, inadequate support, or advanced frailty, while clinic-based settings may be better suited for individuals requiring access to diagnostic technologies or specialized teams.

The setting directly influences the nature and quality of assessment, including how findings are interpreted. Participants noted that the environmental context—such as noise, fatigue, or illness—should always be documented, as these can affect assessment results and risk mislabelling individuals.

There was strong support for embedding specialized dementia care into primary care, particularly through models like MINT Memory Clinics, which provide integrated, multidisciplinary assessment and triage. However, participants also expressed concern about variation across settings, especially in functional assessments and in long-term care, where access to specialized resources is often limited.

Finally, participants called for a standardized yet flexible framework outlining the core components of assessments in each care setting, supported by triage tools and clinical reasoning to determine when and where a more in-depth assessment is needed. In-person assessment remains a priority, with virtual tools seen as useful but insufficient for assessment when used exclusively.

Implications for Education

Participants identified the need for cross-sectoral training on comprehensive geriatric assessment, functional cognition, dementia-specific assessments, as well as education on tool selection, administration, and interpretation.

Diagnosis

Participants emphasized that diagnosing dementia must be a comprehensive, collaborative, and evolving process that balances clinical expertise with emerging diagnostic technologies. While clinical diagnosis remains the current standard, many participants expressed concern about its limitations—highlighting that misdiagnosis rates remain unacceptably high compared to other diseases. There was strong support for developing a standardized, province-wide diagnostic pathway that incorporates cognitive and functional assessments, collateral input from care partners, and access to advanced tools such as neuroimaging, biomarkers, and blood-based diagnostics.

Participants also stressed the importance of culturally safe approaches, equitable access to diagnostic services, and better integration between primary care and specialist services. Diagnosis should not occur in isolation but be closely linked to care planning, treatment, and system-level supports such as registries and centralized intake. Ultimately, participants called for a more accurate, accessible, and person-centred diagnostic process that reflects the complexity of dementia and the realities of Ontario's diverse communities.

Based on the detailed participant feedback, core clinical activities related to diagnosis in dementia care are grouped thematically.

Core Clinical Activities Related to the Diagnosis of Dementia

1. Diagnostic Decision-Making and Confirmation

- Establish a clinical diagnosis of dementia based on a synthesis of assessment findings, collateral information, and clinical judgment.
- Distinguish between clinical diagnosis and biomarker-based diagnosis (e.g. CSF analysis and PET scans), recognizing the growing importance of diagnostic tools in improving accuracy.
- Ensure diagnosis is linked to a provincial dementia registry to support access to future treatments, monitor disease progression, and inform system planning.
- Promote standardized diagnostic pathways across Ontario that are person-centred and allow for equitable access to advanced diagnostics (e.g. imaging and biomarkers).
- Support primary care providers in making or confirming diagnoses through access
 to specialized supports through memory clinics, e-consultations, and centralized
 intake systems that coordinate access to specialized services.
- Ensure diagnosis is integrated with care planning and treatment, avoiding fragmentation where diagnosis is delivered in isolation.

2. System-Level Supports for Diagnosis

- Develop a provincial algorithm to guide referrals to specialized geriatric services, especially for complex or young-onset cases.
- Leverage AI and digital tools to identify individuals at risk using routine health data and support timely diagnosis.
- Ensure culturally safe diagnostic practices, recognizing diverse understandings of dementia and adapting communication accordingly.

Roles and Responsibilities in Dementia Diagnosis

Participants emphasized that the responsibility for diagnosing dementia should usually rest with primary care providers —including family physicians and nurse practitioners—supported by interprofessional teams. These teams may include nurses, social workers, occupational therapists, and other allied health and social care providers, operating in collaborative models. For example, MINT Memory Clinics were frequently cited as an effective primary care-based approach for collaborative diagnosis. To support primary care in diagnosis, there were calls for clear diagnostic pathways, centralized referral systems, and best practice guidance, especially in regions without access to memory clinics.

While primary care providers are frequently the starting point for diagnosis, participants acknowledged that some individuals may be first diagnosed elsewhere (e.g. acute care settings, specialty clinics), highlighting the need to embed diagnostic capabilities more broadly across the system. Specialist involvement—such as geriatricians, geriatric psychiatrists, cognitive or behavioural neurologists, and addictions specialists—should be reserved for complex or atypical cases, including those involving multiple diagnoses or young-onset dementia.

Participants also stressed the importance of care partner involvement in the diagnostic process, particularly for providing collateral information on functional changes, social history, and behavioural symptoms. Ultimately, participants advocated for a team-based, community-anchored approach to diagnosis that is accessible, coordinated, and inclusive of both clinical and care partner perspectives. Participants also noted the need to communicate a dementia diagnosis sensitively, in a manner that individuals and care partners understand.

Where Dementia Diagnosis Should Occur

Participants emphasized that dementia diagnosis should be flexible and accessible, occurring in any setting where it falls within the provider's scope of practice and where appropriate supports are available. While primary care was identified as the most appropriate and common setting for diagnosis, participants acknowledged that individuals may also be diagnosed in acute care, long-term care, community settings, or even at home, particularly when mobility or access is a barrier.

There was also interest in exploring the potential for virtual diagnosis, especially to reach underserved or rural populations, though this would require careful consideration of clinical appropriateness and technological infrastructure. Participants highlighted that many individuals and care partners are unsure where to go for a diagnosis and often feel lost both before and after it is made. This underscores the need for clear public guidance, navigation supports such as the Alzheimer Society of Ontario's First Link program, and standardized provincial tools—such as functional screening protocols—to ensure consistent and equitable access to diagnostic services across all care environments.

Care Planning

Care planning is a foundational element of high-quality dementia care, beginning at the time of diagnosis and evolving alongside the individual's needs. Participants emphasized that effective care planning must be proactive, person-centred, and inclusive of both the individual living with dementia and their care partners. It involves not only mapping out medical and support services but also addressing living conditions as well as legal, safety, and psychosocial considerations.

A strong care plan anticipates and adapts to future changes, supports informed decision-making, clearly communicates goals of care, and ensures continuity across care settings. When done well, care planning empowers individuals and care partners, reduces crisis-driven care, and strengthens the coordination of services throughout the dementia journey.

Core Clinical Activities Related to Care Planning for Dementia

1. Early and Ongoing Care Planning

- Initiate care planning at the time of diagnosis, with a clear roadmap for the dementia journey.
- Assign a dedicated care navigator or coordinator to support the individual and their care partner(s) across the continuum of care.
- Develop individualized, longitudinal care plans that are regularly reassessed and updated as the condition progresses.
- Ensure care planning is person-centred, incorporating the values, preferences, and goals of the individual and their care partners.
- Involve interprofessional teams in developing and updating care plans.

2. Advance and Legal Planning

- Facilitate advance care planning conversations early, including:
 - o goals of care and preferred settings for future care; and
 - o legal planning, such as powers of attorney (POAs) and estate planning.
- Use prognostic indicators (e.g. Hospital One-Year Mortality Risk [HOMR],²⁰ Risk Evaluation for Support: Predictions for Elder-life in the Community Tool [RESPECT]²¹ scores) to guide timing and depth of planning discussions.

3. Safety Planning for Risk of Harms

²⁰ https://homrinitiative.ca/homr-initiative/

²¹ https://www.projectbiglife.ca/calculators/elder-life

- Address known safety concerns in care plans, including:
 - responsive behaviours;
 - o roaming/risk for getting lost or losing one's way;
 - o injury risk (e.g. falls);
 - home safety (e.g. fire risk);
 - o regulated activities (e.g. driving and firearm ownership); and
 - o abuse (e.g. physical, emotional, financial, and neglect).
- Include comprehensive behavioural assessments and management strategies where needed.

4. Care Partner and Family Support

- Identify and engage care partners early, ensuring they understand the dementia trajectory and how to access support.
- Offer access to support groups, both formal and informal, to reduce isolation and build care partner resilience.
- Advocate for policies and resources that support working care partners, including those in the "sandwich generation."
- Use visual tools and roadmaps (e.g. <u>Waiting Room Revolution</u>) to help individuals and care partners understand what to expect and how to prepare.

5. Integrated and Coordinated Care Planning

- Develop shared care plans that are accessible across settings (e.g. community, hospital, long-term care) through shared electronic medical records or interoperable systems.
- Embed care planning tools in electronic health records to support interprofessional collaboration.
- Ensure seamless transitions between care settings through proactive discharge planning, access to transitional support where available, and continuity of care across health and social care providers.
- Include community-based and culturally safe services in care plans to ensure e quity and accessibility.

Roles and Responsibilities in Dementia Care Planning

Participants strongly advocated for a multidisciplinary, team-based approach to care planning in dementia, emphasizing the need for collaboration across both clinical and community-based settings. Identified core team members may include family physicians, nurse practitioners, registered nurses, social workers, occupational therapists, and navigators or case managers, particularly those embedded in primary care, connected

to home and community care services. These health and social care providers are seen as essential for coordinating care, supporting transitions, and ensuring plans are person-centred and responsive to changing needs. Social workers were highlighted for their flexibility and ability to address often-overlooked aspects of care planning, such as housing, emotional support, and system navigation.

Participants also emphasized the importance of including non-regulated providers—such as personal support workers (PSWs), adult day program staff, recreation therapists, and kinesiologists—who often have daily contact with individuals and play a key role in implementing care plans. Community organizations, particularly the Alzheimer Society of Ontario (through its First Link patient navigation program), were recognized as valuable partners in supporting care planning and navigation. To be effective, care plans must be inclusive, regularly updated, and grounded in the lived experience of both individuals living with dementia and their care partners, with all team members trained in dementia-informed communication and planning practices.

Where Dementia Care Planning Should Occur

Participants emphasized that care planning for dementia should occur across the entire continuum of care, rather than being confined to a single setting or organization. Key locations identified include primary care, memory clinics, and community-based organizations like the Alzheimer Society of Ontario. While MINT Memory Clinics were fre quently cited as an effective model, participants acknowledged that not all regions have access to them, highlighting the need for broader integration and equitable expansion of team-based models across Ontario.

Care planning should be a collaborative and shared process, with contributions from multiple health and social care providers and sectors, rather than siloed within one organization. This approach ensures that diverse perspectives inform the care plan and that it evolves with the individual's needs. Participants also stressed the importance of con sistent language and documentation across settings, so that care plans are not recreated at every touchpoint but instead updated and built upon. Additionally, care planning must accommodate adult learning styles, ensuring that individuals and care partners can unders tand and engage with the plan regardless of where it is delivered. Ultimately, care planning should be embedded in all care environments—home, community, primary care, acute care, long-term care, and specialized services—and supported by systems that enable communication and continuity across sectors.

Implications for Education

Providers in all health and social care settings (e.g. acute care, community care, primary care, and long-term care) require education about initiating and maintaining care plans, facilitating goal-based and advance care planning conversations, and sharing information

about when and how to involve specialized services (e.g. behavioural supports, specialized geriatric services, and seniors' mental health services).

Individuals and care partners need proactive education about the disease process and available supports, as well as strategies to help them prepare for future changes in function, behaviour, and care needs.

Treatment and Management

Effective treatment and management of dementia requires a holistic, person-centred approach that extends beyond pharmacological interventions to encompass physical, psychological, social, and environmental supports. Participants emphasized the importance of integrated care models that adapt to the evolving needs of individuals across the disease trajectory—from early diagnosis to advanced stages and end of life.

Core clinical activities include optimizing medications, supporting behavioural and psychological symptoms, enhancing quality of life through non-pharmacological interventions, and ensuring coordinated care through interprofessional teams. Equally critical are supports for care partners, culturally safe services, and access to specialized programs that address complex needs. This section outlines the core clinical activities related to treatment and management in dementia care.

Core Clinical Activities Related to Treatment and Management in Dementia Care

1. Medical and Pharmacological Management

- Optimize pharmacotherapy to ensure appropriate use of medications, including deprescribing where appropriate.
- Address and manage pain as a contributor to behavioural symptoms and quality of life.
- Prepare for future integration of disease-modifying therapies for dementia and ensure timely access to clinical trials and specialized treatment centers.
- Evaluate the appropriateness of invasive treatments (e.g. dialysis, surgeries) in the context of dementia prognosis (i.e. therapeutic harmonization).
- Monitor for delirium.

2. Non-Pharmacological and Psychosocial Interventions

- Expand access to dedicated behavioural support clinicians (e.g. Behavioural Supports Ontario).
- Increase access to education and training on the topic of responsive behaviours for health and social care providers across disciplines.
- Consider adult day programs, reminiscence therapy, music therapy, cognitive stimulation, emotional support, and other psychosocial interventions tailored to the person.
- Support care partners by providing respite care, care partner education, and system navigation support throughout the disease trajectory.

- Leverage community-based programs offered by the Alzheimer Society of Ontario, Seniors' Active Living Centres, and culturally safe services to promote engagement and reduce isolation.
- Monitor and support dietary and hydration needs to maintain health and function.
- Promote early and frequent mobilization and offer modified fall prevention programs.
- Implement strategies in acute, long-term care, and community settings to prevent, identify and respond to delirium.
- Offer slow-stream rehabilitation, geriatric rehabilitation, and cognitive rehabilitation tailored to individuals with cognitive impairment.
- Collect and utilize personhood information (e.g. a person's life experiences, important relationships, personal preferences) to inform tailored care strategies.

3. Integrated and Person-Centred Care Models

- Provide consistent care coordination and navigation support across settings.
- Emphasize autonomy, dignity, and quality of life through emotion-focused and person-centred care
- Balance safety with autonomy in decisions about driving, living arrangements, and other activities.
- Ensure care models address early to late stages of dementia, including transitions from community to long-term care.
- Expand access to virtual care and remote supports (e.g. Baycrest Virtual Behavioural Medicine and GeriMedRisk).

4. Specialized and Supportive Services

- Ensure availability of both in-home and short-term facility-based respite options.
- Develop progressive supportive housing models that adapt to increasing care needs.
- Provide targeted, specialized in-patient care for individuals with complex behavioural needs.
- Provide targeted, specialized behavioural care for individuals with young-onset dementia.²²

²² See for example https://www.tandfonline.com/doi/full/10.1080/13607863.2016.1257563#d1e255

- Tailor services to provide culturally safe and linguistically appropriate care to meet diverse population needs.
- Provide support for individuals with comorbidities to address the needs of people with serious mental illness who develop dementia.

Roles and Responsibilities in Dementia Treatment and Management

Participants emphasized that the treatment and management of dementia should be delivered through a collaborative, multidisciplinary approach that spans the entire continuum of care. Primary care providers—particularly family physicians and nurse practitioners—were identified as the central coordinators or "quarterbacks" of care, responsible for identifying changes, initiating treatment, navigating services, and coordinating with specialists when needed.

However, given the limited availability of specialists, especially in rural areas, participants stressed the importance of optimizing dementia care within primary care settings and reserving specialist involvement for complex cases. MINT Memory Clinics were highlighted as one successful model. These teams—comprising physicians, nurses, pharmacists, social workers, and occupational therapists—support individuals and care partners from diagnosis through to long-term care or end of life, reducing the need for specialist referrals and improving continuity of care.

Community-based models, including age-friendly communities and dementia-friendly businesses, were also seen as vital in supporting individuals in everyday settings. Hospitals and acute care settings were noted as needing significant improvements in dementia care, particularly in preventing delirium and deconditioning. Participants also emphasized the importance of supporting care partners early in the dementia trajectory, helping them anticipate future changes and prioritize their own well-being.

Overall, the feedback underscores the need for a coordinated, person-centred system that leverages local resources, supports care partners, and ensures continuity across settings and stages of dementia.

Where Dementia Treatment and Management Should Occur

Participants emphasized that treatment and management of dementia must occur across a wide range of settings to meet the diverse and evolving needs of individuals living with the condition. There was strong support for expanding care in home and community settings, recognizing that many people prefer to remain at home but often lack sufficient home care support. This gap leaves care partners struggling to manage complex care needs without adequate resources.

Supportive housing and retirement homes were identified as critical but underutilized or inconsistently supported environments, with calls for more standardized care approaches and integration into the broader dementia care system. Specialized memory or behavioural support units in long-term care were also seen as necessary for individuals with advanced or complex needs, though access remains limited.

Participants highlighted the importance of acute care settings, where early mobilization and interprofessional teams can play a key role in managing dementia-related complications, but also noted the need for significant improvements in hospital care to reduce risks such as delirium and deconditioning. Seamless transitions between care settings—from hospital to home, or from community to long-term care—were seen as essential, with a call for better information sharing and centralized care planning to avoid fragmentation.

Looking ahead, participants also raised concerns about the future rollout of disease-modifying therapies, noting that equitable access to these treatments will require coordinated infrastructure across smaller and rural communities, including access to diagnostics, biomarkers, and specialist care.

Implementation Considerations to Enable Dementia Care Clinical Activities

To translate the identified clinical activities into consistent practice across Ontario, a whole-system approach is needed—one that addresses infrastructure, people, tools, culture, and sustainability. The following areas signal essential implementation considerations for planners and architects of a future Provincial Framework for dementia care.

1. System Integration and Design

- **Cross-sectoral Alignment**: Dementia care spans sectors—primary care, home and community care, hospitals, long-term care, and public health. Clear care pathways and shared accountability are essential.
- Information Sharing: Consider how to enable real-time communication and data sharing across care settings (e.g. interoperable electronic medical records, shared care plans).
- **Centralized Navigation and Referral**: Establish mechanisms (e.g. centralized intake, care navigation, diagnostic access) to guide individuals through dementia services consistently across the province.
- Interprofessional Team-based Care: Integration of personnel into team-based care organized specifically around dementia care, embedded in flexible structures that serve the holistic needs of individuals (e.g. complex co-morbid conditions).

2. Workforce Capacity and Scope

- **Role Clarity**: Clarify who is responsible for each clinical activity across settings. For example:
 - o primary care for early screening and diagnosis;
 - primary care-based memory services for interprofessional team-based assessments and care planning support;
 - specialized clinical services (e.g. behavioural supports, seniors' mental health, and specialized geriatric services) for complex multidisciplinary assessments, resolution of diagnostic uncertainty, advanced therapeutics and interventions, and goals of care support;
 - occupational therapy and social work for functional and care partner assessments; and
 - o system navigators for care planning and direct support.
- Training and Education: Equip all relevant health and social care providers (e.g. nurses, PSWs, therapists, pharmacists, physicians, etc.) with role-appropriate training in:

- cognitive screening tools;
- Comprehensive Geriatric Assessment and other forms of comprehensive assessment;
- o behavioural and psychosocial assessment and care planning; and
- o culturally safe care.
- **Workforce Shortages**: The reality of human resource constraints—especially in rural areas—must be addressed through task-sharing, virtual supports, and sustainable workforce planning.

3. Time and Workflow Constraints

- **Feasibility in Practice**: Many clinical activities (e.g. screening and care planning) are time-intensive. Consider how they can be integrated into existing workflows and visit types.
- **Competing Priorities**: Clinicians manage multiple clinical demands. Efforts must be made to minimize added burden through streamlined tools and practical supports.
- **Incentives and Compensation**: Consider how to align funding models (e.g. fee-for-service and team-based care) to support proactive, team-delivered dementia care.
- **Stable Funding Models**: Provide ongoing funding for interprofessional teams, system navigation, dementia-friendly housing, and behavioural supports.

4. Infrastructure and Tools

- Availability of Standardized Tools: Ensure validated, culturally safe clinical tools (e.g. screening instruments and risk assessment templates) are provincially endorsed and accessible.
- **Digital Integration**: Tools must be embedded in electronic medical records with decision supports and prompts to support adoption.
- **Technology Access and Equity**: Virtual tools and data systems must not widen the digital divide; alternatives must be made available for those without internet access or digital literacy.
- Dementia Registry: A dementia registry provides essential data to monitor the
 prevalence, progression, and outcomes of dementia across populations,
 supporting more effective public health planning and resource allocation. It also
 enables research, quality improvement, and the implementation of diseasemodifying therapies by identifying care patterns, evaluating interventions, and
 facilitating timely, personalized care.

5. Equity and Inclusion

- **Cultural Safety and Relevance**: Ensure clinical tools, care models, and messaging resonate with Indigenous, Francophone, ethnically and culturally diverse populations, LGBTQ2IA communities, newcomers, and linguistic minorities.
- Language and Literacy: Materials and interventions must be translated, easy to understand, and adapted to different learning styles.
- **Geographic Equity**: Consider how to provide consistent access to dementia care in rural, remote, and northern regions (e.g. mobile teams, virtual assessments, and local capacity building).

6. Engagement of People Living with Dementia and Care Partners

- **Co-design**: Involve people with lived experience in shaping how the clinical activities are delivered and evaluated.
- Care Partner Inclusion: Care partners must be engaged as part of the care team especially in assessment, care planning, and treatment decision-making unless they are unable to participate or pose an identified risk, in which case alternative supports should be considered.
- Anticipatory Guidance: Activities like advance care planning, driving conversations, and behavioural support require sensitive, timely engagement and clear communication.

7. Policy, Governance, and Accountability

- Mandated Standards: Ensure that dementia care clinical activities are embedded in policy and service delivery expectations across care settings (e.g. Ontario Health Team models, long-term care standards, hospital admission and discharge planning).
- **Monitoring and Evaluation**: Build in mechanisms to monitor the uptake, fidelity, and outcomes of clinical activities (e.g. audit, feedback, and quality indicators).
- **Sustainability Planning**: Consider how the system will support continuity of these activities in the long term—through comprehensive funding strategies, workforce retention, and refresh of tools and training.

8. Public Awareness and Early Access

 Normalize Early Conversations: Public health messaging must support early helpseeking, reduce stigma, and encourage engagement with prevention and screening activities. • **Reach Underserved Populations**: Partner with non-traditional and community-based organizations (e.g. faith groups, libraries, settlement agencies, food banks, etc.) to extend reach beyond clinical environments.

Conclusion

This consultation report underscores the urgent need for a coordinated, person-centred, and system-wide approach to dementia care in Ontario. Through the collective insights of over 130 clinical experts and partners, this report identifies the core clinical activities essential to high-quality dementia care across the continuum—from prevention and screening to assessment, diagnosis, care planning, treatment, and management. Figure 1 depicts these as core components of integrated dementia clinical care.



Figure 1: Core components of integrated dementia clinical care.

Participants emphasized that dementia care must be proactive, inclusive, and adaptable to the diverse needs of individuals, care partners, and communities.

The findings highlight the importance of embedding dementia-informed practices across all care settings, supported by interprofessional teams, culturally safe tools, and equitable access to services. The consultation also revealed critical implementation considerations, including the need for system integration, workforce development, digital infrastructure, and sustained public engagement.

This report is not a prescriptive guideline but a foundational resource to inform the Ontario Ministry of Health's Provincial Framework for Dementia Care. It reflects a shared vision for a future where individuals living with dementia—and those who support them—receive timely, compassionate, and coordinated care. The work ahead will require continued collaboration, investment, and innovation to bring this vision to life.

Appendix 1: Participants (Alphabetically by Organization)

*Includes those who approved the inclusion of their name in this report

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Alzheimer Society of Ontario

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Alzheimer Society of Simcoe County

Ann-Marie Kungl, MPH, CHE ADR, CEO

Baycrest

Deb Galet, President and CEO
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Jackie Houston, Physiotherapist, Director, Strategy and Clinical Business Development
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Canadian Mental Health Association - Ontario

Marija Padjen, MSW, Chief Clinical Officer

Canadian Mental Health Association - Waterloo Wellington

Jane McKinnon Wilson, Waterloo Wellington Geriatric System Coordinator and Waterloo Wellington Older Adult Council Lead

Centre for Addictions and Mental Health

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Centre Francophone de Toronto

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Georgian Bay Family Health Team

Marcia Palonen, Occupational Therapist, Healthy Aging Program Lee Zinkan-McKee, Registered Nurse, Program Lead - South Georgian Bay Healthy Aging Program

GPCSO

Vickie Demers, Occupational Therapist, Executive Director

Guelph General Hospital

Andrea Lucas, Registered Nurse, VP Patient Services/CNE Audriana Di Ruzza, Registered Nurse, Geriatric Clinical Nurse Specialist/ Geriatric Emergency Management Nurse

Haliburton Family Health Team Memory Clinic

Tina Stephenson, MD, Physician Lead

Hamilton Health Sciences

Kristy McKibbon, BAH, MA, GDBA, MBA Candidate, BSO Coordinator, HNHB West Region

Hotel Dieu Grace Healthcare

Jenniffer Clifford, Social Worker BSW, MSW, RSW & Developmental Service Worker DSW, Operations & Clinical Practice Manager of Specialized Geriatrics/ Erie St. Clair Specialized Geriatrics Lead

Kawartha Centre

Jenny Ingram, Geriatrician, Consultant

KW4 Ontario Health Team

Ashnoor Rahim, Physiotherapist, MBA, BScPT, Executive Director

Loyalist Family Health Team

Adedotun Alade, Family physician

McMaster University

Anthony Levinson, MD, FRCPC, MSc, MA, John Evans Chair in Educational Research, Division of e-Learning

Innovation, Faculty of Health Sciences

Elizabeth Wojtowicz, NP, PhD Student

MINT Memory Clinics (Various)

Vandy Paroutis, RPN

Lissa Kuzych, Occupational Therapist, Mint Memory Clinic

Fred Mather, Physician

Jen McKay, RPN, MINT Memory Clinic Mentorship Trainer

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North East Specialized Geriatric Centre

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Melanie Briscoe, Occupational Therapist, Administrative Director

Nadine Paquette, RN, Clinical Implementation Specialist

North Simcoe Muskoka Specialized Geriatric Services

Sandra Easson-Bruno, RN, Director, NSM SGS

Jenna Davis, Recreation Therapist, Manager - Geriatric Mental Health (Community)

Kim Simpson, OT, Manager, Clinical Leadership

Ontario Health - Central

Mario Tsokas, Social Work, Lead, Capacity, Access & Flow, Long Term Care and Behavioural Supports Ontario

Ontario Health at Home

Lesley Williams, Quality Improvement Facilitator, Central East Behavioural Supports Ontario

Ontario Long Term Care Clinicians Association

Sandy Shamon, MD CCFP PC FCFP, Family Physician, Chief Medical Officer Rhonda Collins, Care of the Elderly Physician, GP Focused Practice in Geriatrics, Past President

Orillia Soldiers' Memorial Hospital, North Simcoe Muskoka Specialized Geriatric Services

Amanda Gardhouse, Geriatrician

Perley Health

Ben Robert, MD, Chief Medical Officer

Provincial Geriatrics Leadership Ontario

Kelly Kay, PhD, Executive Director Heather MacLeod, OT Reg. (Ont), DSc(c), Director, Programs and Partnerships

Provincial Geriatrics Leadership Ontario, Waypoint Centre for Mental Health Care

Kevin Young, MD, PhD, FRCPC, Medical Director (PGLO), VP Medical Affairs & Chief of Staff (Waypoint)

Providence Care

Kim Schryburt-Brown, Occupational Therapist, Clinical Resource Project Consultant, Seniors Mental Health

Behavioural Support Services

Providence Village Inc.

Marie-Jo Cleghorn, Registered Nurse, Director of Care

Queen's University

John Puxty, Geriatrician, Director, Centre for Studies in Aging and Health

Queen's University, Providence Care Hospital

Leah Nemiroff, Geriatrician (MD, FRCPC), Division Chair Geriatric Medicine, Clinical Director, Senior's Rehabilitation

Regional Geriatric Program Central

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Regional Geriatric Program of Eastern Ontario

Tammy Pulfer, RN, MN, GNC(C), Program Director

Regional Geriatric Program of Southwestern Ontario

Jacobi Elliott, PhD, Director, Research & Strategy Lyndsey Butler, OT, Clinical Manager

Regional Geriatric Program Toronto

Barbara Liu, Geriatrician, Executive Director

Rehabilitative Care Alliance

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Royal Ottawa Mental Health Centre

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Carol Anne Cumming, RN, Director, Patient Care Geriatric Psychiatry Programs

Senior Care Network

Kerry Shudall, RN, GAIN Regional Manager

Senior Persons Living Connected (SPLC)

Amanda Falotico, Honours Bachelor of Science, Director of Care Services

Sinai Health

Mark Lachmann, Geriatric Psychiatry, Vice President, Medical Affairs

Senior Persons Living Connected (SPLC)

Miu Cheuk, Social Worker (GAIN)

Niksala Krishnan, RN, Registered Nurse-IP member (GAIN)

St. Joseph's Care Group

Alison Denton, Manager, NW Seniors' Care Program/Sociologist, Manager, NW Seniors' Care Program

St. Joseph's Health Centre Guelph

Matt Smith, RN, BN, MHS, CHE, Interim Vice President

Brandy Nellis, M.Sc., B.A.Sc., Director, CSS

Audrey Devitt, Program Manager, Waterloo Wellington Behaviour Supports Strategic Lead & Program Manager, SGS NP Services

St. Joseph's Health Care London

Amy Biderman, RN(EC) PHC-NP, Nurse Practitioner

Jessica Perreault, Nurse Practitioner, Mount Hope Centre for Long Term Care

St. Joseph's Lifecare Centre

Laura McEachern, Nurse Practitioner

St. Peter's Residence at Chedoke

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STAR Family Health Team

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Summerville Family Health Team

Yali Gao, Pharmacist, Clinical Pharmacist

Sunnybrook Health Sciences Centre

Carole Cohen, MD, Clinical Director, Community Psychiatric Services for the Elderly

The Centre for Family Medicine

Jillian Carducci, Pharmacist

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Jennifer Koop, APN, Advanced Practice Nurse in Dementia Care

The Ottawa Hospital, Regional Geriatric Program of Eastern Ontario

Allen Huang, Geriatrician, Medical Director, RGPEO

The Royal Ottawa Health Care Group

Carol Anne Cumming, RN, Director, Patient Care Geriatric Psychiatry Programs

Trillium Health Partners

Diana Nicolici, Geriatric Psychiatrist Mariam Mokhtarzada-Salim, Physiotherapist, Elder Life Specialist Bonnie Joanisse, Nurse Practitioner

University Health Network

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University of Toronto

Emily Norcliffe, NP, Nurse Practitioner, Doctor of Nursing Student

West Champlain Family Health Team

Connie Daiken, RN, Chronic Disease Prevention and Management

Western University

Jaspreet Bhangu, Geriatrician Michael Borrie, Geriatrician

Appendix 2: Selected Evidence

There is a considerable body of evidence to further inform ideas identified in this report. This list is not intended to be exhaustive but instead includes references specifically identified by participants as some of their "go-to" evidence and resources supporting their practice in dementia care.

Advance Care Planning Canada resources (various) https://www.advancecareplanning.ca/.

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